Maternal Experiences of Self-Identity and Family Identity after a Child acquires an Acquired Brain Injury: A Constructivist Grounded Theory Analysis

Jameson Eric Natwick

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Megan Dolbin-MacNab
Carolyn Shivers
Rosemary Blieszner
Joyce Arditti

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Abstract

An Acquired Brain Injury (ABI) can have lasting effects on the self-identity of the injured individual, but also on the self-identity of other family members. Using Contextual Family Stress Theory as a guiding theoretical framework, this qualitative study investigated how mothers experience changes and alterations in their self-identity and family identity, as well as the reconstruction of self-identity and family identity, after a child acquires an ABI. These experiences are important to capture so that clinicians and professionals may better understand the phenomenon of post-ABI self- and family identity and to help inform rehabilitation and professional services. Currently, research has been narrowly focused upon functional gains for individuals and families in rehabilitation while excluding changes in self-identity and family identity. Data were collected via semi-structured interviews and self-report measures of individual mothers' needs and perceptions of the injured child. A constructivist grounded theory analysis was used to analyze the data. Findings reveal the reconstruction processes of mothers' self-identity and family identity after a child receives an ABI, such as internal and external self-identity and intentionality in reconfiguring family identity. Furthermore, results suggest that positive adaptation in self-identity and family identity promote resilience to the changes from the child's ABI. Future research directions, theoretical, and clinical implications are discussed.

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General Audience Abstract

An Acquired Brain Injury (ABI) can happen in many ways, such as a hard hit to the head or the brain not getting enough oxygen. Children and adolescents are among the age groups that have the highest rates of ABIs. The effects from an ABI are long lasting and impact the injured person in many ways, including their identity or sense of self. When a child receives an ABI, the parents' self-identity and the overall family identity is also affected. The goal of this study was to provide a better understanding of changes in self-identity and family identity for mothers who have a child or adolescent with an ABI. For this study, I recruited 14 mothers of a child with an ABI, and the mothers engaged in interviews and completed several short surveys. The mothers shared important information about changes in self-identity and family identity and made suggestions about how medical and rehabilitation services can better support families affected by ABIs. Findings revealed that families who are intentional about discussing changes to the family, such as role shifts or changes in routine, and expressing emotions adapt more effectively to the consequences from an ABI. Furthermore, the results suggest recommendations for rehabilitation professionals in supporting mothers and families. These include, educating the family about ABIs and involving mothers and families as part of the treatment process. Future directions for further research studies are identified as well as a discussion on best practices for clinicians.

Dedication

I dedicate this work to all of my participants. I was honored to meet with you and hear your stories. I cannot express my gratitude deeply enough for your trusting me with your experiences and insights. I am humbled by your resilience and strength.

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Chapter I: Introduction

Background and Significance

An Acquired Brain Injury (ABI) is an injury to the brain which occurs after birth, and the injury is not related to a congenital condition, a degenerative disease, or induced by natural birth trauma (Brain Injury Association of America, 2019). “An ABI changes to the brain’s neuronal activity, which alters the physical integrity, metabolic activity, or functional ability of nerve cells in the brain” (Brain Injury Association of America, 2019, p. X). There are two categorizations for ABI: traumatic brain injury (TBI) and nontraumatic brain injury (nTBI). The differentiation between the types of brain injury emphasize the manner in which the ABI was caused.

A TBI is defined as the brain acquiring damage through blunt force trauma, penetrating objects, or the brain ricocheting within the skull due to acceleration forces (Taylor et al., 2017). The estimated number of diagnoses of TBI in the United States have increased from 1.4 million in 2006 to 1.7 million in 2010 to 2.8 million in 2013 (Faul et al., 2010; Langlois et al., 2006; Taylor et al., 2017). The increase in TBI diagnoses has been attributed to sports-related concussions in youth and older adults and fall-related TBIs among younger children (Taylor et al., 2017). Another factor that may contribute to increased rates of TBI diagnoses is the increased knowledge of sequelae, leading to earlier diagnosis and management of TBI as this research has become more prevalent (Coronado et al., 2015).

nTBIs are acquired through events that lead to internal factors such as lack of oxygen (drowning, choking), exposure to toxins (lead, carbon monoxide), stroke, brain tumors, infectious disease, or electric shock (Elbaum, 2019). Specific data on nTBI are often separated by the source of the cause (i.e., stroke, drowning, assault) instead of the overall diagnosis of nTBI. For example, the reported incidence of combined ischemic and hemorrhagic pediatric stroke ranges from 1.2 to 13 cases per 100,000 children under 18 years of age (Earley et al., 1998; Lynch et al., 2002). Due to statistical reporting by each specific injury that could fit under the umbrella of nTBI, there are no overall statistics on the incidents of nTBI.

Whether a TBI or nTBI, an ABI is unique to each person, as no two brains are the same, and the effects of an ABI on an individual's functioning are complex (Brain Injury Association of America, 2019). Management of each ABI needs to be attentive to contextual factors such as cause, location, and severity of the injury as well as support systems to help manage the rehabilitation. Despite the differences in the cause of the injury, the consequences of a TBI or a nTBI have similar functional sequelae, and the rehabilitation process is similar. For this reason, this study will look at ABIs in general.

The extent of the consequences is connected to the spectrum of severity an ABI, ranging from a mild temporary concussion to severe damage or death (Laureys et al., 2010). Determining the severity of the ABI is part of the diagnostic process of the injury with one primary diagnostic criterion being how long a person experiences a loss of consciousness (Taylor et al. 2017). A mild ABI is characterized as the loss of consciousness from 0 to 30 minutes, the classification of a moderate ABI is 30 minutes up to 24 hours, and a severe ABI is the loss of consciousness greater than 24 hours (O'Neil et al., 2013). Another diagnostic criterion for severity is the extent of the injury on the brain, as not all ABIs will lead to a loss of consciousness (Brain Injury Association of America, 2019). The severity of the ABI is linked to the impact on the functionality of an individual, with individuals with a severe ABI displaying the most deficits in functioning (O'Neil et al., 2013).

The spectrum of severity of an ABI helps to describe the damage acquired to the brain and helps clinicians and families understand the potential long-term consequences of the injury.

An ABI can affect virtually every aspect of an individual’s functioning including cognitive, social, and physical domains. There is overlap between these domains evident in executive functioning, the cognitive process that facilitates problem solving, and goal-oriented behavior (Miyake et al., 2000). The negative effects an ABI has upon executive functioning have been well documented (McDonald et al., 2014**;** Muller et al., 2010). The reduction in executive functioning also impacts social processes (Byom & Turkstra, 2017). The person with an ABI may be affected by the cognitive demands of social communication, which can contribute to poor social performance and thus, impaired socialization (Byom & Turkstra, 2017).

Language is important to social performance, and the deficits ABI can bring to language processes has been robustly documented (Douglas et al., 2016; Ownsworth, 2014; Ponsford et al., 1995). An individual with an ABI can experience word retrieval problems, slow speech patterns, and difficulty with mental state words (e.g., thoughts, feelings, desires; Byom & Turkstra, 2017; Douglas, 2017). The challenges of language along with the cognitive challenges can make employment or education difficult to continue. It is common for individuals with an ABI to reduce hours of work, change employment, or stop working due to the deficits caused by an ABI (DiSanto et al., 2018).

Behavioral and psychosocial challenges are also common with ABI. Studies indicate that between 35% and 70% of ABI cases result in behavioral difficulties (Costeff et al.,1985; Max et al., 1997; Ylvisaker et al., 2007). Early in the recovery from an ABI, common behavioral problems include aggressiveness, self-injury, disinhibition, and agitation (Asarnow et al., 1991; Slifer & Amari, 2009). Later stages of rehabilitation may include behavioral difficulties of restlessness, inappropriate sexual behavior, distractedness, and impulsiveness (Gerring, 1986; Ylvisaker et al., 2007).

In sum, an ABI affects multiple domains within a person's life, and these areas influence one another. The rehabilitation process for ABI seeks to address the multiple aspects of a person's functioning by employing occupational therapy, physical therapy, social supports, neurology, speech/language therapy, and psychological services (Ownsworth, 2014). It is important to highlight that rehabilitation is not treatment; treatment would lead to a cure, and there is no cure for an ABI. The broad spectrum of ABI becomes more complex when an ABI occurs to a child still in the process of development.

ABI in Children and Adolescents

Childhood and adolescent ABI have garnered particular attention, as these cohorts are at increased risk of acquiring an ABI compared to most other stages of the lifespan (Taylor et al., 2017). This increased attention is due, in part, to the recognition that ABIs have the potential for life-altering consequences. Although there has been progress in the prevention of motor-vehicle crashes, child fall-related accidents, and sports-related injuries, children and youth still have comparatively high rates of ABI. For instance, Taylor et al. (2017) found that children and youth between the ages of 0 and 4 and 15 and 24 had, respectively, the second and third highest rates of ABI. Similarly, Coronado et al. (2015) found that, both males and females across the age range of 5 to 14 had significant increases in ABI from 2001 to 2012. Even with the increased awareness of risk factors, interventions, and preventative measures, childhood ABI remains a topic that requires the attention of researchers and practitioners to improve on the knowledge in practice of prevention and rehabilitation care.

An ABI in childhood or adolescence can have unique consequences because the injury can interrupt, slow, or completely stop developmental processes, such as executive functioning, language, or emotional self-regulation (Ewing, 2006; Ownsworth 2014). For a child or youth, there are multiple skills and abilities, such as executive functioning, memory, language, and emotional self-regulation, that are developing and becoming more complex, and an ABI will delay or limit the development of these skills (Ewing, 2006; Ownsworth, 2014).

For children and adolescents, the physical development of the structure of the brain can result in multiple trajectories of recovery, including initial deficit with a return to premorbid levels of functioning, a consistent decline in functioning when the child is compared to peers, and delayed deficits manifesting over time (Babikian & Asarnow, 2009; Ownsworth, 2014). These trajectories are unique to childhood and adolescent ABI because the plasticity of the brain is greater compared to an adult brain. Plasticity is the process in which "the nervous system can modify its organization and ultimately its function throughout an individual's lifetime" (Kolb et al., 2003, p.1). Children, even more than adolescents, have greater plasticity since their brains have not gone through extensive pruning of the neural passages in the brain (Johnson, 2001). Therefore, the brain of a child may be able to adjust to the ABI, creating new neural connections to replace those that were lost due to the injury.

Though multiple trajectories of outcomes have been identified, it is generally recognized that the more severe the ABI, the more likely the child or adolescent is to suffer poorer outcomes (Ownsworth, 2014). For example, a moderate to severe ABI to the prefrontal cortex region of the brain can lead to problems in executive functioning, emotional regulation and behavioral control, and attention (Babikian & Asarnow, 2009; Ownsworth, 2014). Furthermore, the typical environmental shifts of a child going to school or participating in activities outside the home can further illuminate the difficulties in functioning as the child is asked to be more independent and there are clear expectations on appropriate behavior and emotional regulation (Ewing, 2006).

Due to the consequences on functioning rehabilitation services for children and adolescents focus on training, skill development, and functionality. For example, Seguin et al. (2018), advertise their program “Ready! Set? Let’s Train!” as a childhood intensive program to train and improve attention and executive functions after an ABI. Children with an ABI would also engage in rehabilitation services similar to adults (e.g., speech therapy, physical therapy, occupational therapy, etc.). Embedded in many rehabilitation services is psychoeducation, which is important for the individual with an ABI and those closely connected to the individual such as parents and other family members (Ownsworth, 2014). When a child or adolescent has an ABI, psychoeducation is especially important in helping parents to understand the extent of the injury, implementing strategies at home to support the child, and becoming more aware of sequelae from the ABI. Specifically, looking at mothers, who are often in caregiving roles and more likely to stop work for caring tasks, is important. Though all parents and caregivers will be affected by an ABI to a child, mothers who have a child with an ABI will need to adapt to new challenges on both personal and systemic levels.

ABI, Mothers, and the Family

The effects of an ABI extend beyond the child that acquired the injury, as non-injured family members are also impacted by the ABI. This study is focusing on how an ABI to a child affects mothers, who are often positioned to be the primary nurturer in a family and take on more caregiving tasks. The functional changes in multiple domains to a child with an ABI can disrupt mothers’ functionality. Caregivers, including mothers, may have to adapt to new responsibilities, which could include attending more appointments for rehabilitation, increased supervision and care for the child, and other changes in how they and their family functioned before the injury (Ownsworth, 2014; Schonberger et al., 2010). Depending on the needs of the child, a parent may need to reduce or eliminate employment to respond to the increase demands in caregiving from the child with an ABI (Rashid et al., 2014). With the sudden on-set of an ABI to their child, mothers are forced to respond quickly to new needs that require a shifting of their previously established roles and expectations.

Family rules, roles, responsibilities, and expectations can all be altered by an ABI to a child (Kirton et al., 2014; Ownsworth, 2014; Rashid et al., 2014; Tam et al., 2015). The roles and responsibilities can reference the parents' employment status, as previously mentioned, but also refer to how the role of the parent shifts in the family. A parent may become the primary caregiver so that their partner can work full time (Tam et al., 2014), which is often the case with mothers, so that they might facilitate the behavior of the child with an ABI in social settings (Ownsworth, 2014; Schonberger et al., 2010), or so that they might function as a case manager to fulfill the needs of the child in multiple settings (e.g., school, social, rehabilitation services, transportation; Bedell & Dumas, 2004; Greenspan & Mackenzie, 2000). Furthermore, there can be an additional financial burden placed upon the family with the potential decrease in parental employment and increase in costs from rehabilitation services (Hawley et al., 2003).

The new roles and responsibilities that a parent experiences can have influences on their mental health and relationships with multiple family members (Li & Lui, 2012; Godwin et al., 2014). An ABI that is sudden and unexpected creates a situation in which the parents must quickly respond to the new needs of the child with an ABI as well as the effects the ABI has upon the family; they do not have time to process the events that transpired (Ownsworth, 2014). Additionally, in these rapid changes, the main focus is not upon the parent's psychological health and existential processes; however, these needs should be considered as important as other more concrete needs to the support of a child with an ABI. A parent's mental health is important to consider, as poor parental psychological health can lead to increases in behavioral problems in children and adolescents with an ABI (Raj et al., 2013). Furthermore, caregiving or adjustment to new roles can be draining, especially immediately after the injury, when learning new responsibilities of how to provide effective care for a child with an ABI (Tam et al., 2014).

Beyond the mothers, other family members will experience change in how the family functions. The introduction of an ABI into a family system can bring about a loss of the future, as family members realize that certain events, vacations, or activities are no longer possible (Godwin et al., 2014). These revelations of change can create a compounding effect within the family. If the family struggles to adjust to the long-term consequences, poor family functioning and psychological health (e.g., anxiety and depression) tend to reinforce each other (Schonberger et al., 2010). The family environment is important for a child with an ABI; multiple studies have revealed that family environment is essential to functional outcomes of the child (Nalder et al., 2012; Ownsworth, 2014; Degeneffe, 2001). Furthermore, the premorbid functioning of the family is a predictor of outcomes that Pepping and Roueche (1991) referred to as pre-existing assets and liabilities.

An ABI impacts the whole family system, and rehabilitation services have begun to address systemic needs and needs of non-injured family members. Even so, rehabilitation services continue to focus primarily on functional gains for the person with the ABI, which could include restorative interventions (e.g., repetitive training of cognitive skills; Anderson & Catroppa, 2006), family-based interventions (e.g., implementing positive behavioral supports through communication and executive strategies involving the whole family; Ownsworth, 2014), or family therapy to promote positive behaviors and communication among family members (Ylvisaker et al., 2005). While the body of literature on ABI and rehabilitation has provided advancements in functional gains for the child with ABI, the parents, and the family, there still remains a deficit in addressing the experience of mothers in processing changes and making meaning about the changes which is rooted in self-identity. Recently, the connection between self-identity and ABI has gained more attention. The changes in functioning, roles, and responsibilities on individual and family levels have a deeper effect in shifting how a person understands oneself.

ABI and Self-Identity

The heterogenous impacts an ABI can have upon a person can influence the self-identity of the individual. Self-identity is often an all-encompassing concept that encapsulates multiple facets of the ‘self’ (Ownsworth, 2014). There are many inter-connected parts to the self, such as self-awareness, self-concept, self-esteem, and self-efficacy. Self-awareness is the capability of a person to experience one’s distinctiveness from others and be conscious of abilities and internal states **(**Damon & Hart, 1982). The term self-concept refers to the overarching thoughts and feelings about oneself to arrive at the definition of oneself (Rosenberg, 1965), such as the awareness of one’s unique and stable characteristics, values, and behavior (Ownsworth, 2014). Another aspect of the self is self-esteem, which is the value or competence a person has about oneself (Schweitzer et al., 1992). Finally, the concept of self-efficacy is the personal agency or the sense a person has of their ability to perform tasks or cope with a situation (Bandura, 1989).

In examining self-identity within the context of ABI, another important term to define is that of identity. Identity is one’s perceptions of one’s sameness (Ownsworth, 2014). Dumont (2013) refers to identity as unique and persisting qualities that differentiate the self from others across time. All of these definitions of various aspects of self or identity are interconnected. For the purposes of this study, the concept of self-identity was defined broadly to include these multiple variations of self and identity. Specifically, self-identity is defined as the unique and persistent qualities and characteristics of self as experienced and perceived through the person's conscious awareness of inner sameness and continuity (Allport, 1961).

The nature of an ABI alters the perception of a person's continuity of inner sameness (Gelech & Desjardins, 2011). As addressed earlier, an ABI can impact multiple areas of functionality. A person's conscious awareness of sameness and continuity will be connected, in some fashion, to their functional abilities (Ownsworth, 2014). When that sameness and continuity of ability is interrupted, and a person cannot return to their pre-injury state, this experience can be disorienting. "Overall, change in physical, cognitive, and socio-emotional functioning can alter the experience of self in the world" (Gracey et al., 2008, p. 639). With many of the changes bearing negative consequences, the child with an ABI and non-injured family members can experience a loss of agency, independence, and participation in society (Ownsworth, 2014). Turner et al. (2011) illustrate the experience of individuals with an ABI in their qualitative study investigating the perspectives of these individuals when returning home from the hospital. The findings suggest that participants were aware of changes in their functioning and acknowledged the need for more assistance (Turner et al., 2011). Although adults with an ABI can consciously be aware of shifts in one's self-identity, an ABI to a child adds intricate layers to the intersection between ABI and self-identity. In terms of self-identity, children aged 18 and younger generally are in the process of having their personalities emerge and starting the on-going process of understanding self-identity (Erikson, 1963; Ownsworth, 2014).

Therefore, a child or adolescent who receives an ABI may experience unique outcomes related to self-identity. With a lack of life history compared to those in later stages of development, younger children may not experience a disorienting change in sameness and continuity as these aspects are not firmly established in childhood (Higgins, 1987; Ownsworth, 2014). “If children are injured before they have formed a stable self-concept it is possible that the brain injury will have less detrimental psychological effects because they are less likely to experience self-discrepancy, or unfavorable comparisons between current self with past or ideal selves” (Ownsworth, 2014, p. 46). Adolescents are in the middle of their own identity development (Erickson, 1963). Thus, a wide range of identity-related outcomes is expected, as adolescents are becoming more stable with self-concept, but formation of self-identity is still progressing.

However, the functional deficits a child or adolescent with an ABI can experience in cognitive, social, and physical realms can create more difficulties in establishing a positive sense of self (Harter, 2012). With the potential of lagging or limited skills, a child could be aware of how they are different from their peers. This can occur as the child or adolescent with an ABI experiences day-to-day feedback through social interactions and sees all the deficits firsthand. The perception social experiences can lead to lower self-esteem, loneliness, and maladaptive social functioning (e.g., aggressive and antisocial behavior, delayed speech; Andrews, Rose, & Johnson, 1998). Though the child with an ABI most directly experiences the deficits; an ABI is not a private injury, for parents are aware of how the ABI has alter their child.

Parents whose child has an ABI will witness changes to continuity and sameness in various aspects of their child including personality, behavior, or cognitive shifts from before and after the injury (Bloodgood et al., 2013; Keck et al., 2017). Just as an individual with an ABI struggles to reconcile who they were before the injury with the person they are after ABI, parents also can experience a similar phenomenon with recognizing that the child after ABI may be different than the child they had before. In fact, research has demonstrated that parents often experience significant grief and loss when an ABI occurs to a child (Kirk et al., 2014; Ownsworth, 2014). Parents must grieve the loss of their and their child's old self-identity, as previous self-identities may be incompatible with the new reality of having a child with an ABI.

Additionally, an ABI can shatter the hopes and expectations that the parents held for their child. The plans for the child will now need to be adjusted to the present situation (Bowen et al., 2009; Wade et al., 2011). The self-identity of a parent can be invested in their role as a parent, and when an ABI occurs to the child, the understanding of the parent about who they are as a parent is changed. Shifting meanings about being a parent can bring about the recognition that the relationship with and hopes a parent had for their child can no longer exist in the same way, leading to grieving the loss of a potential future (Ownsworth, 2014). For example, a parent may realize that they will not be able to teach their child to ski due to physical consequences of the ABI. Self-identity can be projected into the future, and, when unexpected events shatter future expectations, it can lead to a loss of a potential future and the need to re-negotiate self-identity.

Additionally, self-identity for parents can be connected to roles and responsibilities within and outside of the family system (Rashid et al., 2014). Such roles and responsibilities could include financial provider, cook for the family, involvement in church or community, recreational activities, attending children's events, disciplining children, or volunteering time. For mothers, the role of mothering can often be important, and mothers can have specific ideas about what it means to be a mother (Choi et al., 2005; Ruddick, 1982). An ABI to a child can change how a parent is able to participate in roles and responsibilities, which can impact their self-identity. Parents may need to scale back involvement in social and community activities to attend to the increased needs associated with an ABI. Roles and responsibilities influence self-identity beyond the observable changes parents will experience, as roles and responsibilities can foster meaning and purpose for parents (Tam et al., 2015; Thompson, 2009).

Meaning is the comprehension of how people make sense of their selves, the world around them, and the interactions between the two (Steger et al., 2013). Purpose is an outward drive, such as goals or aims of a person, that is stable and enduring and leads to meaningful productive engagement in the world (Damon et al., 2003). The sudden and unexpected nature of an ABI forces a parent to reprocess meanings and purpose within their life. For example, not being able to participate in church functions or work full time due to a child with an ABI can cause an alteration in self-identity, as sameness and continuity have been altered and the comprehension once utilized by the parent to make sense of themselves and the world is not relevant to their current situation. Lastly, the purpose gained from employment or volunteering is gone and the parent will now have to find purpose through another outlet. These changes in meaning and purpose are unsettling and break up a person’s sense of sameness and continuity.

A disrupted self-identity can lead an individual to utilize maladaptive coping strategies, such as substance misuse, withdrawal from responsibilities, or avoidance of problems or relationships to cope with the meaninglessness or confusion about self-identity (Hart & Carey, 2014). For example, a parent may have found purpose and meaning in a career but then, when their child received an ABI, had to quit employment to render care for the child. The parent may avoid discussing their pain and feelings of loss because they believe it is what a good parent should do for their child, and this avoidance could lead to depression.

Finding meaning and coming to an understanding may take more time for parents. Often, after a child acquires a brain injury, parents do not know all the services potentially needed, how the ABI will influence the family, and how it will impact them individually (Saban et al., 2014;

Tam et al., 2015). Parents may also experience guilt, anger, or self-blame about the accident or circumstances that caused the ABI (Degeneffe, 2001). The process of creating meaning and understanding emotions and thoughts is important to the re-construction of self-identity. There is a need for further investigation into the experiences of mothers in reforming self-identity, due to their heavy caregiving roles, to integrate this self-identity knowledge into rehabilitation and other professional services utilized by families with a child with an ABI.

Gender, specifically as it relates to the role of motherhood, has implications for self-identity in the context of ABI. There are specific social norms of the Western world that are projected onto women and, living up to these norms become the responsibility of women (Ruddick, 1982). Such expectations include being the primary caregiver across the lifespan of children (Daikin & Naidoo, 1995), being naturally nurturing and selfless (Choi et al., 2005), and regulating the moral behavior of children (Donzelot, 1977; Ehrenreich & English, 2005). These extensive expectations upon mothers are unrealistic to achieve. Furthermore, the challenges in the construction to the role of mother become further complicated when disabilities are present, for the mother or a child (Malarida, 2008). Leiter et al. (2004) identified, in their quantitative study, that mothers with a child with a disability are more likely to assume nursing roles, become the primary caregiver to the disabled child, and sacrifice work and career goals and aspects of their identity. The Western norms of motherhood and gender can influence how families adjust and carry assumptions into who will provide care to the child with an ABI and sacrifice other aspects of self-identity. These changes in self-identity and unspoken assumptions within roles and the family are often not addressed in rehabilitation services.

Wilson (2011) has described how self-identity needs to be a focus in the rehabilitation process. The research on self-identity has led to the integration of multiple disciplines, such as social psychology and cognitive neuroscience, which has led to a holistic approach to rehabilitation (Ownsworth, 2014). Self-identity is a product of neurobiology, culture, social interactions, personal meaning, and their interactions (Jetten et al., 2012; Walsh et al., 2014). Furthermore, this holistic approach, grounded in research, reveals that rehabilitation of self-identity for all family members needs to be included throughout the rehabilitation process.

The effects of an ABI can influence multiple members of a family, and though the child with an ABI is most directly impacted by functional differences, the self-identity of mothers is an area that needs to be addressed further, due to mothers' likelihood of having great changes in self-identity. For example, the meaning of being a mother could change or sacrifice a career to take on caregiving responsibilities. Reforming self-identity is an individual process, and from the discussion on ABI there is a large body of literature that reveals that an ABI impacts the whole family. Given the evidence to systemic changes stemming from an ABI, the family identity is another form of identity that needs attention. My dissertation study addresses the attention that is needed to further understand the changes and alterations that occur to family identity after an ABI to a child.

ABI and Family Identity

As each person in a family will have an individual self-identity, each member of a family participates in creating a family identity. The family identity is a collaborative, co-constructive process that includes the family's subjective sense of sameness and continuity over time (Bennett et al., 1988; Ownsworth, 2014). Whereas self-identity is an individual process of perceiving the world and one's continuity and sameness over time; family identity is a systemic process of recognizing the input of multiple family members, though some members may have a stronger voice (e.g., in our family we all enjoy skiing; religion is important to our family; Bennett et al., 1988). Additionally, individual (e.g., I am the peacekeeper in my family) and relational identities (e.g., My wife and I greatly value being able to take trips without the children) interplay with family identity. Within family identity there are differing interactions, coalitions, and bonds between members.

Despite the fact that the whole family can be influenced by childhood and adolescence ABI, family identity has received little attention in research. Current research has focused upon the functional outcomes of the family and the family member who has an ABI. Multiple studies have illuminated that positive communication and emotional processes are predictors for stability and support (Schonberger et al., 2010), whereas negative communication (e.g., authoritarian parenting, yelling) and emotional processes can lead to poorer outcomes, specifically in the child with an ABI (Ownsworth, 2014).

The research on roles and responsibilities has also been focused on caregiving tasks and influences of the injured individual on family members (Degeneffe, 2001). This includes caregiving tasks being draining physically and emotionally, feeling more isolated, and the potentially dangerous behaviors, such as physical or verbal aggressive outbursts (Schonberger et al., 2010; Tam et al., 2015). Additionally, the disruption in roles and responsibilities has led to investigations in cohesion between family members after an ABI, as families adjust from the “old us” to the “new us” (Godwin et al., 2014; Saban et al., 2014). Though these functional areas of a family are necessary to address for the purpose of adjustment and long-term benefits, addressing family identity is also a crucial part of rehabilitation as it addresses how the family has processed systemically how an ABI has changed values, meanings, and sameness of the family.

Though previous research has addressed how an ABI can impact family identity, the focus has been upon functional shifts, supporting families in the changes, and the experience of the change in other family members, primarily the member with an ABI (Godwin et al., 2014; Ownsworth, 2014; Rashid et al., 2014; Tam et al., 2015). However, there still remains a lack of understanding in how mothers experience, perceive, and comprehend family identity and the reformation of family identity after an ABI. Gaining the mother's perspective is important due to the traditional centrality mother's hold in the family system in nurturing and caring (Ruddick, 1982). A child with an ABI can become a chronic stressor as mothers become aware of changes to their child and how the ABI is impacting the greater family system (Ownsworth, 2014). The effect of a childhood ABI to the family system could cause the loss of collective identity (e.g., in our family we all like to ski) or of relational identity (e.g., after our child received an ABI my wife and I cannot get away from the children).

As the roles and responsibilities have changed for the parents, these shifts affect the relationship between parent and child with an ABI and the entire family system (Degeneffe, 2001; Kreutzer et al., 2002; Ownsworth, 2014). For mothers, role shifts often are unique and more drastic as mothers in western cultures would sacrifice careers, hobbies, and other passions to provide care to the ABI child (Choi et al., 2005). Each member of the family has to understand their new position and role in the family system. For example, if an individual once held the identity of being the peacemaker in the family, after an ABI to a child this role may no longer be appropriate or functional for the individual. The perceptions of sameness and continuity of a family disappear as the family adapts to the new situation.

Rationale for Study

While the study of individual self-identity after an ABI is on the cutting edge of research (Wilson, 2011), the self-identity of mothers with a child with an ABI and their perception of family identity remains relatively unexplored. Specifically looking at mother's self-identity was chosen due assumptions, cultural norms, and expectations place upon mothering and women. The meanings and beliefs placed upon mothers position them to take on roles that will be the most involved in caring for the ABI child. The body of research on ABI and caregiving parents has focused on the struggles, challenges, and areas of support that parents need when becoming a caregiver for a child with an ABI (Rashid et al., 2014; Tam et al., 2015). With the numerous studies investigating caregiver mental health, well-being, and challenges in caregiving (Degeneffe, 2001; Lefebvre, Cloutier, & Levert, 2008; Tam et al., 2015), there still remains a lack of understanding of how a child with an ABI influences a mother's overall self-identity and the family identity. When there is an identity struggle, it can lead to the use of negative coping skills, such as substance misuse or avoidant behaviors, as a way to engage in the changes of the family and the accompanying depression and meaningless that could be present.

This study focused on how a mother's self-identity is influenced by a child who received an ABI. Mothers will have to adapt, personally and as a family system, to the functional, affective, and relational changes to a child with an ABI (Rashid et al., 2014; Schonberger et al., 2010). The experience of mothers making sense of and trying to understand the shift in self-identity is important to understand, as this human experience is often viewed as secondary to other rehabilitation needs and services and mothers have heavy caregiving responsibilities that will support the treatment and goals of rehabilitation. Additionally, parents are more likely to be the source of structure, direction, and power within a family. This positions mothers to be in a role to shape the family identity as they themselves are at a developmental age where self-identity is more concrete (Erikson, 1963). Therefore, this study investigated how mothers understand and experience their reconstructed self-identity and how their self-identity is integrated with other family members' self-identities to re-construct a family identity following an ABI to a child. The struggles with self-identity and family identity can create further distress for the parent and the family.

The final part of this research study focused upon the rehabilitation services utilized after an ABI. With the multitude of changes a family can experience from an ABI, the advancement of literature on rehabilitation services is necessary to better enhance, improve, and stabilize areas of functioning for the individual and the family (Ownsworth, 2014). Furthermore, the heterogeneity of deficits an ABI can have makes the rehabilitation process complex, often involving multiple services and professionals (Godwin et al., 2014; Judd & Wilson, 2005). For childhood and adolescent ABI, the mothers and other care providers will be intimately involved in the rehabilitation is various ways (Rashid et al., 2014). More often than not, the child with the ABI will be the direct recipient of services, but that does not mean that mothers are not influenced by or influence rehabilitation. Exploring mothers' perceptions of services and how services address self-identity and family identity is needed to further develop effective interventions and services. The knowledge of maternal experience can help to identify areas to foster more targeted services or an area for rehabilitation that is missing.

Purpose Statement

This research study explored process of mothers who have a child with an ABI in reconstruing self-identity and family identity and how rehabilitation services address these aspects (or not) with mothers and the family. The processes of reestablishing self-identity and family identity will be informed by the Contextual Model of Family Stress (CMFS; Boss et al., 2017), which will be explored further in the next chapter.

Research Questions

1. How do mothers of a child who has received an ABI construe and reconstruct their self-identity?
2. How do mothers reestablish family identity, after a child has experienced an ABI?
3. When a child receives an ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive maternal self-identity and family identity?

Chapter II: Literature Review

Childhood and adolescent ABI has garnered particular attention, as this cohort is more at risk for acquiring an ABI - specifically ABIs due to accidents or sport related injuries - compared to most other age groups (Brown et al., 2008; Ownsworth, 2014; Taylor et al., 2017). The three age groups that are at the highest risk of receiving an ABI are those 75 and older, those between 0 and 4 years of age, and those between the ages of 15 and 24 (Langlois et al., 2006; Taylor et al., 2017). These age groups are most susceptible to falls, motor vehicle crashes, and sports injuries.

However, some studies report that children between the ages of 4 and 12 are most at risk for acquiring an ABI compared to those in other age groups (Coronado et al., 2015). Coronado et al. (2015), in an analysis of the National Electronic Injury Surveillance System-All Injury Program, highlights that research regarding childhood ABI has established many protective measures and interventions (e.g., helmet use, wearing seat belts, and the "Heads Up" program to improve prevention, assessment and response for athletes) to prevent and reduce the occurrence of childhood ABI. Though death is a possibility with an ABI, the majority of individuals diagnosed with an ABI survive, and they and their families must deal with the long-term effects brought on by the injury (Faul et al., 2010; Taylor et al., 2017).

One long-term effect of an ABI is the financial burden. The cost of hospitalizations, rehabilitation, loss of income and productivity, and other indirect costs related to ABI totaled to an estimated $60 billion in the United States in 2000 (Finkelstein et al., 2006). More recently, these costs have increased. The Brain Injury Association of America (2013) estimates that direct and indirect costs of brain injury have risen to $76.3 billion annually. The financial burden of an ABI on families is significant, with an increase in use of medical and mental health services

(Homaifar et al., 2009). Due to an ABI, families often access an increased number of rehabilitation services which could include speech therapy, physical therapy, neurological and psychological testing, or occupational therapy. Not only do these services have independent costs, the cost of travel and time spent accessing appointments needs to be considered to recognize the total financial burden to the family. Furthermore, when an adult family member receives an ABI, the person may be unable to work or have a reduced employment status (Cuthbert et al., 2015). An ABI to a child can have a similar effect on parental employment, reducing or terminating employment as family members allocate more time to caregiving tasks (Kean, 2010; Landau & Hissett, 2008).

An ABI is classified under the category of acute onset, meaning that the injury comes about suddenly and often unexpectedly (Rolland, 2018). Acute onset injuries bring about unique challenges for individuals and families, for in "experiencing an acute-onset condition the emotional and practical changes are compressed into a short time and require more rapid family mobilization of crisis management skills" (Rolland, 2018, p. 21). In a short time, the mother of a child with an ABI tries to understand deficits and the extent of the injury and prepare for potential changes (Rolland, 2018). The differences between families must be recognized as some families and individuals will have more resources, coping skills, and/or supports to deal with rapid change.

Another distinguishing trait of an ABI is that the injury is a non-normative life event that no family or individual can anticipate (Ownsworth, 2014; Taylor et al., 2017). The interplay between individual development in a child and the developmental stage of the family provides an intersection with unique challenges for individuals and families who experience this non-normative event (Degeneffe, 2001; Rolland, 2018). The sudden and unexpected nature of an ABI can influence families in a multitude of ways and how the family responds to the changes that occurred in the child that received an ABI.

The functional outcomes for a child with an ABI, compared to outcomes for an adult, will differ, in part, due to the continuing maturation processes of the brain and the development of multiple skills occurring during childhood including language development, executive functioning, and fine motor skills (Babikian & Asarnow, 2009; Ownsworth, 2014). The developing brain is a contributing factor to the complexity of an ABI in a child. From birth to about 4 years of age, there is significant grey matter growth, which indicates growth of a child's neural passages (Johnson, 2001). This is followed by a second wave of synaptogenesis, which is the formation of synapses between neurons, between the ages of 6 and 12, and is necessary for the development of more sophisticated skills and functions (Gogtay et al., 2004; Johnson, 2001). All of this growth occurs before the pruning of cells and synapse during adolescence. During this growth of the brain, an ABI can disrupt skills that are currently developing and delay the development of other skills, such as emotional regulation, attention, and processing speed of cognition and memory retrieval (Anderson et al., 2010; Ewing, 2006; Ewing-Cobbs et al., 2006). The deficits or interruptions in multiple skills from a childhood ABI can have multiple trajectories, including a) an initial decline followed by recovery to premorbid levels, b) consistent delays in comparison to other children of the same developmental cohort, and c) a delay in the recognition and diagnosis of deficits (Babikian & Asarnow, 2009; Levin, 2012). Though there are multiple trajectories, an ABI is a lifelong injury to the child, as deficits and problems are found to persist into adulthood (McKinlay et al., 2009).

The life-long persistence of problems associated with an ABI into adulthood positions ABIs as constant-course conditions, meaning that after the initial recovery from the injury, the

ABI is characterized by an observable and diagnosable deficit in functioning that will remain stable into the future (Rolland, 2018). An ABI being categorized as a constant-course condition can shift family roles and responsibilities as the family adjusts to functioning with the deficits brought on by an ABI to a child. Findings from qualitative interviews with ABI caregivers conducted by Tam et al. (2015) highlight the struggles of a constant-course condition as caregivers recognized “it’s ongoing” and how “they had been working on the same issues over many years” (p. 4).

Beyond the initial crisis of an ABI, when stabilization of the injury is occurring, death is not typically a long-term concern for the family. As a result, families and mothers will not focus on when will our child die but rather be focused on when will this end as caregiving can be exhausting and draining (Godwin et al., 2014; Rashid et al., 2014). An ABI to a child can be a life-long unexpected task. McKinlay et al. (2009) found that evidence of hyperactivity and attentional and conduct problems were more likely to persist into adulthood if the ABI was sustained before the age of 5. Similarly, Anderson et al. (2005), found that children 8 years-old and younger who sustained an ABI had an increased likelihood of poor cognitive outcomes in memory, goal directed tasks, and lower IQ scores at 12- and 30-months post-injury compared to other children their age. Furthermore, McKinlay et al. (2002) found that, when they were between the ages of 10 and 16, children who experienced a mild ABI before the age of 10 had higher rates of hyperactivity, attention, and conduct problems than their peers.

A meta-analytic study of 28 peer reviewed articles on pediatric ABI, birth to 16 years-old, conducted by Babikian and Asarnow (2009), revealed that children with severe ABI had a distinct trajectory of deficits in cognitive performance that increased over time. In most neurocognitive domains, there were decreases in functionality in working memory, visual perceptual skills, and general intellectual functioning relative to controls for the study, that being the functional abilities of peers of the child with ABI. Another study conducted by Ylvisker and Feeney (2007) found that there were more evident longer-term communication deficits, from impairments to executive functioning and perceiving social situations negatively, in children who acquired a severe ABI at a younger age. In comparison to mild and moderate ABIs, a severe ABI to a child at any age will more likely result in poor outcomes in cognitive, social and behavioral functioning (McKinlay et al., 2009; Ownsworth, 2014). That said, mild and moderate ABIs can still have significant influences on functioning, although a severe ABI is much more likely to result in persisting functional impairments (McKinlay et al., 2002; Ownsworth, 2014).

Childhood ABI and the Family

Beyond the effects of ABI on the injured individual, ABI has long been recognized as a "family injury" due to its effects upon the non-injured family members (Degeneffe, 2001; Kreutzer et al., 2002; Ownsworth, 2014). Family can consist of all members of the current household and may also include members of the extended family system, friends, professionals, or other individuals who may function as family members (Rolland, 2018). A family's experience of an ABI is influenced by multiple factors that can prove to be either protective or risk factors. Protective factors could include pre-injury positive communication patterns, cohesion between family members, or coping and social resources (Ownsworth, 2014; Sherwood et al., 2004). Risk factors could include severity of the ABI or negative interpersonal interactions in the home (Bowen et al., 2009; Degeneffe, 2001).

The prognosis of functional outcomes in a child with an ABI is greatly influenced by the quality of the family environment. Li and Liu's (2012) review reveals that a family's socio-economic status (SES) and the parenting style used by the parents influenced the child's behavioral outcomes. For example, an authoritative parenting style has been associated with increased development of social skills due to the combination of warmth and limits (Li & Liu, 2012), whereas authoritarian and permissive parenting styles are related to long-term behavioral problems such as aggression (e.g., verbal and physical) and emotional dysregulation; Yeates et al., 2010).

The study by Li and Liu (2012) supports literature within the broader field of disability studies that families with limited socioeconomic resources struggle to provide the services and assistance that the child needs (Van der Mark et al., 2017). Furthermore, Taylor et al. (2002), in their longitudinal study of 189 children with severe or moderate ABI, found that children from a dysfunctional social background, meaning low SES, with a lack of parental support or engagement, or with negative parent-child interactions, were two times more disadvantaged in understanding social situations and responding appropriately and academically performing in mathematics and reading comprehension than other children with a similar ABI diagnosis. The children were also less likely to ‘catch up’ to peers without an ABI (Taylor et al., 2002). Additionally, Kurowski et al. (2011) found that, when there were lower levels of family dysfunction such as positive conflict resolution, communication and non-permissive parenting, the injured child had better outcomes in executive functioning and attention.

Children with an ABI are more dependent upon a positive and supportive family environment for the best outcomes in multiple domains of functioning (Greenberg & Crnic, 1988; Landry et al., 1997). It is necessary for the social environments of a child with an ABI to be supportive in order to facilitate experience-dependent recovery (Ownsworth, 2014). The pre-morbid social environment is also important as research on families and ABI has revealed that the impact of the ABI on later family functioning and cohesion is related, in part, to the pre-injury quality of the relationships, family cohesiveness, social resources, care demands, and availability of support and resources (Sherwood et al., 2004; Taylor et al., 2002). With research demonstrating the importance of a supportive and structured family life, this further highlights the importance of promoting and supporting self-identities among family members and the family as a whole post-ABI.

An ABI can dramatically alter the functioning of a family. Since an ABI is a constant-course condition, meaning that there is not a prognosis of death, it is important for families to develop a plan for caregiving or managing other potential changes informed by the trajectory of the ABI and the limitations brought on by the injury (Rolland, 2018). This adjustment will lead to changes in roles and responsibilities in the family as the individual who received the ABI and the family need to reorder the functionality of the family to the semi-permanent change that will likely remain stable over time (Rashid et al., 2014; Saban et al., 2015). For example, relationships within the family can change due to shifting roles and responsibilities (Godwin et al., 2014), or parents' career or social pursuits may be restricted due to the increase in caregiving tasks (Ownsworth, 2014; Rashid et al., 2014). Kirk et al. (2014), in a qualitative study of parents' emotional and information support needs, revealed that parents felt unsupported in taking on their child's behavioral and psychological difficulties, leading to feelings of uncertainty in their parenting skills and competence. These findings illustrate the struggle parents face in understanding their new roles and responsibilities.

The acute onset of ABI requires a family to make decisions quickly about roles and responsibilities (Rolland, 2018). The suddenness of ABI, paired with the long-term consequences, reveal the importance of communication between family members to promote a positive family environment. Tam et al. (2015) reported that parents of children with an ABI experienced frustration in communicating directions to the injured child. Additionally, between non-injured family members, it was common for assumptions to be made about who did what task which led to further frustrations between family members (Godwin et al., 2014; Tam et al., 2015).

Clear and consistent communication, effective processes, and problem-solving collaboratively are all essential to families of individuals with an ABI. This importance is supported by a Hobart-Porter et al. (2015) clinical trial of effective communication between parental caregivers and adolescents with an ABI. Results revealed that parents that utilize problem-focused coping strategies (i.e., strategies that look for solutions by problem solving) had more effective communication and lower levels of caregiver negativity (Hobart-Porter et al., 2015). These communication characteristics help to build cohesion and foster a positive home environment, which is important to the improvement of the child with the ABI (Kreutzer et al., 2002; Wade et al., 2011).

The changes to roles and responsibilities and the communication of needs influence more than the practical functionality of the family. The interpersonal relationships between family members can be affected, creating further distress. For example, Godwin, et al. (2014), in a grounded theory analysis on couple relationships with an ABI, found that couples can experience a tension between the “old us” and “new us.” The experience of the “old us” and “new us” can create a loss of connectivity, security, future, and relationship identity (Godwin et al., 2014). Tam et al. (2015) supports the difficulty of family relationships adjusting to the new norm after an ABI. Interactions and responses with the injured child need to be modified as previous methods of parenting or communication may no longer work. Furthermore, the new family system may not allow for as great of an investment in leisure activities (Rashid et al., 2014; Tam et al., 2015). The tension between the "old us" and "new us" reveals a perception from the caregiver that the family has changed and there is a loss of the who they were before the injury (Godwin et al., 2014; Tam et al., 2015).

When a family member obtains an ABI, grief and loss occur in multiple ways for individuals within the family. The individual with the ABI may grieve the loss of functional skills and mental abilities, if the individual is aware of and notices these changes (Ownsworth et al., 2011). Furthermore, non-injured family members may grieve the loss of the premorbid family member (Saban et al., 2015). Specifically, parents of a child who experienced an ABI may feel the profound loss of the child's future and the expectations the parents had for the child (Ownsworth, 2014). In Ownsworth et al. (2004) qualitative interviews of parental caregivers, the results revealed the loss parents experienced due to their child with an ABI struggling socially and not being able to live the life the parents expected for the child. The feelings of loss and grief associated with an ABI can be classified as ambiguous loss (Boss, 2006; Kreutzer et al., 2016), as there are psychological and relational losses to the family, but the family member is still physically present. With ambiguous loss, "meaning is ruptured, relationships go awry, and family conflict increases" (Boss & Carnes, 2012, p. 456). The loss of meaning is important to understand for meaning is greatly influenced by an ABI and how a person understands all of the changes.

Though it can be clear an ABI requires long-term care and lifestyle adjustments, an individual may struggle to adjust meanings and emotions to the current situation. The parents will need to re-construct their understanding of the world as changes to lifestyle due to an ABI are unpredictable (Ownsworth, 2014). This can be an ambiguous process which can lead to challenges in navigating the relationships, responsibilities, and roles within the family (Godwin et al., 2014). Meaning is defined as the comprehension of how people make sense of their selves, the world around them, and the interactions between the two (Steger et al., 2013). The process of making sense of oneself and the world is vital to parents who had a child experience an ABI (Ownsworth, 2014). With an ABI being a sudden and unexpected injury, the experience of an ABI puts a family in a situation of not knowing how to makes sense or meaning of the experience initially. Previous meanings or beliefs may no longer be helpful to the parent or the family system. Making meaning is the process of understanding the events of an ABI and the transpiring impacts the injury has had upon the parent and the family system. This study attempted to address this gap by studying maternal meaning after a child acquires an ABI, specifically concerning self-identity and family identity.

Though there are gaps in how meaning in constructed after a unexpected injury, Claudio et al. (2016) address meaning after a spinal cord injury. A spinal cord injury shares commonality with an ABI in that both are acute onset and constant course conditions. Claudio et al. (2016) addressed the process meaning has in adjustment from before the injury and after the injury. Several important findings to highlight are the discrepancy between situational meaning, meaning that "embodies what happens within an individual in the aftermath of trauma" (Claudio et al., 2016 p. 264), and global meaning, which would include beliefs, goals, and subjective feelings. There is a greater distress in an individual when situational meaning is inconsistent with the global meaning of a person. For example, the situational meaning of an ABI (e.g., my life is focused on my child now) may not fit with the previously possessed global meanings (e.g., I hope to be promoted soon in my career). Additionally, Claudio et al. (2016) point out that not all people will need to search for meaning; some will be able to adjust without the processes of searching and reconstructing meaning.

Since some individuals may not need meaning to adapt after a child receives an ABI, it can become complicated when another family member needs to make meaning after the injury. Family members are interconnected with each other, and when one member has distress in meaning and it is not important to another, it can be difficult to support or understand the distress of the other (Ownsworth, 2014). This is an important underlying aspect that parents and families need to have addressed in the rehabilitation of an ABI (Ownsworth, 2014). Meaning, values, and beliefs can provide purpose and direction, allowing for sudden changes and ambiguous situations to have more clarity (Boss, 2006). Even if a person is not directly struggling with meaning, having services that help to explain and engage the distress of another family member would be beneficial. Meanings and values are connected to self-identity and family identity, as meanings and values will influence and shape perceptions of self-identity and family identity.

Self-Identity and Family Identity

An ABI to a child can cause the family to access their belief systems, values, and comprehension of self and the world to create meaning and thus promote competence and mastery of the situation (Rolland, 2018). The sudden onset of an ABI forces the family to adjust relationships, rules, roles, and meanings from pre-injury to post-injury (Ownsworth, 2014). The shifts in multiple aspects of a person's life result in changes to identity, both individual and systemic. As noted previously, self-identity is defined as the unique and persistent qualities and characteristics of self as experienced and perceived through the person's conscious awareness of inner sameness and continuity (Allport, 1961).

The changes that have been highlighted throughout this chapter to individual and family functionality, roles and responsibilities, interpersonal relationships, and meaning all influence self-identity (Ownsworth, 2014). The changes to self-identity are complex, involving multiple aspects to a person, and are therefore not easy to address. Given the challenge in addressing such abstract parts of the human person, research on post-injury self-identity has been increasing, as have the use of neurorehabilitation and psychotherapy approaches in combination to address self-identity transition after an ABI (Gracey & Ownsworth, 2008; Ownsworth, 2014; Ylvisaker et al., 2008). For example, Ylvisaker et al. (2008), in a qualitative study, utilized metaphoric identity mapping with individuals who acquired an ABI and found that this intervention was successful in facilitating meaningful goals for the participants. However, though self-identity is recognized as cutting-edge research in people with an ABI (Wilson, 2011), future work should address self-identity of non-injured family members and how self-identity is based on not only functional gains and abilities but on the experience of meaning of the individuals. My dissertation has started this process of exploring self-identity of non-injured family members, specifically mothers.

The experience of self-identity of parents after a child receives an ABI is relatively unknown but is important to understand because the struggles of parents could impact the rehabilitation of the injured child and the family (Degeneffe, 2001; Ownsworth, 2014). Self-identity for a parent can be difficult to process, as Godwin et al. (2014), through qualitative interviews, demonstrates that caregivers are able to see “old versions” of themselves, the injured family member with the ABI, and the relationship between the two. These “old versions” are then intermingled with the “new versions.” However, at the same time, these oscillations between the two can generate frustration and grief over what has been lost (Godwin et al., 2014; Ownsworth, 2014). Ownsworth (2014) highlights that parents may feel the loss of the child they “should have had” and grieve the anticipated future of the child (e.g., graduating from university, getting married, having a career, etc.). This guilt can lead to changes in understandings of who they are as a parent, thus shaping a parent's self-identity.

The role of mothers is important in self-identity, and previous literature has explored the gendered expectations projected upon mothers, such as being the nurturing parent, the moral teacher to children, and the primary caregiver (Coll et al., 1998; Heisler & Ellis, 2008), and the ideology of motherhood (Choi et al., 2005). Mothering is constructed through societal and cultural beliefs about women and the role of mothers (Ruddick, 1982). The importance of this role in self-identity and the growing demand to attend to gender has garnered particular attention of mothering in the literature of disabilities studies. For instance, Leiter et al. (2004) found that more than half of the mothers of children with disabilities in their study reported reducing their hours at work, and more than half of the mothers were required to completely stop employment to take on full time caregiving tasks. Furthermore, the results described intensive caregiving duties that often had a long duration (Leiter et al., 2004). Similarly, the qualitative study conducted by Muthukrishna and Ebrahim (2014) highlighted important themes of struggle, resilience, and agency. Mothers discussed the importance of the intersection of personal histories, spirituality, and the economics and politics in negotiating access to social benefits.

Much of the research on parents and identity is focused on family identity, which describes interpersonal interactions and meanings (Ownsworth, 2014). Family identity is a collaborative, co-constructive process that includes the family's subjective sense of sameness and continuity over time (Bennett, Wolin, & McAvity, 1988; Ownsworth, 2014). Ownsworth et al., 2004, demonstrate the struggle parents can experience with the disrupted sameness and continuity of the family and this disruption can have implications upon the reconstruction of family identity. In a qualitative study of caregivers (Ownsworth et al., 2004), a common theme was that parents wanted their child to live as normal a life as possible. Though the parents wanted to give their child independence, this desire was at odds with the child's increased needs of supervision and support. How the family functions, expectations, hopes, and meanings about what it meant to be a parent in this family changed due to an ABI. Furthermore, the current research highlights the impact an ABI has upon interactional patterns in relationships, thus redefining how family members understand these relationships (Ownsworth et al., 2004; Saban et al., 2014; Tam et al., 2015). This is why the reforming of family identity is necessary in the rehabilitation process. Family identity, as well as self-identity, can help mothers to understand and make sense of all the transitions that stem from the ABI to the child. This study provides findings to progress the understanding of the process family identity undergoes after an ABI to a child and how to support family identity.

Self-Identity and Family Identity in Rehabilitation Services

When a child acquires an ABI, families often have a need for services, education, and additional support, depending on the deficits that have emerged. Common rehabilitation services for a child with an ABI include speech therapy, neurology, occupational therapy, physical therapy, Individual Education Plans (IEP), and psychotherapy (Judd & Wilson, 2005; Ownsworth, 2014). The literature on ABI and other disabilities, such as intellectual disabilities or autism, reveals that parents can experience anxiety, doubt, stress, or a lack of awareness when engaging with professional services to assist with challenging behavior brought on by a disability (Cuzzocrea et al., 2016). Many times, parents are so overwhelmed by the unexpected changes of having a child with an ABI that the information regarding best practices and psychoeducation can be overwhelming (Ownsworth, 2014; Rolland, 2018).

Even if families and mothers are able to identify services to meet their needs of the child with a disability, the individual needs of the mothers and family are not always being addressed by the service providers connected to the family (Zuna et al., 2016). For example, Robert et al. (2014) found that parents of a child with a developmental disability wanted to be more involved in decisions regarding the services their child and family were receiving. Even if mothers voice needs, it does not guarantee that the rehabilitation services will be able to grant these requests. That being said, research has demonstrated that it is best practice for the well-being and satisfaction of the parents that support services meet the needs to the family as well as the child (Robert et al., 2014).

Helping families to receive the support and services that will be most beneficial for them and the child with an ABI is important to the rehabilitation process. Many services and supports for ABI involve family interventions, as an ABI is a family injury (Ownsworth, 2014; Woods et al., 2013). Many of the current family interventions being utilized are focused upon psychoeducation, communication skills, parenting with warmth and limits, and providing a space to discuss challenges (Ownsworth, 2014; Zuna et al., 2016). For example, the Making Sense of Brain Tumor Project (Ownsworth et al., 2013), which includes a combination of individual and couples therapy sessions, provides some of these interventions. During these sessions, goals that were addressed included managing effect of the brain tumor, managing anxiety, depression, and mood swings, supporting occupational re-engagement (e.g., returning to work, parenting skills), communicating fears about having a brain tumor, and improving relationship functioning (Ownsworth et al., 2013). These goals are all valuable in rehabilitation but miss addressing the experience of self-identity and family identity directly. My study clearly identifies the processes of self-identity and family identity which can allow for more direct intervention on self-identity and family identity in the rehabilitation process.

The literature on rehabilitation services for ABI has been primarily attentive to physical, cognitive, and emotional-socio rehabilitation (Ownsworth, 2014). What is not being addressed is the personal experience of self-identity and family identity. Just as self-identity and family identity cannot be defined by objective gains (Ownsworth, 2014), rehabilitation services need to recognize that there are parts of the human experience that are beyond quantifiable measures and progress. The lack of attention given to interventions relevant to meaning, self-identity, and family identity can make it difficult to approach these topics for consumers and providers in the rehabilitation process.

Theoretical Framework: Contextual Model of Family Stress

For the current study, I used the Contextual Model of Family Stress (CMFS; Boss, 2002; Boss et al., 2017) as the guiding theoretical foundation. CMFS provided a framework to understand the stressors, resources, perceptions, and the contextual factors surrounding a family who have a child that has acquired an ABI. Self-identity and family identity can be resources (or barriers) in adaptation and how a person views their own self-identity or the family identity will influence the perceptions that are being made about the ABI event and following consequences. The definition of stress is a “disturbance in the steady state of the family system” (Boss et al., 2017, p. 2). Notice that this definition highlights an event that has disrupted the family. Stress is therefore not a judgement or a negative event to the family; rather, the outcome of the family will depend upon the resources and perceptions available to the family. An ABI, though the injury is undesirable, is a disturbance to the equilibrium of the family, and the family will now have to adjust.

The fundamental understanding of family in CMFS is “a continuing system of interacting persons bound together by processes of shared roles, rules, and rituals, even more than shared biology” (Boss et al., 2017, p.4). This definition of family emphasizes process and function over structure (Boss, 2016). The attention on process and function stems from CMFS’s conceptual foundation of symbolic interaction, a school of thought which focuses on a family’s interactions and the symbols of interaction, such as language and rituals (Bowen et al., 2013). This interactive process, defined as family perception, constructs a symbolic reality based upon shared meanings and role expectations within the family. The family then develops a unified group view to process situations (Boss et al., 2017). When a stressor event, such as an ABI, occurs, the family will have a unified view of the ABI event and the subsequent consequences.

The adaptation to a stressor event will depend upon the family’s resources and perceptions. Resources can reside in individuals, families, and communities, such as financial means, religious community support, or factors in family organization. These resources, or lack thereof, could help or hinder the manage the stressor event. Perceptions of the stressor event are part of the adaptation process. However, not all families are able to develop a unified view of the stressor event, leading to problematic perceptions. Boss et al., (2017) point out that families who remain rigid with troubling perceptions struggle to adapt to the stressor, for example, a family member who denies the needs of a child with an ABI needing quiet rest time or activities with low stimulation. The goal is that eventually the family will have a convergence of perceptions about the stressor event and what it means, even if the meaning is that the event will never make sense (Boss, 2006). For example, a mother, overprotective of ABI child, and father, treating the child normally, could converge their perceptions of the ABI child to find a balance between their perceptions.

The CMFS model emphasizes that the family and the individuals within the family have the ability to avoid or survive a crisis, and that ability is influenced by internal and external contexts (Boss, 2002). Internal context, which the family has some control of, includes the structural, psychological, and philosophical domains, as well as the values and beliefs of the family (Boss et al., 2017). Connecting the internal context with ABI literature on self-identity and family identity, each of these dimensions in internal context are connected to a person's and family's sense of continuity and sameness.

The internal context is an important concept to this research study. Each family member's perceptions of the ABI will need to be communicated within the family to adjust meanings, beliefs, and values within the family system. Furthermore, as previous research has demonstrated, an ABI will impact a family's structural functioning, belief and value systems (philosophical domain), and psychological processes (cognitive and affective). For example, a parent who gave up a career to focus on caregiving tasks (structural domain) may struggle with emotions of resentment for the loss of their career and guilt for feeling that way (psychological domain; Degeneffe, 2001; Ownsworth, 2014). How family member perceives an event will determine their ability to activate coping mechanisms and problem-solving strategies (Boss et al., 2017).

External contexts demonstrate that individuals and families do not live in isolation. The domains of external context include culture, history, economy, development, and heredity. The family has less control or influence of external contexts compare to internal contexts (Boss et al., 2017). External contexts are crucial to understanding self-identity and family identity because larger contexts are influential in the perceptive process of individuals and the family. For example, cultural beliefs of not showing emotion can interfere in the psychological domain of affective processing after a child receives an ABI and could hinder positive adaptation. Ownsworth (2011) highlighted that families with an ABI family member with less financial resources or live communities with less medical care fare worse compared to similar families with great financial means and access to resources.

The internal and external contexts for mothers and their families can further be described using identity theory (Thoits, 1991). Thoits (1991) posits that individuals have role identities that are defined through social roles, social attributes, characteristics, and social types. These role identities are the self-conceptions of "enduring, normative, reciprocal relationships with other people" (Thoits, 1991, p. 103). Role identities provide meaning and a sense of who a person is (in an existential sense) and how one ought to behave and act (Thoits, 1991). A stressor, such as an ABI to a child, "disrupts or threatens to disrupt an individual's most salient role-identities" (Thoits, 1991; p. 106) and can be identity-threatening or identity-enhancing, depended upon how individual appraises the disruptive event or experience. For example, the role of mothering can be enhanced (i.e., finding new meaning and purpose in mothering a child with an ABI) or threatened (i.e., not wanting to be a mother to a disabled child).

Other concepts important to the CMFS are ambiguous loss, boundary ambiguity, and coping. Ambiguous loss refers to a loss that is unclear and is without closure (Boss, 2004). An ABI is such a loss as individuals and families often have to grapple with the phenomenon of processing the change from the "old us" to the "new us" (Godwin et al., 2014; Saban et al., 2014). Both self-identity and family identity can experience this change from the "old us" to the "new us." As roles, structures, and responsibilities transform in the aftermath of an ABI to a child individuals' self-identity and the family identity be reconstructed in the new context of the ABI. This ambiguous loss is a stressor situation (Boss et al., 2017), as the ABI child is still physically present but, due to the injury, is not psychologically present in the way before the injury. Connected, but distinct from ambiguous loss, is the concept of boundary ambiguity, which refers to a lack in understanding of who is in or out of a family system (Boss & Greenberg, 1984). This creates confusion in perceptions among family members regarding who is part of the family and who is responsible for specific roles and tasks. For example, there may be confusion about new caregiving tasks or who is responsible for working with insurance companies to ensure services for the ABI child. An ABI to a child can create confusion as roles and tasks are often taken on without clear communication, which leads to ambiguity (Godwin et al., 2014; Rashid et al., 2014). Like ambiguous loss, boundary ambiguity is a perceptual response to a stressor that is the ABI.

Another important concept to integrate into a CMFS (Boss et al., 2017) application when looking at self-identity and family identity is resilience. Resilience scholars have differentiated between individual and family resilience (Boss et al., 2017; Patterson, 2002). Resilience has been defined in multiple ways across disciplines. An interdisciplinary integration of resilience exemplifies the concept of individual resilience, which can generally be understood as higher than expected functioning following a stressor event(s) (Boss et al., 2017). Boss et al. (2017) and Patterson (2002) provide conceptualizations for resilience and stress adaptation within families. Both emphasize family processes (i.e., structure, rules, communication) and shared meanings between family members that promote positive outcomes following stressors that would normally lead to crisis (Boss et al., 2017; Patterson). Furthermore, Patterson (2002) continue to build on resilience and adaptation, highlighting that a family’s positive adaptation to stressors is due, in part, to the process of interactions among on-going demands and capabilities.

The Present Study

The goal of this research study was to contribute to the literature on families of individuals with an ABI by gaining a better understanding into the processes of reconstruing self-identity and family identity for mothers, after their child receives an ABI. This study responds to the call for further research to illuminate self-identity and family identity as a means to better support mothers and families (Ownsworth, 2014). Furthermore, this study aims to expand the ways rehabilitation services can better support mothers of children with an ABI and the overall family. To that end this study aims to answer the following questions:

- How do mothers of a child who has received an ABI construe and reconstruct their self-identity? (RQ1)
- How do mothers reestablish family identity, after a child has experienced an ABI? (RQ2)
- When a child receives an ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive maternal self-identity and family identity? (RQ3)

Chapter III: Methodology

Overview of Research Design

The first step in the research design was to conduct intensive in-depth interviews with participants. This process began with participants completing, by verbal response to the researcher, a demographic questionnaire and two subscales from the Family Impact Questionnaire (Donenberg & Baker, 1993). Once the questionnaires were completed, an in-depth interview was conducted. After audio recordings were transcribed, I analyzed the data from the questionnaires and the interviews, utilizing constructivist grounded theory, to develop a conceptual framework of the reconstruing of self-identity, the reconstruction of family identity, and maternal perceptions of rehabilitation services. After finalizing the conceptual model, I engaged in several methods to demonstrate the trustworthiness of the data.

Constructivist Grounded Theory

Constructivist grounded theory (Charmaz, 2014) was chosen as the qualitative methodology for this research study as this approach is consistent with my goals to understand the process of how self-identity is reconstrued and family identity reconstructed after a child receives an ABI. Furthermore, this research study highlights the process of rehabilitation from the mothers' perspectives, providing insight to needs of the ABI child and the family.

As Charmaz (2014) states, "grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories for the data themselves" (p. 1). Constructivist grounded theory researchers move beyond the description of a phenomenon or the exploration of experience to developing a theory, or explanation, of the phenomenon that is being researched. Constructivist grounded theory was chosen because this methodological approach aligns with the research questions, which are process oriented.

Specifically, I sought to discover how mothers, after a child has an ABI, construe and construct self-identity and family identity, and to better understand the experience of mothers when accessing rehabilitation and medical services.

Constructivist grounded theory (Charmaz, 2014) was specifically chosen for its ability to allow participants to speak to their reality and experiences. The methodology of constructivist grounded theory acknowledges multiple realities and accentuates that people construct their own perceptions, meanings, and reality (Charmaz, 2000; Charmaz & Mitchell, 1996). In addition, this methodology “places priority on the studied phenomenon and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data” (Charmaz, 2014, p. 239). The participants are the experts of their perceptions and realities, and I was able to collaborate with their experiences to draw out the process and develop a conceptual framework to better understand the reconstructing of self-identity and family identity after an ABI to a child.

Sample

Size and Selection Criteria.

For this study, the process under investigation was the reconstruction of parental self-identity and family identity after a child receives an ABI. The sample was obtained through purposive homogeneous sampling (Patton, 2015), meaning that participants were recruited intentionally for their particular experience - being a mother to a child with an ABI. This study recruited 14 mothers who have a child who acquired an ABI to participate in this study.

Inclusion criteria required that the child obtained the ABI at the age of 18 years-old or younger, is currently living, and had experienced the ABI at least one year ago. Furthermore, a diagnosis of ABI from a medical professional must have formally been given. The medical classification of a mild, moderate, or severe ABI was not used to determine inclusion in the study, but this information was requested and documented. The event that caused the ABI must have occurred at least one year ago. This time frame was established so that mothers and families had enough time since the ABI occurred to transition and be removed from the potential initial shock and crisis ABIs can bring upon families. The separation from the initial crisis is necessary as mothers and families would start the process of reestablish self-identity and family identity. Further inclusion criteria include that the mother must have lived full time with the child with an ABI since the injury. An exclusion criterion for this study was if a potential participant had a partner who already participated in the study. This research study did not address linked data, so individuals with a partner who participated were excluded. See Appendix A for the screening and recruitment script.

All 14 of the mothers who participated in this study had a child with ABI, though one mother had two children diagnosed with an ABI. Both children were discussed as part of the study, with the mother completing all demographic and questionnaire forms for each child. Thus, there are 14 mothers and 15 children diagnosed with an ABI represented in the study. See Table 1 for a summary of the demographic information for each of the participants.

Recruitment

I utilized purposeful homogenous sampling (Patton, 2015), which was informed by the inclusion and exclusion criteria developed for this study. To obtain participants, recruitment for this study was accomplished through posting flyers on social media platforms (Appendix B), attending support groups and ABI organization functions, emailing leaders of support groups (Appendix C), giving presentations at conferences, and making personal connections. I would consult leaders and administrators of social media groups and support groups first to gain permission to recruit for my study and to build rapport with the ABI community. Through my rapport building efforts, I fostered further connections, was invited to present at a conference, and was invited to serve on a board of a statewide organization supporting ABIs. The development of these relationships allowed for successful use of snowball sampling (Patton, 2015).

Procedures

The IRB of Virginia Tech approved this study in July 2019 and approved amendments to the protocol on November 2019 and February 2020 (See Appendix D). Through recruitment efforts, all participants who were interested in the study emailed the researcher. Screening for inclusion criteria and setting up time for data collection were completed through email. Most participants, when first emailing me, would inform me of the source of their child's ABI, when it occurred, and how it has been impacting their life. I would follow up in an email if I had more questions that needed to be answered to complete the inclusion criteria assessment.

All interviews and collection of data from questionnaires were conducted over the telephone. Participants chose times that would best suit their schedules, and I confirmed verbally that they were in a place that the participant felt comfortable conducting the research protocol. At the time of the interview, I first reviewed the informed consent form (See Appendix E) and answered any of the participant's questions or concerns. Upon completing the informed consent form, the participant completed the demographic questionnaire (See Appendix F), and the two subscales from the Family Impact Questionnaire (Appendix G; Donenberg & Baker, 1993), though the marital subscale was only given to those participants who were married.

Table 1

Participant Demographic Information

Participant	Gender	Marital Status	Race	Education	Income	Employment	Time since ABI Event	Cause of ABI	Number of Children
P1	Female	Married	White	Some College	$80,001 – $100,000	Part-time	7 years	Bike Accident	3
P2	Female	Divorced	White	Associates Degree	$65,001 – $80,000	Full-time	10 Years	Motorcycle Accident	3
P3	Female	Married	White	Some College	$65,001 – $80,000	Disabled Vet	8 Years	Hit by car	4
P4	Female	Married	White	Some College	$50,001 – $65,000	Retired	19 Years	Snowmobile Accident	2
P5	Female	Married	White	Some College	$65,001 – $80,000	Unemployed	2 Years	Car Accident	2
P6	Female	Married	White	Associates Degree	More than $100,000	Full-time	10 Years	Car Accident	2
P7	Female	Married	White	Some College	More than $100,000	Part-time	6 Years	Ischemic Perinatal Stroke	2
P8	Female	Divorced	White	Some College	$35,001 – $50,000	Full-time	3 Years/ 5 Years	Car Accident/ Fall	4
P9	Female	Single	White	Associates Degree	$50,001 – $65,000	Full-time	4.5 Years	Car Accident	2
P10	Female	Married	White	Some College	More than $100,000	Not Working	7 Years	Snowboarding Accident	2
P11	Female	Married	White	Associates Degree	$80,001 – $100,000	Not Working	2 Years	Assault/Strangulation	3
P12	Female	Married	White	Bachelor’s Degree	More than $100,000	Part-time	6 Years	Struck by Lightning	3
P13	Female	Married	White	Master’s Degree	More than $100,000	Part-time	4 Years	Vacuum Extraction at Birth	2
P14	Female	Married	White	Associates Degree	$65,001 – $80,000	Unemployed	2.5 years	Ruptured AVM	1

After the participant had completed the questionnaires, the semi-structured interview (Appendix H) was conducted. I completed the procedures for all of the interviews in this research study. All participants were interviewed individually, and the interviews were recorded using an audio recorder and a back-up recorder to ensure that all data was collected. The entire data collection process took between 90 to 150 minutes. Upon conclusion of each interview, the participants received, through an identified email, their compensation of a 40-dollar Amazon gift card.

At the conclusion of each interview, I also obtained permission from the participant to contact them during the analysis process for the purpose of member checking (Patton, 2015). See Appendix I for the member checking protocol and Appendix J for the consent form for member checking. I discussed with participants the member checking process during the consent process of the initial interview to gauge their interest in participating. The five participants who were willing to partake in the member checking process were sent, via email, a summary of the study themes and conceptual model. Next, I established a time to have a telephone conversation with the participant regarding the themes from the analysis and how these themes reflected their experiences. The telephone calls for the member checking process took between 5 and 30 minutes.

Measures

Demographic Questionnaire

The demographic questionnaire (Appendix F) was constructed for the purposes of this study and was used to collect information about participants’ age, gender, race, ethnicity, marital status, number of children in the home, level of education, household income, and current employment. The demographic questionnaire also included ABI-specific items such as severity of ABI (e.g., mild, moderate, severe), when diagnosis occurred, cause of the ABI, the age of the child when the ABI occurred, and the current age of the child.

Family Impact Questionnaire

Developed by Donenberg and Baker (1993), this measure has 50 Likert-type questions, on a 4-point scale (i.e., not at all, somewhat, much, and very much) for mothers to indicate areas where behaviors of a child with an ABI affect the mother and the family. For this research study, only two subscales were included: Feelings and Attitudes about my Child (11 items), these questions investigated participants perceptions of their child’s behaviors in different contexts and their child compared to other children of similar age to their child, and Impact on Marriage (7 items), exploring the mothers’ experience of how the ABI child has influenced their marriage. These subscales are located in Appendix G. These subscales were chosen for their consistency with the research questions and to limit the burden on participants in responding to questionnaires. An example of an item from the FIQ: Feelings and Attitudes about my Child is “My child brings out feelings of frustration and anger,” and an item from the FIQ: Impact on Marriage is “My spouse and I disagree more about how to raise this child.” Cronbach’s Alpha for reliability for the subscales range from 0.83 to 0.92 (Donenberg & Baker, 1993).

Interview Protocol

The interviews were in-depth and semi-structured (see Appendix H), meaning that the interview questions were open and expansive, allowing for participants to speak to their experiences and to emphasize the perceptions, meanings, and beliefs related to having a child with an ABI. Congruent with constructivist grounded theory methodology (Charmaz, 2014), I, in my role as the researcher, collaborated in the construction of meaning and understanding of the process being researched. I collaborated in the construction of meaning by drawing from my experience, professional, personal, and participation in the interviews to inform and guide how I was making sense of the data.

The interview guide itself consisted of open-ended questions, which were informed by a substantive review of the literature on self-identity, family identity, and current rehabilitation practices provided for mothers and their child with an ABI. Topics covered in the interview include changes in inner sameness and continuity in self and other family members after a child acquires an ABI, how changes from an ABI have changed family identity, how the parent has experienced these changes to self-identity and family identity, and how services are or are not addressing areas regarding self-identity and family identity. Examples of questions from the semi-structured interview included: “How has having a child with an ABI impacted the way you view yourself?” “How would you describe your family before/after ______ received an ABI?” “To what extent did professionals talk to you about how you’re feeling about yourself and your family, about how the outside world might view your family now or react to your child and your family?”

As self-identity and family identity are abstract concepts and could lead to participants not fully understanding how to answer questions, I piloted the interview questions. The process of piloting questions included having my dissertation committee review the interview questions, asking peers to read through interview protocol assessing for understandability, and asking friends and family not familiar to the concepts and theories in self-identity, family identity, or ABI rehabilitation to review questions to provide unbiased feedback. From the feedback I received, I made the necessary edits to the interview questions. Examples of feedback I received included simplify my questions investigating self-identity and to avoid jargon words or becoming too philosophical.

Role of Researcher

Charmaz (2014) states that constructivist grounded theory holds the assumption “that social reality is multiple, processual, and constructed, then we must take the researcher’s position privileges, perspective, and interactions into account as an inherent part of the research reality” (p. 13). I was not a neutral observer or interpreter of the data gathered during this research process. I brought in my own values, assumptions, and beliefs that impacted the construction of the conceptional framework. Throughout the research process, I intentionally made space for reflections on my role of the researcher through journaling and having conversations as needed with my advisor. Building this awareness demonstrated my efforts to develop reflexivity, which is the process by which researchers reflect on how their biases, values, and personal experiences and background will shape and influence the interpretations formed during the research process (Creswell, 2014). Exploring my personal and professional experiences was important in exploring my reflexivity towards the process under investigation.

Reflexivity

I am a white male from a middle-class family in rural Minnesota. My family did not experience any sudden unexpected physical injuries or an ABI. However, my family did experience an adjustment to the diagnosis of Tourette’s Syndrome in my younger brother when I was 10 years old. Though Tourette’s does not have the same impacts on functioning that an ABI can cause, my brother’s diagnosis of Tourette’s Syndrome did require unplanned adjustments to family expectations, roles, and affective processes. The social struggles my brother had during middle and high school influenced the way my family behaved in public situations. My brother was resistant to going to places where he could be visible, and my sister especially was aware of my brother’s motor and vocal tics and was embarrassed when the tics drew attention from others outside the family. My brother’s tics combined with my sister’s reaction always made me anxious, as I could see both perspectives though struggled to reconcile how these both could co-exist together in one family.

The dynamics with my siblings demonstrated to me how differently each family member experienced my brother’s diagnosis and understood how Tourette’s Syndrome influenced the family system. I had to reorder my thinking of what it meant to have a brother with Tourette’s Syndrome. At home, nothing changed, as my brother and I still were able to play and interact with each other. Furthermore, I witnessed my parents trying to balance compassion for my brother for the social difficulties brought on by Tourette’s Syndrome with not allowing my brother to use his tics as an excuse. Throughout my childhood, my parents disagreed on how this balance should look, with my father being more compassionate to my brother’s withdrawing behaviors and my mother wanting my brother to have a normal high school experience.

It is in my clinical experiences as a therapist that I encountered a family with a child that acquired an ABI. As part of my clinical work in a high-crisis wrap-around service program, I provided family therapy to a family with a daughter that experienced a mild ABI at the age of two. When I met with the family, it was two years after the event of the injury. In working with this family, I witnessed the parents’ struggle with self-identity and their family identity. Both parents struggled in the process of collaborating to reconstruct a family identity. This was evident in their disagreements about parenting, boundaries, and parental responsibilities. Furthermore, though self-identity had been reformed, it seemed that these reformations occurred in isolation from each other. This made it difficult to have cohesion in the family and to co-construct a family identity. The mother and father often disagreed over whose perception of the family and situation was more correct. I hypothesized that the parents’ perceptions were so interconnected with self-identity and their understanding of self-identity was so rigid that no new information could enter. My clinical work has biased my understanding of self-identity by seeing the reformation of self-identity after a non-normative event occurring in isolation. These experiences have shaped my understanding of how roles and behaviors in family members shift and can differ from other family members. A diagnosis, in my experience, can alter how a family functions, for the meanings and perceptions about the diagnosis can have grave impacts upon the family.

My personal experiences could have impacted my approach to the analysis of the data in several ways. First, I see the formation of family identity after unexpected transitions as difficult due to family member processing events and meanings differently. It is difficult to collaborate in constructing a family identity when all the individuals of a family have various understandings, needs, and desires. Additionally, there are philosophical assumptions I hold about human nature. I hold the assumption that the experiences and perceptions each person has informs the meanings a person makes about the world around them and how each person understands their place in the current context. These experiences are subjectively unique to each person, even when experiencing the same objective reality. Another assumption I hold is that individuals project their experiences, meanings, and beliefs into the family system. Family members may see the child with an ABI differently from another family member, and this difference may create conflict in how the family interacts and functions. Furthermore, this difference in perception can also create difficulties in re-establishing a family identity.

My experiences, both personal and professional, have shaped the lens through which I conducted this study and analyzed the data. My experiences have led to assumptions that the introduction of an injury or diagnosis will alter the perceptions, functionality, and meanings of individual self-identity and the family identity. I also hold the assumption that an ABI to a child will have negative consequences to a parent's self-identity and family identity. Finally, I believe that people lack awareness in self-identity and family identity, which leads to further distress for them and their families. To remain accountable to the assumptions and biases I bring to this research study, I employed several strategies to demonstrate trustworthiness for my interpretation of the interviews. I will address my strategies for trustworthiness at the end of this chapter, as part of the discussion of the data analysis process.

Data Analysis

The data analysis for this study examined 14 interview transcripts and 15 demographic questionnaires (one parent filled out two questionnaires, one for each child with an ABI), 15 FIQ Attitudes about my child subscale questionnaires, and 11 FIQ marital subscales (Donenberg & Baker, 1993). All interviews were transcribed by Rev, a HIPAA-compliant company (see Appendix K for security privacy overview). Upon receiving transcripts from Rev, I reviewed the transcriptions, included page numbers, ensured that all identifiable information was removed. Next, I printed off transcripts in preparation for coding. All audiotapes and written transcriptions on computers were saved using HIPAA-compliant software. Hard copies of data were secured when not being used, and I followed guidelines that I articulated in my IRB application.

Analysis Process.

The analysis of the data was occurring concurrently during the collection of data, which is consistent with constructivist grounded theory methodology (Charmaz, 2014). The demographic questionnaires were primarily used to provide context for each participant. This information proved to be valuable to the analysis process. For example, how the ABI occurred and the severity of the ABI were influential factors in impacts upon the parent and the family.

This will be further explored in the results section. The FIQ (Donenberg & Baker, 1993) questionnaires provided statistical based contextual information to perceptions and beliefs the participants have about their child with an ABI and, if applicable, how the ABI has impacted their marriage.

During the analysis process, I frequently referred to my research questions and wrote analytic memos. The data were coded in three phases: 1) initial coding, 2) focused coding, and 3) theoretical coding (Charmaz, 2014). These phases are not linear steps to analysis; rather, it is a cyclical process, allowing movement back and forth between phases as the data were coded (Charmaz, 2014; LaRossa, 2005). The cyclical process of analysis is used to become immersed in the data to draw out the rich description of participants experiences, perceptions, and meanings leading to an abstraction of the data to develop a conceptual framework to understand the process of self-identity and family identity after an ABI. Coding is the pivotal link between the collection of data and the emergent theory from the analysis process (Charmaz, 2014).

The start of the coding process began with me reading through the transcripts to orient myself to the interviews and immerse myself in the data. Next, initial coding involved line-by-line coding in each transcript, sticking close to the data. This research study has three research questions. The analytic process occurred once transcriptions were complete. Due to having three research questions, the analysis process was organized so it was clear what codes were connected to the specific research questions. For example, during initial coding, codes on self-identity were black, codes about family identity were blue, and codes on rehabilitation services were green. Initial codes were transferred to an Excel sheet, and each coding group got its own column. Focused coding was organized on an Excel sheet, again, with each research question having its own column. Codes were color-coordinated to specific themes that emerged during focused coding. This organizational structure helped me in the processes to build conceptual models for each research question and to engage in comparative methods to see how there is interaction between the conceptual models. Organizing and labeling my data in this manner allowed me to easily compare data within a participant and between participants. I used hard copies to conduct my initial coding, writing my codes, thoughts, and reflections in the margins of the hard copies. I utilized a different color pen for each research question. First, I went through the whole transcript coding for self-identity, then went the transcript for family identity, and one last time went through the transcript and conducted line-by-line coding for rehabilitation services.

These initial codes brought the data into categories and allowed for processes to emerge. Charmaz (2014) suggested asking the following questions during initial coding to help see actions and identify significant processes:

- What process(es) are at issue here? How can I define it?
- How does this process develop?
- How does the research participant(s) act while involved in this process?
- What does the research participant(s) profess to think and feel while involved in this process? What might his or her observed behavior indicate? (p. 127)

Before and during my immersion into the data, I reflected on these questions. These questions helped to guide the coding process so that my codes fit the data, and I was not forcing the data to fit codes I wanted. Throughout the initial coding process, I was intentional about being open to data and reflective on my own bias and assumptions. The line-by-line coding lead to the development of initial codes, which was followed coding the codes to find patterns and to push myself to think more analytically (Charmaz, 2014). The initial codes were “provisional, comparative, and grounded in the data” (Charmaz, 2014, p. 117). This step in the analysis process brought the data from concrete events and descriptions to theoretical insights and possibilities (Charmaz, 2006). After a transcript had been initially coded, the codes were categorized in an Excel document and participant labels were given to each code.

Focus coding is the next stage in the analysis process. These codes are more conceptual and theoretical than the initial codes (Charmaz, 2014; Glaser, 1978). “Focused codes advance the theoretical direction of your work” (Charmaz, 2014, p. 138). To advance the theoretical direction in the analysis, I used the comparative process, comparing codes with codes from the initial coding process and determining which codes have analytic power (Charmaz, 2014). To accomplish this process, I grouped initial codes together that created a focused code that identified with all the initial codes (Auerbach & Silverstein, 2003). I used the initial codes in the Excel sheet and started to highlight boxes specific colors to initial codes were starting to come together to form focused codes. For example, I grouped the initial codes, *protective of child*, *attentive to behaviors and signs*, and *sacrifice for ABI child* under the focused code, *focus on ABI child*. The process of focus coding first addressed self-identity and then the process was repeated to focus code family identity and rehabilitation services. Upon completing focused coding, I presented my coding process to my advisor. Further refinement of the focused codes was completed by integrating the feedback from my advisor.

The next step in the analysis process was using Charmaz’s (2014) approach to axial coding, which is focused upon emergent analytic strategies, instead of procedural applications. Axial coding reflects how I made sense of the data. Through this process I was organizing my focused codes into themes. I complied focused codes that were similar together and started to identify a theme that would incapsulate all or most of the focused codes. For example, focused codes in the family identity column, *hyper attentive to ABI child, functional changes to family,* and *communication struggles* all referred to the changes the family had to adjust to after the ABI. From the gathering of these codes together I named the theme *reactive functioning*.

By creating a chart of my coding process, I was able to see how my initial codes, focused codes, and themes fit together. Throughout this process I was referencing my notes and memo writing to assist in the process of creating themes. The creation of conceptual figures was most beneficial in helping me to visualize the processes that were emerging from the data. I collaborated with my advisor in the editing and refinement of the conceptual figures. Theoretical coding was useful during this process. Theoretical codes are emergent and are integrative (Stern, 1980). "Theoretical codes not only conceptualize how substantive codes are related, but also may move your analytic story in a theoretical direction" (Charmaz, 2014, p. 150). In this stage of coding, I was including how I was making sense of the data and integrating my theoretical framework, Contextual Model of Family Stress (Boss et al., 2017). The inclusion of theory in my analysis process provided a lens to describe how mothers were perceiving and making sense of self-identity and family identity. For example, the internal contexts detailed by Boss et al. (2017) contributed to the creation of conceptual models in that I considered the structural, psychological, and philosophical contexts referenced in the interview transcripts. Through the process of theoretical coding, I was able to identify an emergent process through the relationships between categories I identified in the analysis process. This will be further explored and expanded upon in the results section.

Trustworthiness

In any research study, validity is important to demonstrate. Validity is a strength to qualitative research, as it looks to see if the findings are accurate from the standpoint of the researcher and the participants (Creswell & Miller, 2000). With any qualitative methodology, rigor and trustworthiness of the data analysis process are imperative as these aspects demonstrate validity. The use of multiple procedures adds to the trustworthiness of the study ensuring accuracy of the findings from multiple perspectives (Creswell, 2014).

Data Saturation

The quality and understandability of the interview questions are important so that the interviews can capture the experience of self-identity, family identity and service needs in these areas. Well-formed questions will lead to saturation, which in the interview process, is when I feel I have heard it all and can anticipate the answers of participants (Sandelowski, 1995). The interview questions allowed for me to thoroughly explore the experience of the participants and gather rich data. My knowledge on the phenomenon under study, along with my therapeutic ability to track dialogue, was useful in obtaining rich data and reaching data saturation. I was in dialogue with my dissertation advisor in conversations regarding saturation.

Memoing

Throughout the data collection process, I was actively engaged in memo-writing. To be attentive to a potential bias and my own interpretations throughout the study, I used memo-writing. Memo-writing provided detailed records of my analysis, helped to increase my level of abstraction, and allowed for codes to stand out and develop into theoretical categories (Charmaz, 2014). Detailed notes were taken during every interview and, afterward, I wrote in a dedicated memo-writing journal to express ideas, connections, and concepts. This memo-writing journal was an “interactive space for conversing with [myself] about data, codes, ideas, and hunches” (Charmaz, 2014, p.162). The memo-writing process continued my reflexivity awareness, highlighting how my biases, assumptions, or perspectives influenced the way I engaged with an interview or interpreted the data during the analysis process (Creswell, 2014). For example, in my practice of writing after every interview, I noted across all participants the amount of time each person wanted to spend in detailing the initial crisis of when they first found out about their child having an ABI. This highlighted the intense emotions still present for the participants about the ABI event and the profound impact it had on their self of self- and family identity.

Audit Trail

The use of an audit trail provided the concrete step-by-step record of the entire research process. An audit trail refers to the transparent steps that the research process took, from the start of the project to the reporting of the findings (Daly, 2007). This detailed narrative of the research process has the ability to answer questions from consumers of the research about how decisions were made, how data was collected and analyzed, and how the final results came to be finalized (Patton, 2015). The clear detail of the steps of this study bolsters trustworthiness by giving readers a basis for determining whether the findings are accurate from their point of view (Creswell, 2014). Another journal was used for my audit trail. I documented all my actions and concrete steps that were necessary to complete this research study. My audit trail provides a clear step-by-step narrative of my entire research process.

Peer Debriefing

A final strategy to demonstrate trustworthiness was to employ peer debriefing. This procedure involved me locating peers who reviewed and posed questions about the study to ensure that the findings and steps of the study will resonate with other people (Creswell, 2014). This was accomplished by providing peers with a summary of my results in a Microsoft Word document, including theoretical concepts, themes, and my conceptual figures. This process extended the interpretation beyond my own ideas, thoughts, and hunches and allowed another person to be invested in the process (Creswell, 2014). I separately recruited three of my peers -

an occupational therapist working with individuals with an ABI, physical therapist working in a neurology clinic, and a graduate student who understands the methodology I used for this study – via email and asked them to review my findings to confirm that themes resonate with others beyond myself. Discussion with peers confirmed and validated my findings and no significant changes were necessary. Prior to consulting peers, I had worked extensively with my advisors in the creation of codes, themes, and conceptual models. This often involved me providing drafts to my advisor and then communicating through email, phone, or Zoom to discuss areas that revisions were needed to fully capture the process of a mother reconstructing self-identity and family identity after a child receives an ABI.

The procedures of member checking, memo-writing, an audit trail, and peer debriefing were employed by this research study to demonstrate the trustworthiness. The combination of these strategies bolstered the accuracy of the findings from multiple perspectives and provide detailed accounts of the research process and my personal process throughout the study.

Member Checking

One procedure to ensure trustworthiness I used was member checking. This consisted of bringing polished findings back to the participants to determine if the participants felt that the findings were accurate to their experiences (Creswell, 2014). I provided the participants with a one-page summary of the results through email. Next, I set up a time to have a 10 to 15 minute telephone conversation with the participants about the summarized results provided. The comments of the participants serve as a check on the validity of the interpretation of the findings (Creswell, 2014). Five participants engaged in the member checking process. Participants agreed with the initial results and some articulated how it was “difficult to read but accurate.” It seemed that participants agreed with the findings and at the same time the results were a mirror to the realities that each participant was living in. No significant changes to the results were necessary, and the member checking process validated what had emerged during my analysis. Member checking was another step to ensure that participant experiences and voices are part of the collaborative constructive process associated with constructivist grounded theory.

Chapter 4: Results

In this research study, I sought to explore and understand how mothers, after a child receives an ABI, 1) construe their self-identity, 2) reconstruct family identity, and 3) perceive the role of rehabilitation services in terms of identity changes and the family. Based on the experiences and perceptions of mothers who have a child that has an ABI, I developed conceptual frameworks to better understand the process of construing and reconstructing self-identity and family identity after a child in the family receives an ABI. In this chapter, I will first review the various contexts of the ABI for my participants, as that played a significant role in family functioning post-injury. Next, I will explore the findings and display the conceptual model for maternal self-identity. Third, the results and conceptual model for family identity will be presented. Finally, I will address maternal perceptions of rehabilitation services.

ABI Context

To better understand how the participants' families reconstructed their self- and family identities following their child's ABI, a more detailed look into the contextual factors of the ABI is necessary. As mentioned in the literature review, ABIs are complex injuries - each injury and the outcomes/consequences associated with each injury are unique. This uniqueness is evident in the diagnoses, ranging from mild to severe, and in the spectrum of trajectories that the healing process of an ABI can take. Ultimately, outcomes and impacts upon an individual and their family vary from ABI to ABI.

Of the fifteen children with an ABI included in this study, five (33%) had ABIs caused by a car accident, four (27%) had ABIs obtained through a recreational activity (e.g., skiing, snowmobiling), three (20%) had ABIs that occurred through biological means (e.g., pediatric stroke, problematic birth), one (7%) through an assault, one (7%) from a lightning strike, and one

(7%) acquired through a fall. Of the 15 children with ABIs represented in the study, five (33%) had received the ABI between the ages of 0 and 3, one (7%) between the ages of 4 and 8, one (7%) between the ages of 9 and 12, and eight (53%) between the ages of 13 and 18.

All 15 children received a formal diagnosis of ABI from a medical provider (e.g. neurologist, emergency medicine physician). Though all children included in this study received a formal diagnosis of ABI, not all mothers were given the severity (i.e., mild, moderate, severe) of the injury with the diagnosis. Due to this, the totals for severity of the ABI do not total 15. **Error! Reference source not found.** reports only the medically diagnosed severity of ABI cases. The reported medically diagnosed severity of ABI includes two (17%) mild, three (25%) moderate, and seven (58%) severe cases.

Table 2

ABI Context of Participants' Children

	n	%
Cause of ABI		
Car Accident	5	33
Recreational Activity	4	27
Biological	3	20
Assault	1	7
Struck by lightning	1	7
Fall	1	7
Age child received ABI		
0-3	5	33
4-8	1	7
9-12	1	7
13-18	8	53
Severity of ABI[a]		
Mild	2	17
Moderate	3	25
Severe	7	58

[a] Reflects the participants' report of medically diagnosed severity. Three participants did not report a medically diagnosed severity.

Participants completed two subscales from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993): the couple subscale and the feelings and attitudes about your child subscale. Participants answered all items on these subscales, except for one participant who declined answering one question as it did not apply to her situation. The participant with two children diagnosed with an ABI completed the FIQ subscales for each child. The descriptive information from the FIQ: Feeling and Attitudes about your child subscale can be located on Table 3. Though not utilized for any type of statistical testing, the data gathered from the FIQ offers a quantifiable information to position each participant’s feelings and attitudes about their child, their relationship with their child, and how they parent the ABI child. Though this is no statistical significance in the data from this FIQ subscale, it does provide more context to each mother that participated in the study and their views about their child’s behavior and influences the ABI child had upon their marriage.

As part of the interview procedure, I investigated sequelae that were present due to the ABI and the level of care the mother needed to provide for their child. The sequelae reported by participants include learning and cognitive difficulties (e.g. trouble reading, mental exhaustion), sensory processing sensitivity (e.g. loud noises, busy, fast moving environments), social norm and behavioral problems (e.g. taking shirt off in public, inappropriate boundaries with strangers of the opposite sex, emotional and physical aggression, risky sex with multiple partners), delusions (e.g. seeing people in trees outside window, being convinced that family members are stealing money), and sequelae requiring intensive care (e.g. changing feeding tubes or diapers, providing a comfortable and enjoyable environment).

The level of care varied across participants, though all participants were actively and routinely involved in the ABI child’s life in some capacity. Those participants requiring a less intense level of care reported joining their ABI child to run errands or having the child live close by so the mothers could be there to help if needed. On those requiring an extreme amount of

Table 3

FIQ: Feelings and attitudes about your Child

	Mild				Moderate				Severe				No Diagnosis			
	n	M	SD	Range	*n*	M	SD	Range	*n*	M	SD	Range	*n*	M	SD	Range
More stressful	2	0.5	0.70	1	3	2.00	1	2	7	2.57	0.43	3	3	1.33	1.53	3
Enjoy time with child	2	0.5	0.70	1	3	2.67	0.57	1	7	2.00	0.49	3	3	0.67	0.58	1
Frustration and anger more	2	1.5	0.70	1	3	0.67	0.58	1	7	1.42	0.48	3	3	0.33	0.58	1
Happiness and pride more	2	1.5	0.70	1	3	2.67	0.58	1	7	1.86	0.55	3	3	1.33	1.15	2
Less effective parent	2	1.5	2.12	3	3	0.33	0.58	1	7	0.85	0.46	3	3	0.33	0.58	1
Play and have fun	2	1.5	2.12	3	3	2.33	0.58	1	7	1.57	0.38	3	3	0.67	0.58	1
Behavior bothers me	2	1.00	0.00	0	3	1.33	0.57	1	7	1.28	0.52	3	3	0.33	0.58	1
Feel more loved	2	1.00	0.00	0	3	1.67	1.15	2	7	2.14	0.40	2	3	1	0	0
Alone in dealing with child’s behavior	2	2.00	1.41	2	3	1.67	1.53	3	7	1.71	0.52	3	3	0	0	0
More energetic	2	0.50	0.70	1	3	1.33	1.53	3	7	0.57	0.30	2	3	0.67	1.15	2
Be better with my child	2	2.00	0.00	0	3	1	0	0	7	2.29	0.36	2	3	1	0	0
More confident as a parent	2	1.00	1.41	2	3	1.67	1.15	2	7	1.14	0.26	2	3	1	0	0
Better control over child’s behavior	2	1.00	1.41	2	3	0.33	0.58	1	7	0.71	0.42	3	3	0.33	0.58	1
Child follows directions	2	2	1.41	2	3	1.33	0.58	1	6[a]	1.33	0.42	3	3	1	1	2

[a] One mother declined to answer this question due to her daughter having such a severe ABI that child is completely bedridden and incapable of following directions.

care, two participants had to alter their home to establish a room that could support a hospital bed and other devices so that their ABI child could be properly cared for. The majority of participants reported having the child with the ABI live in the home with them or family, and that the child was able to be independent in some ways but always needed support.

Self-Identity

The interviews conducted with participants aimed to answer the research question: How do mothers of a child who has received an ABI construe and reconstruct their self-identity? The analysis of how participants reconstructed their self-identity revealed three theoretical concepts, and six overarching themes emerged. The theoretical concepts were: (a) *pre-ABI event self-identity: perceptions of continuity and sameness*, (b) *external self-identity*, and (c) *internal self-identity*. The themes within these theoretical concepts included (a) *social attributes*, (b) *values*, (c) *social roles*, (d) *others*, (e) *ABI event*, (f) *focus on ABI child*, (g) *emotionally overwhelmed* (h) *transcendent sense of self*, (i) *being an active agent*, and (j) *light bulb moments*. For an outline of theoretical concepts and themes with descriptions along with the prevalence of participants that talked about each theme, see Table 4.

Figure 1 illustrates the interactions and processes among the identified theoretical concepts and themes. The theoretical concept pre-ABI event self-identity: perceptions of continuity and sameness highlights the various ways participants understood their self-identity. The awareness of social attributes, values, roles, or others were the means by which participants were conscious of an inner stability of sameness and continuity. The theoretical concept external self-identity captures how the stability of sameness and continuity of the participants is disrupted

Table 4

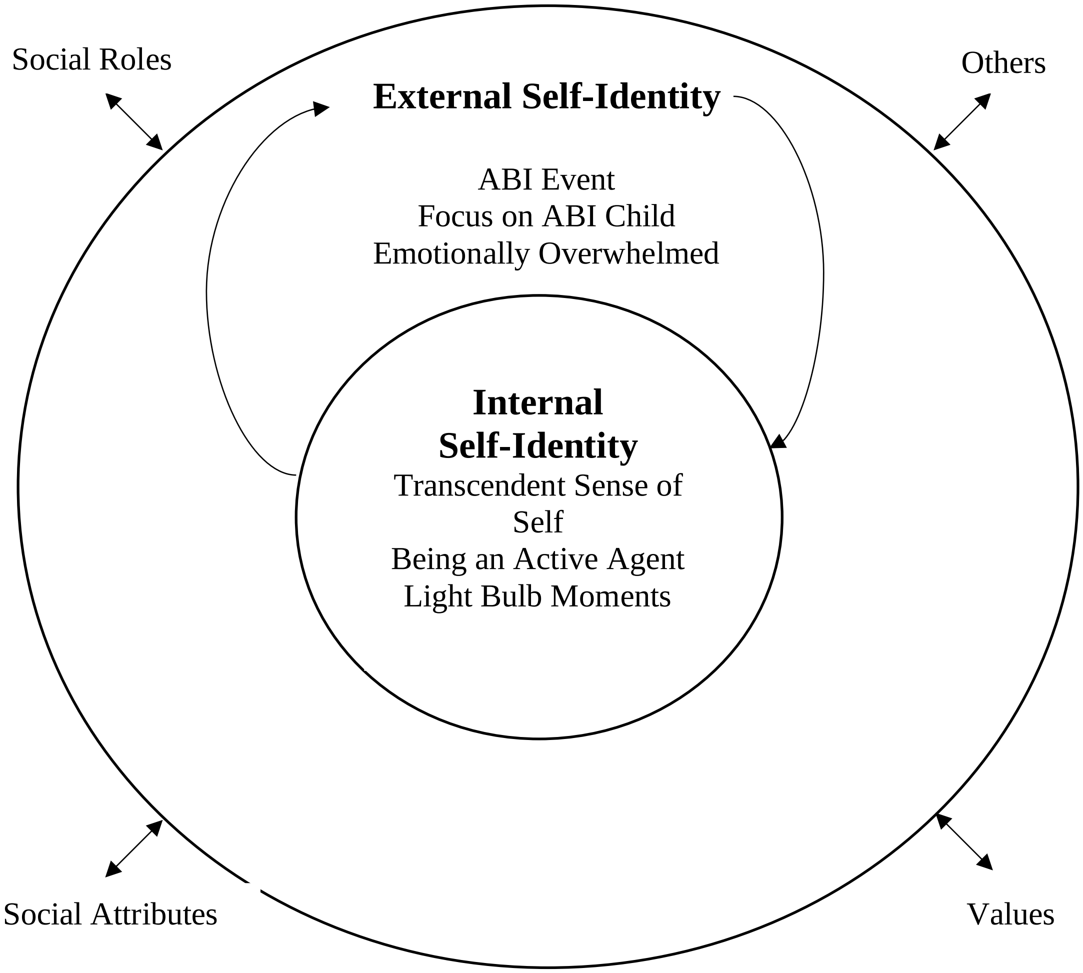
Summary of Theoretical Concepts and Themes for Self-Identity

Theoretical Concepts and Themes	Definition	n (%)
Pre-ABI Event Self-Identity: Perceptions of Continuity and Sameness	Self-identity defined through various factors before the ABI event	
• Social Attributes	• Identified qualities important in defining Self-identity	10/14 (71)
• Values	• Core beliefs that provide significant meaning to identity	9/14 (64)
• Social Roles	• Positions determined by their responsibilities, expectations, and beliefs.	14/14 (100)
• Others	• Other people shape and influence self-identity	11/14 (79)
External Self-Identity	Self-identity is positioned outside of the participant and focus upon functionality	
• ABI Event	• Context event that is the catalyst in disrupting self-identity	14/14 (100)
• Focus on ABI Child	• Self-identity absorbed in ABI child	14/14 (100)
• Emotionally Overwhelmed	• ABI experience emotionally too difficult to process	14/14 (100)
Internal Self-Identity	Self-identity is positioned within the participant	
• Transcendent Sense of Self	• New awareness of aspects of self-identity, such as expand view of spirituality or role of mother	10/14 (71)
• Being an Active Agent	• Responding to events and experiences in an effective and proactive manner	8/14 (57)
• Light Bulb Moments	• Experiences or inspirations that prompt awareness, change, or intentionality	5/14 (36)

by the ABI event. This experience of the ABI to a child shifts the focus of self-identity upon this child. The last theoretical concept, *internal self-identity,* depicts the transition out of the external self-identity into internal self-identity where continuity and sameness are regained. The catalyst for the move from external to internal self-identity is the conscious awareness of the transcendent sense of self. The transcendent sense of self is the recognition of the aspect(s) of self that transcend time, space, and contextual events. The awareness of the transcendent aspects of self-identity promote positive adaptation mechanisms such as being an active agent and can bring about light bulb moments. These mechanisms foster the transition to internal self-identity.

Figure 1

Conceptual Model of Self-Identity



Pre-ABI Event Self-Identity: Perceptions of Continuity and Sameness

The definition of self-identity used in the research study provides a theoretical perspective on the interpretation and meaning of self-identity. Briefly summarized, self-identity is a person’s conscious awareness of their sameness and continuity through time and experiences (Allport, 1961). In the interview protocol, participants were asked for their definition of self-identity. Common responses were “how you feel you are as a person,” “core values, your esteem, how you think about yourself,” or “what you like to do, your character, your personality.” Through the interview questions, participants spoke to the consistency of these aspects. For example, “core values” remaining intact or “how you feel about yourself” are not a reference to emotions but an overall experience of identity that is always with a person. Participants revealed how pre-ABI self-identity factors remained intact or were changed in the process of adapting to the ABI. Through this awareness, participants identified continuity and sameness in factors important to their self-identity and that there was room for flexibility and change with self-identity.

Participants in this study identified specific social attributes, values, social roles, and others as primary ways to interpret their continuity and sameness in self-identity. Though overlap and interconnectedness are evident among these four components of self-identity, for clarity, I will individually address how each component influenced the participants’ interpretation of their self-identity.

Social Attributes (*n* = 10; 71%). The majority of participants interpreted their self-identity through social attributes. This theme name borrows from Thoits (1991), referring to nominal categories (e.g., female, Christian) and extending to characteristics and qualities the mothers desired to emulate in their thoughts and actions. Participants would often reference social attributes such as compassion, hard-work, or persistence to define their self-identity and then explained how these social attributes manifested in their lives. For example, P5 discussed a social attribute of herself that is core to her self-identity:

> I've always thought of myself as a doer and don't wait for others, you know, to take care of yourself, independent. I grew up in a really bad environment, an alcoholic home and so I've always kind of, even at age six, recognized when things weren't going the way they should within the family dynamics that it wasn't my fault. I needed to divorce myself from it and figure out what was right going forward for myself. I'm still that person and maybe that's what helped us get through that [ABI injury].

P5's conscious awareness of the sameness and continuity of being a doer or independent person is present throughout time and space, including her child's ABI event. The participant holds significant meaning in the social attribute of being independent and a doer; these social attributes were necessary to overcome an alcoholic household and now are important in managing and coping with the changes that an ABI brought to the family. These social attributes have allowed this participant to be resilient and overcome barriers and crises throughout her life.

The analysis of the data also reveals transformations in social attributes over time. Frequently, participants would reference how their patience or compassion has increased or decreased since their child had an ABI. For example, P4 discussed her change of a social attribute: "I would say at one time I was very patient, and I'm not as patient as I used to be." There is a notable shift in meaning about the social attribute of patience. The participant has a conscious awareness of a diminishment of a trait due to the ABI. The social attribute is still present in the participant's life, though the meaning about being patient and how the trait manifests has been altered. Other participants spoke about becoming more compassionate. What became clear from the interviews was that social attributes never emerged spontaneously; rather social attributes, such as patience or compassion, were always present and the ABI event prompted either an increase or decrease in the expression of the social attributes.

Values (n = 9; 64%). Participants would often reference values as a mode to define their self-identity. Based on the analysis, participants identified values as beliefs and meanings that provide a framework for what a person finds important, and these values guide how to live, work, and play. Frequent values that emerged during the study include faith, family, getting outdoors, helping others, and personal growth. P8 discussed her values of being outdoors and active, and how being with family fed her definition of her self-identity:

> What is important to me? I think being outdoors, nature, you know, and helping the earth and stuff is important. Also, raising awareness for ABI. I try to do that stuff as well. Family time is really important…Spiritually wise, my shifts have…my beliefs have kind of changed since this whole accident, so I really wouldn't probably put so much on the spirituality thing.

This participant uses values to define areas of importance in her self-identity. Across participants, some values remained constant over time, such as being outdoors or investing in family time.

Other values shifted as a result of the child's ABI, as seen in the participant's statement on spirituality. The participant is wrestling with her new understanding of spirituality and how to interpret this shift in self-identity. Several participants discussed spirituality as an important value and aspect of self-identity. Some participants found deeper sense of belonging and meaning by investing further into "my relationship with God" or a church community. For example, P11 whose child needs care all day every day (24/7), discussed that her child "still has a purpose on earth or else God would've taken her." The value of spirituality provided participants a spiritual relationship or connection as a context in which to wrestle with questions, emotions, or thoughts stemming from the disruption of the ABI.

Many participants spoke about new values that emerged since the ABI, one prominent value being raising awareness and support for ABI families. P7 took it upon herself to establish a statewide organization to support families affected by pediatric stroke. This participant spoke on the value of “wanting to help others,” and the pediatric stroke to her daughter prompted her to invest in helping other families who were having similar experiences. Other participants revealed the importance of having conversations with others and educating people about ABI. It was important for participants to bring understanding of the consequences of an ABI to others. Life experiences and contextual changes influence values and allow for the emergence of new values. The modifications to a value or the introduction of a new value need to be brought to conscious awareness to help interpret self-identity through values.

Social Roles (n = 14; 100%). All participants interpreted their self-identity through social roles. Thoits (1991) identified social roles (i.e., mother, wife, teacher) in regards to one’s positioning a social structure. Prominent social roles participants referred to in the interviews were: mother, advocate, caregiver, participant’s career, and person “holding the family together.” The participants had a conscious awareness of the identified social roles they performed. Participants conceptualized social roles as positions determined by their responsibilities, expectations, and beliefs. That is to say that social roles may have the same name across individuals, but that the meaning, responsibilities, and conceptualization of the social roles may differ from person to person, or from family to family. In this way, the differing definitions of social roles allow for unique interpretations for each person, and this was evident in the data. For example, P6 discussed her social role as a mother, important to her self-identity, in this way:

> I was always the PTA mom. I was always the football president, the president of the wrestling team. I was in charge of hospitality in junior high. I mean, I’ve always been super, super involved in my kids’ lives, so it’s a natural role for me.

The participant continues to invest in the fundamental social role of mother and being engaged, present, and helpful for her children. Now, however, the investment of being a mother manifests in adjusting the meaning of how being the “PTA mom” functions within the context of having an ABI child. The importance of investment in her children has remained, but the responsibilities and expectations changed due to the ABI. P1 captured how changing existing social roles is enacted stating: “I’ve always wanted to be a mom…it just looks different now.” Participants still value social roles that hold meaning to their self-identity, but it is clear that the portrayal of the social role looks quite different after an ABI.

The transformation of existing social roles is only one aspect of how role interpretation influences self-identity. The ABI to a child will also generate new social roles taken on by the participants. P2 differentiated additional tasks and responsibilities due to the ABI from the role of mother, “My first thought was caregiver, but then, I don’t want that to be my identity. But it seems to be the role I’ve been in for so long. And then mom.” P2 has taken on a new social role as caregiver, which the participant perceives as different from the social role of mother. Furthermore, the social role of the caregiver is unwanted. Social roles that a person has can be chosen or an unintended consequence due to life events. Participants often spoke of certain social roles, such as caregiver for their child with an ABI, as unwelcomed. Difficult aspects of caregiving frequently mentioned by mothers were attending to medical needs, managing behavior and social interactions, and managing the logistics of appointments and treatment. Even so, the reality of being a caregiver is present and has become part of the participant’s new self-identity. Mothers of a child with an ABI may have to process unwanted social roles and manage how these social roles define and give meaning to their self-identity.

Others (n = 11; 79%). The final component of self-identity, as described by the participants, is through the perspectives of others. Others were included in participants' conceptualizations of their self-identities in two ways, (1) *the participants' perception of self in relation with others*, and (2) *others' perceptions of the participants*. The interpretation, meanings, and beliefs about a relationship with another influence the participants' self-identity. For example, P11, whose child is now bedridden, due to the severity of the ABI, said this about her relationships with her children:

> I see (ABI Child) as my baby, my daughter (18), and I see my other two, I call them my kids. It's not something you do on purpose, it's just, there's a differentiation there, because they're all your kids, but the one, it's different. It's she has a new normal, it's not the same.

The participant identifies all three of her children as "my kids," but there is a differentiation about the child with an ABI. The perception of this child, to the mother, has changed: "she has a new normal, it's not the same." This experience was common for participants: to always see the ABI child as a child, but also dealing with changing perceptions about the child.

When the relationship with others changes, new meanings and ways to process the new relationship with others are necessary. Participants frequently used relationships as a lens to interpret self-identity. Common relationships cited by participants were intimate relationships (e.g., marital, partner), relationship with children, or close friends. An ABI to a child can influence and change all of these relationships. Participants spoke to not retiring the way they expected with their spouse, changing how time is spent with children, or not being available to meet up with friends. The previous ways used to interpret self-identity through the participants' relationship with others are now ineffective. For example, P9 reflected on changes in her relationships, "Everything changes. Your day-to-day life changes. Your focus is changing. The way you see the world changes. The way you see other people changes. Everything changes." The participant acknowledges the change in how "you see other people."

Other participants shared this perspective of seeing other people differently. A predominant shift in how participants' perception of others changes is the low tolerance for when friends or co-workers would complain about superficial or everyday issues. For example, P2 voiced her frustration of a friend speaking about their child's poor school grades: "Really! That's your fucking problem! I'm sitting over here with a brain injured kid." Participants spoke of feelings of isolation from friends, extended family, and, at times, even within the family system because other people "just don't get it." For instance P13 discussed her perception of how others view her:

> So you kind of just stay away from people and so I guess in that way it's changed everything we do. It is sad that people aren't more understanding but it's just not how our society is set up. People just assume they know the situation and make judgments on it.

The quote above reveals the judgment the participant experienced from other people and the lack of authentic investment in relationships. Participants highlighted how the consequences of the ABI are often misunderstood, or people do not have the compassion, patience, or the desire to deal with the ABI child. These experiences - the isolation felt and the impact of other people's perceptions of the ABI child and the family - weighed heavily upon the participant. Negative comments about the ABI child were often internalized by the participants and impacted their interpretation of self-identity.

In summary, the interpretation of self-identity happens through the factors of social attributes, values, social roles, and others, and the consequences of the ABI will affect each of these factors. Participants spoke to how social attributes, values, social roles, or others can be altered, diminished, or increased depending on the interpretation of events and experiences. P14's reflection that "everything changes," captures the changes in interpretation each participant experienced through these factors.

Shifting Identity: External and Internal Self-Identity

Before exploring the theoretical concepts of external and internal self-identity independently, it is important to explain in more detail the conceptual model and the relationship between these two concepts. The ABI event disrupted previous meanings and interpretations of social attributes, values, roles, and relationships with others in participants' lives. The ABI shifts self-identity to be external, meaning that the focus is upon the ABI child. The self-identity of the mother becomes about the ABI child.

To escape the cycle of external self-identity, participants eventually attained an awareness of a transcendent sense of self. This conscious awareness of the transcendent self allowed participants to shift to internal self-identity. Internal self-identity allows for participants to process, create new meanings, and adapt and thus, regain their sense of continuity and sameness. Throughout the process of adapting and creating meanings, the factors of social attributes, values, roles, and others informed and influenced a person's interpretation of their self-identity. However, whether a person was positioned in the external or internal affected how interpretation occurred, which I will explore in more detail in the following sections.

The terms *external* and *internal* self-identity refer to the positioning of the participant's sense of self-identity. External self-identity, as the name reveals, positions the sense of self outside of the person. In a sense, a person's self-identity is within the ABI child. Participants in this study demonstrated external self-identity by being focused upon the ABI child. The internal self-identity refers to when the sense of self is positioned within a person. The internal self-identity can identify transcendent aspects of the self, thus holding a conscious awareness of sameness and continuity. This process is not linear and unidirectional, as participants demonstrated that shifts between the external and internal self-identity could continue to happen as more challenges, barriers, and crises that disrupted self-identity emerged over time.

External Self-Identity

The theoretical concept of external self-identity, that being self-identity that is positioned outside of the individual, was informed by three themes that emerged from the interviews with participants: (a) *ABI event*, (b) *focus on the ABI child*, and (c) *emotionally overwhelmed*.

ABI Event (N = 14; 100%). The ABI event is unexpected and often can have traumatic features. Participants spoke in great length and detail of the ABI event, long hospitalizations, frustrations with a myriad of professionals and, for some, being told your child is going to die. In the narratives of the ABI event from the participants, it was evident that participants and their families engaged in changes to functioning, communication, and meaning making. It was a natural shift for the identity to be disrupted and become external to the mothers in order to manage the crisis. The ABI event served as a stressor event to which the participants were required to adapt.

The ABI event is the source of the external self-identity. Participants spoke of the disruption of the ABI event on multiple levels. It was clear from the participants that there was no return to their previous manner of functioning after the ABI event. P6 stated, "a brain injury leaves nothing unturned. Spiritually, emotionally, physically, financially. It interrupts, disrupts, ruins, turns everything that you knew existed upside down. There was nothing left unturned as far as your life as you knew it." The participant revealed the immense reach of an ABI upon the life of the mother, ABI child, and family. The idea of "nothing left unturned" demonstrates that going back to previous modes of functioning in not an option. The ABI event has "interrupted, disrupted, and ruined" the self-identity of the mother. Similarly, P11 reflected:

> I look at pictures of other people my age and they look so young and they look like they have so much energy and I feel like my mother, you know, I feel like I'm super super old. I don't think you can go back from that. I don't think you can go from that to being the person that you're supposed to be had this not happened. I feel like that person is lost or changed or gone.

This participant revealed previous roles, values, or social attributes from a past self-identity that had been changed and disrupted due to their child's ABI. The sense of loss of self-identity was common in the statements of participants, especially during the initial crisis of the ABI event. Participants stated, in some manner, how they never expected an ABI to a child to happen to them. The disruption, interruption, and ruin the ABI event brought to the participants introduced the second theme from my analysis, a focus on the ABI child.

Focus on the ABI Child (N = 14; 100%). Throughout the interviews, it was evident how much time, energy, and effort went into functioning and caring for the ABI child. This functioning emerges with the ABI event and, in this context, refers to scheduling and accessing professionals, caregiving tasks for the ABI child, and being there for the ABI child in any way possible. The response to the new ways of functioning is reactive. The mother's self-identity is being determined by external forces and to function in this context the mother hastily takes on the new roles to fulfill the present demands. The participants transitioned into roles without conscious choice and focused on completing the functional tasks of the new roles. P11 posed this statement on how unanticipated roles impact self-identity: “I think from an identity standpoint, I think you lose your identity as a caregiver.” This participant in particular described the 24/7 care she provided to her daughter with ABI and how every minute of every day was focused upon the ABI child. The role of caregiver for the ABI child became the sole focus of this mother’s self-identity. The caregiver is a functional role that is necessary to support the ABI child, but the new role of the caregiver was not integrated into the self-identity.

Another example is P8 spoke of her role during the hospitalization for a severe ABI: “I felt like I was his advocate. I needed to be there to advocate for him at all times.” The importance of becoming an advocate for the ABI child was common amongst all participants. The role of advocate manifested in multiple ways as described by participants: never missing any appointments for the ABI child; arguing with professionals about needs of the child or direction of treatment; or standing up to family members who did not understand – or chose not to understand – the consequences and sequelae of an ABI. The focus on the ABI child is a natural adjustment to the ABI event, as the participants and their families quickly had to respond to the situation.

Furthermore, focus on the ABI child alters relational investment for the participants. Instead of balancing attention, time, and energy between multiple children, a spouse, or extended family and friends, the ABI event created a dynamic in which participants prioritized relational investment in the ABI child. P5 stated:

> My husband, he was angry at the world, focusing on himself and I was focused on (ABI child), not even myself. I basically felt at the time, “Hey listen, you’re an adult. You can take care of yourself. I can’t divide my attention any further than what I’m doing right

> now. At this point in our lives (ABI child) is the most important and at some point we will reconnect.

The ABI event is a crisis that demands attention. Participants in this study all reflected similar experiences of leaving other children with family and friends to be at the hospital with the ABI child or having one parent working and caring for other children and the other parent seeing to all of the ABI child's needs. P9 reflected on the long hospitalization of her child due to a car accident: "for a month or two I only saw my husband when he came to be in the hospital so I could go home to shower and change." The participants of this study all identified as the parent who was the most invested in and present for the ABI child. This relational investment in the ABI child exemplifies how self-identity of the mother can be externally focused upon the ABI child.

Emotionally Overwhelmed (N = 14; 100%). As noted previously, the ABI event is a crisis. The external self-identity is often focused on the ABI child, which does not allow the participants to attend to their own emotional needs and processes. Participants spoke about "not having time to feel emotions" or being "scared" of being "overwhelmed if I allowed myself to feel." One method to manage the plethora of emotions, often defined as unfavorable by participants, was to focus on functioning and being strong to distract from processing emotions. Part of external self-identity is the attention on functioning which is focused upon the ABI child and attending to changes in the family, and these processes perpetuated external self-identity. For example, P7 stated:

> I think there were times that I felt if I honestly gave into those emotions, I might not recover. I might just sit and wallow in those emotions too long, and I needed to just be

> strong…I didn’t want anyone to know I was vulnerable to hurting. It was just way easier for me to power through.

The participant used the rationale of being strong and powering through, as the means to avoid emotion. The focus on functioning tasks such as caregiving, setting up appointments, or managing a household were primary methods for participants to dismiss their emotions. Participants stated that focusing on functioning provided a legitimate reason to avoid emotion, because to feel emotion could lead to being overwhelmed, which, in turn, would take away from the ability to function as caregiver, advocate, or mother to the ABI child. Mother is external self-identity were absorbed in the care tasks for there ABI child.

The dismissal and avoidance of emotions was not always possible. Several participants told stories of times when their emotional expression was displaced. For example, P6 spoke of going the hospital to be with her child. While there, a hospital chaplain tried to slow the participant down by saying a prayer with her before she went in to see her child. “I don’t wanna say a fucking prayer. I wanna see my kid,” she reported yelling. The natural fear, worries, and anxiety in this context were projected as anger onto a person trying to help. Displaced emotions, as described by participants, can also push others away to retain the focus on the ABI child. This participant identified as a Christian but in that moment this aspect of her identity was pushed aside so the priority, and the mother self-identity, would remain focused on the ABI child.

The possibility of being overwhelmed by emotions was a fear many participants addressed. Participants spoke with insight about emotions they were aware that they had been avoiding. For example, P11 stated:

> I feel like you would disappear if I felt emotions. I have, I have thought about it, I think that I would probably become useless to the rest of my family. I think I would become

> super depressed; um, I think I would feel lost, and at that point I would have nothing better to do than to think about the man that hurt my daughter. I would have nothing better to do than to think about how my life got put on hold and where I should be or could be, but I'm not. All the things that I don't think about now, all the things that I put off, um, I feel like would overwhelm me and consume me, um, m- 'cause right now you're bottling up all of those things. Um, you... It's, it doesn't even make sense to think about those things because for one, you can't change it, so ye- ye- and you can't let yourself go there. But if something happens to her, what's gonna take up all my time?

The participant uses language of "disappear," "lost," and "super depressed" to describe what would occur if emotions were felt. Participants often had this perspective that emotions would dissolve or vanish their self-identity. External self-identity is functional and to feel emotions would be to risk being lost and never return. The quote above reveals the participant's fear that feeling emotion would take away from supporting and being there for the family and ABI child.

Years after the ABI event, emotions can still be overwhelming, especially when new complications stemming from the ABI injury emerge in the family. Participants spoke of these new problems from the ABI bringing back memories, thoughts, and emotions from the initial ABI event. P1 voiced her resistance to emotions as new complications emerged several years after the ABI event: "I don't wanna do this again, I don't wanna go through this. This is pain. I don't wanna, you know, and I'm like here." This participant is experiencing the ABI event again due to new problems from the ABI. The external contexts are once again being the primary mode that determine how self-identity is perceived by the participant. Emotions are overwhelming, and, due to new complications, the focus can once again be on the ABI child. Emotions come from within a person and can be a highway to reestablishing internal self-identity, but when emotions are avoided or displaced external self-identity remains. Several other participants discussed this dynamic that even years after the initial injury, a new issue with the ABI child could trigger emotions and cause a reversion to functioning focused on the ABI child.

Internal Self-Identity

The theoretical concept of internal self-identity represents the self-identity being positioned *within* the mother. Three themes informed the emergence of internal self-identity: (a) *transcendent sense of self*, (b) *being an active agent*, and (c) *light bulb moments*.

Transcendent Sense of Self (n = 10; 71%). A person positioned in the external self-identity will remain in that cycle until conscious awareness of the transcendent sense of self emerges. Referring back to Figure 1, the second movement of the process is the conscious awareness of the transcendent sense of self as the mechanism that shifts one from an external self-identity to an internal self-identity. I have used the term transcendent to refer to the aspects of one's self-identity that remain constant and intact across time and experiences. P10 reflected: "I don't think the core of me has changed." Though this mother has an awareness of her core self-remaining intact despite her child's ABI, she struggled to explain how this occurred, moving to discuss social attributes (kind, caring, compassionate) that were still in place. P1 provides greater detail into the transcendental self-identity by stating:

> My goal in life was to be a wife and mother. That's what I always wanted to be, to be a good person to my husband and I wanted to be there for my kids. So, when I changed my perspective (about being a mother and wife) I was just sitting outside daydreaming and I realized that I still could have goals. I was still a wife and mother, but just in a new way.

Even if participants experienced that they had "completely changed" as a result of their child's ABI, they indicated how the transcendental aspects of self-identity continued to be present and intact because of the transcendent meanings, qualities, or social attributes recognized by the participants.

Participants described an evolution to the social attributes, roles, and perceptions of others that were part of their self-identity. For example, some participants referenced changes in their relationship with God or spirituality. Specifically, P11 reflected on changes to her relationship with God:

> I'm not on speaking terms with God. All I can think of is what could possibly have happened in your life to make you turn from God, because God is the one thing that's keeping me going. God gives free will. I don't believe he caused this to happen. He gave free will and this man used his free will to hurt my daughter. But God protected her. He kept her here. So that tells me, as a Christian I believe we all have a purpose on Earth. And I feel like her purpose, obviously, she hasn't met it.

This participant's relationship with God is evolving; an active part of her processing the ABI event and the changes to her self-identity. Even with the changes and transformations to spirituality, participants referenced often using spirituality, their relationship with God, or faith as a way to find meaning and understanding. "I just have to trust God", stated in various ways, was a common statement among participants. Many participants understood God as omnipotent and omniscient and constant and transcendent throughout the ABI experience. A participant's relationship with God/spirituality can become a space to wrestle with ambiguity and process the transitions in self-identity.

Participants suggested that the conscious awareness of the transcendental sense of self often involves the recognition of factors from the old self-identity that are present in the newly forming self-identity. For example, P10 stated: "I don't know that anything good necessarily has come from this. I mean, the compassion, the compassion was already there." Participants were able to identify qualities or factors that were always with them. The ABI event may have prompted changes or evolution to the factors, but the core factors transcend the event.

Being an active agent. (n = 8; 71%) The theme of being an active agent addresses participants' intentional response to managing the crisis of the ABI event. Functionality was always important to participants, whether they were in external or internal self-identity. The concept of being an active agent demonstrates the shift back into internal self-identity from external self-identity. Instead of external factors and contexts determining actions and functioning, mothers, being an active agent, intentionally chose to respond to the ABI event in positive ways that promoted adaptation and resilience. Being an active agent captures the changes that participants experienced in how they were perceiving the ABI event. Some important characteristics of being an active agent include *changing perspective*; *developing life around values, meanings, and purpose*; and *feeling emotions*.

The choice of *changing perspective* involves the openness to see the world, others, and oneself differently. The ability to perceive the world in a new way demonstrates a shift in self-identity from external to internal, as the participant demonstrated the ability to have agency in choosing how they want to see the world and others around them. P3 described her process of changing perspective and processing unanswerable questions:

> My kid was in my husband's care when the accident happened. I remember making a conscious choice, you know, (participant's name) it was an accident and you cannot blame him, you cannot. It was an accident. We need to bind together in order to be able to care for her the best, to be there, to support one another.

The participant is consciously active in making meaning about the accident and choosing a narrative that will not pit herself against her husband. The role of wife and the support it can bring is present, and through wrestling to understand the accident, the wife realizes that the spousal relationship can be a source of further assistance in the future. This awareness demonstrates internal self-identity as the participant is able to be active in reframing her perceptions and understandings of her own role and relationships with others. The role of wife and her relationships with others were important to the formation and understanding of the participant’s self-identity. Engagement in changing perspective allowed for richer narratives on factors connected to their self-identity.

Participants captured another method of being an active agent: to *develop life around values, meaning, and purpose*. For instance, participants identified that their values could continue to support self-identity adjustment if the value could adapt to the new context of the participant. P13 described her transformation of the value to care for others:

> I’ve always loved caring for people. Before I had kids, I volunteered for hospice and stuff. You know, that was always like caring, so it became a natural role, being a mom and even having a kid with special needs.

This quote reveals the evolution of a particular value: in this case, caring. The evolution of this value allowed the participant to engage in providing care more actively to the child and also to find purpose in giving that care. Being a caregiver was not an unwanted obligation but a choice based on pre-existing values. The participant continued to hold to the value of caring and this value transcended the ABI event. The continued presence of this mother’s value of caring demonstrates the presence of an internal self-identity and actively using internal values to encounter events and experience, such as an ABI to a child. Additionally, participants demonstrated that the continued development and transformation of values, meanings, and purpose assisted them in a stressful context.

Other participants became active agents by finding purpose in unexpected places where their natural gifts were useful. For example, P7 details this transformation:

> I kept telling the counselor how much I missed my own identity. I missed work. Right? I started connecting with all these families and realizing that they were local. I was like "Wow! You know, there's something here." Hey, you know what? I don't want another family to feel alone ever again. I'm gonna create an organization that bands us together.

This participant is referring to a statewide organization that supports families who have been affected by a pediatric stroke. The transcendent social attributes of ambition and initiative allowed this mother to create a community of support and find a new purpose in the development of this organization. Mothers who engaged in processes to further develop values, meaning, and purpose participated in active steps to bolster conscious awareness of the transcendent self.

The transition into the internal self-identity is aided by intentionally *feeling emotions*. Multiple participants spoke of the conscious choice to feel emotions as a means of reconnecting with their transcendent identity, even though they dreaded participating in the experience. Many participants spoke of being "overwhelmed" by emotions and how distressing emotions were to experience. However, some mothers found the importance of recognizing emotions. P12 spoke of her decision to encounter emotions:

> When I need to cry, I cry. If something triggers… There are a lot of triggers, every day, every single day there's a trigger; and so, I give myself that moment to be there, and then I come back. It used to be I'd give myself the time in the car, I would tell myself, "You have this time in the car going from home to the hospital," which is about a half-hour;

> "and do whatever you need to do and when you get there, you pack it up and you know, put it aside and go be what you need to be with the hospital walls."

This participant revealed the need for being an active agent to access and process her emotions. Emotions are an authentic expression of participants' experiences of the ABI event and the following consequences, and feeling emotions informs the mothers' perceptions of the ABI event. The authentic expression of emotion and the ability to process the emotion demonstrates that a person is positioned in internal self-identity. In expressing emotions, participants identified the value of emotions as part of their authentic expression and self-identity. Furthermore, mothers who spoke about this intentionality of feeling emotions demonstrated a strength in being in control of emotions by being able to set boundaries around them.

As previously detailed, the possibility for participants to be overwhelmed by emotions is highly relevant. Participants described how important and intentional they were in choosing to engage emotions connected to the ABI event. Choosing to feel emotion often involved mothers seeking out time, relationships, or a safe space. The ability to choose to feel emotion reflects being an active agent and positioned in internal self-identity, as a mother has the agency to potentially cope with distressing emotions in a positive manner. One participant discussed how she would wait for meetings with a social worker to discuss marital and parenting dynamics that were creating stress. Other participants, like the most recent participant's quote, referenced setting time boundaries around the experiences of emotions. It was important for participants to feel a sense of control in the experience of emotions.

The perception of emotions by the participant influenced the narrative of emotions. Participants that viewed emotions as "unhelpful" or "I don't have time to cry" resisted feeling or acknowledging emotions. Participants that felt emotions had further insight into how experiences and perceptions of emotions could influence self-identity. For example, P10 was intentional in framing emotional narratives:

> I don’t want to be a bitter person. I don’t want to be an unhappy person. It’s a choice, you know, it’s like you wake up in the morning and say, “You know, this is going to be a good or a bad day.”

This participant integrates the themes of *feeling emotions* and *developing values, meanings, and purpose* which connect back to values and social attributes of the pre-ABI self-identity. There is a recognition of emotions and an intentional decision to interpret the emotions and experiences in a manner that leads away from being “an unhappy person.” Participants discussed that they could not choose what emotions they had, but they could choose how to respond to their emotions.

Light bulb moments (n = 5; 36%). In several interviews, participants described times that insight about who they are, their desires, or changes they need to make just happened upon them. Light bulb moments were sudden shifts from external self-identity to internal self-identity. This phenomenon served as an effective facilitator to prompting a shift to a more internal self-identity. This is best illustrated by P1 speaking about her marital relationship:

> My marriage was falling apart and I’m sitting in the front yard saying, ‘I wish I had this, like, ideal husband.’ Right? I was like, “Man I wish I had a…,” and that was, you know, I was daydreaming about this ideal husband that I wanted. My husband was in the house somewhere doing something. We’re totally opposite people. We weren’t very communicative. So, I’m sitting on the porch just daydreaming about this ideal husband and something came in my thought like, “Why dream about it? You can make it happen!”

As this quote highlights, there was that moment that altered the participant’s processing and provided her the opportunity to engage in her marriage in a new way. Initially, the participant was disconnected from her self-identity and focused on fantasies. The light bulb moment served as a catalyst to engage in other themes that promote internal self-identity, “why dream about it? You can make it happen” (i.e. being an active agent).

Another way a light bulb moment occurred was through the frame of “it’s time to deal with this.” This experience described by participants showed a drastic shift in how the ABI event and consequences were being perceived and interpreted. This change in perception highlights the shift from external to internal self-identity. For example, when being asked about when P10 knew it was time to go to psychotherapy and process the ABI event P10 answered:

> I don’t know. I suppose it’s like everything else. I’ll just wake up one day and go, “oh, you know what? I think I need to move on. I think I need to go to therapy now. I think I need a haircut.” Yeah, that’s how it works with me.

Several mothers discussed the feelings of being ready to process or approach a situation in a new way. Participants knew it was time to address the thing that had been avoided. In addition, some participants referenced a knowledge of what needed to be attended to, but it was never spoken out loud until they were ready to “deal with it.”

Family Identity

The development of the family identity conceptual framework illustrated in Figure 2 addressed the second research question: How do mothers reestablish family identity, after a child has experienced an ABI? Eleven of the 14 participants identified as being married or in a long-term relationship and completed the FIQ Marital Subscale (Donenberg & Baker, 1993). One participant chose not to answer a question on the questionnaire, as they did not apply to her situation. Table 5 summarizes participants’ responses to the items on the questionnaire. Again,

Table 5

Family Impact Questionnaire: Marital Subscale

	Mild				Moderate				Severe				No Diagnosis			
	n	M	SD	Range	*n*	M	SD	Range	*n*	M	SD	Range	*n*	M	SD	Range
Disagree how to raise child	2	1.5	0.71	1	2	1.0	1	2	5	0.8	1.30	3	2	1.5	2.12	3
Supportive of how I handle behavior	2	1	0.0	0	2	2	1.41	2	5	1.4	1.34	3	2	2	1.41	2
Child pits parents against each other	2	1.5	0.71	1	2	0.5	0.71	1	5	1	1.41	3	2	0	0	0
Child brings parents closer together	2	1	1.41	2	2	2	1.41	2	5	1.2	1.30	3	2	1.5	2.12	3
More Disagreements	2	1.5	0.71	1	2	1.0	1.41	2	5	1.6	0.45	3	2	1.5	2.12	3
Less Supportive of dealing with child’s behavior	2	0.5	0.71	1	2	0.5	0.71	1	5	0.8	0.45	1	2	0.5	0.71	1
Raising child pushed parents apart	2	1.0	1.41	2	2	0.5	0.71	1	5	1.8	1.30	3	2	1.5	2.12	3

[a] Participant did not answer as the participant did not feel that question was relevant to her situation due to her child with ABI being bedridden.

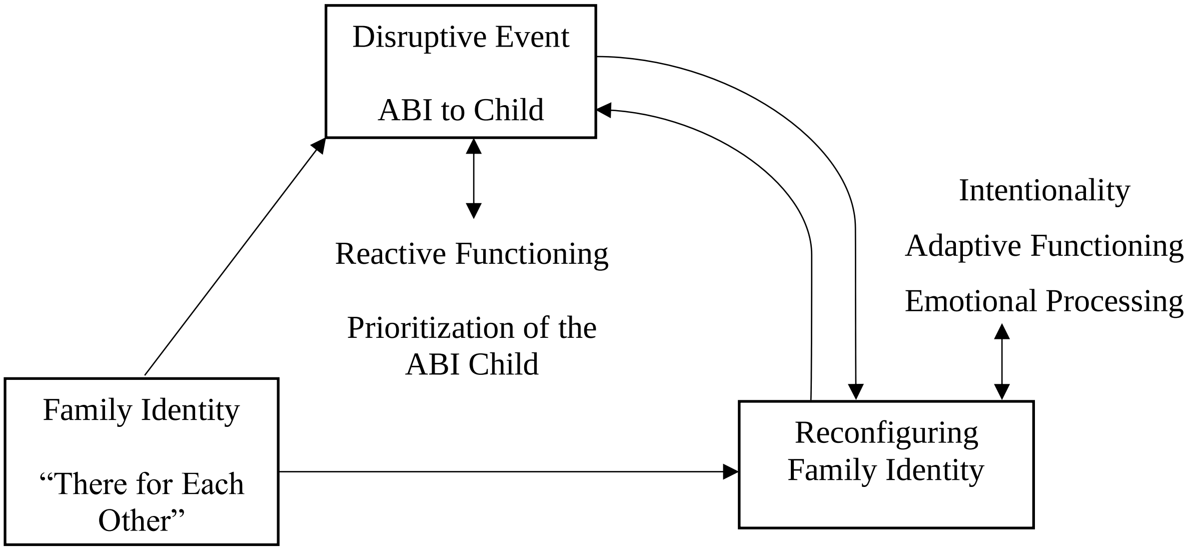
the data from the FIQ marital subscale is not statistically significant, but it does provide further contextual information on how participants of this study perceived their committed relationships.

My analysis of the interviews revealed the following theoretical concepts: (a) *family identity: "there for each other,"* (b) *disruptive event: ABI to child*, and (c) *reconfiguring family identity*. Table 6 provides a summary of the theoretical concepts and associated themes with brief definitions. The themes included, (a) *prioritization of the ABI child*, (b) *reactive functioning,* (c) *intentionality*, (d) *adaptive functioning*, and (e) *emotional processing.*

The concepts are reflected in Figure 2, which illustrates how families reconstruct family identity after an ABI. The conceptual model first addresses the meaning of family identity, being there for each other, before the disruptive event, or the child's ABI. From the experience of the ABI event, the family must reconfigure their family identity, being there for each other, to complement the new context of the family. The reconstruction of being there for each other as a family identity involved the transformation to the processes of communication, functioning, structure/roles, and shared meaning between family members.

Figure 2

Conceptual Model of Family Identity



Family Identity: "There for each other" (N = 14; 100%)

In terms of defining family identity, all participants identified that a core meaning and identity to their family was being "there for each other." Every participant spoke to this aspect of family identity, though in various ways. For example, P2 defined family identity as, "Family…they stick with you through thick and thin. No matter what comes up, your family sticks with you." P3 spoke of her conceptualization of family identity: "What it means to be family? Unconditional love and support."

The theme of being "there for each other," whether defined as unconditional love or sticking with you through thick and thin, was the undercurrent to giving meaning to family functioning, communication, and expectations. Participants described efforts to support family members, prioritizing family before other relationships and responsibilities and building trust, even before the ABI event.

However, the manner in which family identity manifested for each family was diverse, as differing family values, histories, beliefs, and functional practices were unique to each family. Some participants spoke of how "Jesus comes first in our house" and detailed how religion was influential in determining family identity. Whereas, other participants valued complete openness in communication wanting their children to come to them about sex, substance use, relationships, etc. The descriptions of participants' family identities were unique to each family but the core meaning of being there for each other was present in all of the descriptions.

Disruptive Event: ABI to Child

Participants were able to identify, in detail, all of the various changes that occurred to the family due to the ABI to a child. The mothers reported shifts in relational dynamics, such as not

Table 6

Summary of Theoretical Concepts and Themes for Family Identity

Theoretical Concepts and Themes	Definition	n (%)
Family Identity: "There for each other"	Identity of family is centered on supporting each family member.	14/14 (100)
Disruptive Event: ABI to Child	The ABI event is disruptive to how the family understands how to be there for each other	
• Prioritization of the ABI child	• The family is absorbed in supporting the ABI child. Other family members become secondary.	14/14 (100)
• Reactive Functioning	• Family members respond to events individually	14/14 (100)
Reconfiguring Family Identity	The family has processed the ABI event and transformed meanings to supporting each family member	
• Intentionality	• Deliberate awareness to address conflict and process family identity after an ABI	9/14 (64)
• Adaptive Functioning	• Purposeful decisions to address roles and responsibilities to support all family members	9/14 (64)
• Emotional Processing	• Family is able to manage differing perceptions and connected emotions to reconstructing family identity	6/14 (42)

giving as much time to non-injured children or to the marital relationship. Participants described difficulties within the whole family regarding communication about the changes, specifically in emotional expression. Furthermore, mothers described functional changes in family leisure time and family routines and schedules. Lastly, participants described the direct (e.g. co-pays, insurance) and indirect (e.g. transportation costs, missing work) strain on finances due to the cost of direct treatment.

Due to the disruption from the ABI, the family is left to answer the fundamental question: "How are we there for each other in this new context?" Participants revealed the disruptive event included the initial crisis of when the ABI occurred and the continuing struggles of adaption, over time throughout the treatment and rehabilitation process. This is due to the fact that the ABI never fully heals and therefore will continue to impact the family identity.

The disruptive event of the ABI to a child, especially during hospitalizations, intensive rehab, and transitions back home, put a great deal of focus on the ABI child. As such, the needs and desires of other family members were often left unattended. Participants reflected on feeling “guilty” or recognizing “we were not there for…” other family members. It bothered mothers that the ABI child received the most attention, and they often expressed notions that this is just how the family is now.

Prioritization of the ABI Child *(N = 14; 100%).* The focus of the family identity is upon the ABI child to the extent that the rest of the family experiences separation, whether it be geographical, emotional, or cognitive. Participants described non-injured children withdrawing emotionally or a spouse not being mentally present to talk about the day. One common manifestation reported by participants was when parents divided the responsibilities of family functioning, with one parent remaining with the child with an ABI and the other working, holding the home together, and/or caring for other children. Even with the divide attention, it was clear from participants that the ABI child was the focus of the family. Divided responsibilities often led to one parent being absent from the hospital or appointments and thus being left out of decisions. Participants talked about this dynamic creating frustration between spouses or ex-partners. P6 reflected on her marriage during the hospitalization of their child for a severe ABI:

> There’s just a lot of emotion and my husband was having to go to work, he got left out of decisions that have to be made right then and there. Hearing things second hand from

> other people was very upsetting to my husband. You know, it’s if he’s not there and doesn’t hear it first-hand, it’s hard for you to remember to tell him every single thing.

The parent not involved experiences being left out and participants discussed the guilt these parents had for not being there. Furthermore, the participants talked about how the parent that was involved would become frustrated and resentful with their spouse or other family members because they were not as invested in the rehabilitation or understanding the ABI. Both experiences, though functionally different, were focused on attending to the ABI child. Even though function tasks of the family continued (i.e., paying bills, caring for other children, working) family identity for participants’ families were shifted to focus on the ABI child.

The prioritization of the ABI child is further evident in participants descriptions of transformations that structurally occurred in the home. Multiple participants detailed how the physical arrangement of a house was transformed to attend to the needs of the ABI child. This could involve creating a room specifically designed to be the ABI child’s “hangout room” or making space to bring in necessary medical equipment. For example, P11 was highly aware of the house changes and the effects upon her other children:

> We had to transform part of our living room into basically a hospital. So, when my kids have other kids come over to play or watch TV, you know, half of our living room is a hospital, and so it makes their friends uncomfortable and stuff. We have no other option at this point.

With the focus being on attending to the needs of the ABI child, the family prioritizes the ABI child and thus the family identity becomes about being there for the ABI child first. Participants, when discussing changes to the physical structure of their home, often referenced not having a choice or having “no other option” in the transformation. This belief, though necessary to a point, perpetuated the prioritization of the ABI child and often resulted in other family members being pushed aside. The changes in functioning and physical environment can create isolation both within the family and between the family and the greater community. P11 reflected on how her other children being hesitant about bringing friends over, and P1 stated that there were prohibitions on having guests over at all depending on the status of the ABI child.

Another source of isolation to the family and an increased focus on the ABI child was the display of behavioral difficulties as a sequela from the ABI. Participants spoke in detail about the amount of vigilance and energy that went into monitoring behaviors and intervening in and facilitating social interactions for the ABI child. The attentiveness towards the ABI child limits other aspects of life. For instance, P4 stated:

> I don’t want to travel for personal reasons like we have done, because I travel so much and it’s hard to get into something on a weekly basis. Things like curling. Our friends, if we went out, our friends didn’t understand, (ABI child) was around and if he had an outburst, they just don’t get it, right? It’s kind of embarrassing and you don’t know how to explain it.

For many mothers it was easier to arrange life around the ABI child and to withdraw from aspects of life that were previously important. The prioritization of the ABI child highlights the participants’ awareness of needing to support the ABI child, and to accomplish this, other aspects of the family were sacrificed to make the adjustment easier. The sacrifice of other aspects to the family demonstrate the prioritization of the ABI child in the family system.

The time spent parenting non-injured children often was reduced due to the mothers being absorbed in the needs of the ABI child. Participants discussed how they often let friends or other family members come in and manage other aspects of family functioning so the participant could focus solely on the ABI child. For example, P12 discussed functioning and schedule changes to the family:

> Every aspect of our life was managed. There was food coming to our house, I think for about a year. There were three different days of the week where meals were coming to the house. There were people who stepped in to take care of our daughter who was 10 at the time. There was one family who reach out and said, “Look, every Tuesday we’re picking her up from school when she gets off the bus and she’s coming to our house and she’s going to do homework, she’s going to have dinner, she’s going to take a shower and we’ll bring her home for bedtime.” And that was every Tuesday.

The prioritization of the ABI child can last beyond the initial crisis, as this quote demonstrates. Participants spoke about the need of assistance to manage the family, as the participants felt it was their responsibility to be with their ABI child. Some participants discussed not having community support which led non-injured children to become more independent or more involved in the care for the ABI child.

Reactive Functioning (N=14, 100%). The disruptive event can introduce reactive functioning into the family due to the prioritization of the ABI child. Participants described experiences in which the family was so quickly trying to still be there for each other, but the ABI child, who is in most danger, got the focus of attention, resources, and energy. With the family quickly prioritizing the ABI child, the family identity of being there for each other becomes reactive and focuses upon the family member who is most vulnerable, the ABI child. One prominent change identified by mothers was the rapid shifts in family structure. Participants discussed the physical structural shifts, especially for families from rural settings. Several mothers described times that their family was living in multiple locations, such as the mother at the hospital and older non-injured children still at home attending school. For example, P3 lived in Montana and was airlifted to Seattle, WA and remained in Seattle for the better part of four months. P3 discussed how she left her eldest child, 17 at the time, in Montana, and the mother's two youngest children joined the mother in frequently going back and forth from Seattle to Montana.

> I know for a fact she (17-year-old daughter) felt abandoned. You know, literally, we all up and left. And then the people that were supposed to be supporting her as she was going through these growing pains and then just losing her family instead of understanding they sort of shunned her. So, I know it probably affected her the most. My other two (youngest two children), I think they had to grow up really fast and they essentially got put on the back burner. It sorta all became about (ABI child) and her doctors' appointments and now they're changing school twice, well, actually, three times in a year, making new friends, leaving everything they've known. They've both adjusted well but it was a lot.

Every participant discussed this emphasis on structure to support the ABI child at the cost to other family members. As participants described their methods to adjust to the situation of the ABI, the narratives of the mothers stressed the speed in the decision-making process with the care of the ABI child being prioritized. The reactive functioning reveals how the previous meanings of family identity are ineffective to managing the ABI stressor event.

Additionally, reactive functioning includes adjusting roles, shifts in family structure, and changes in communication. Many participants spoke about changes in employment status and non-injured children taking on more responsibilities. P2 discussed quitting her job because her boss was not accommodating to her situation. This decision of the mother led to complications with health insurance and other financial challenges due to the quick departure from her job. The mothers acknowledged that often the changes in roles or family structure occurred with little communication between family members. Things changed rapidly, and everyone in the family just had to go along with it.

Another aspect of reactive functioning was that family members who were not injured, close to dying, or needing special attention were expected to participate in being there for the ABI child or to be more self-reliant. There was an unspoken change in family identity as attention, resources, and time were needed to be devoted to the ABI child. The descriptions of participants identified an awareness of this trend and that spouses, non-injured children, or other relationships were put "on the back burner." To illustrate, P3 spoke to the focus on her daughter with the ABI:

> Life was consumed from one therapy to the next. I would say that like our other kids' kind of just got put on the back burner, and their interests and their activities were just…gone. Thankfully, they were young and so it wasn't as noticeable.

Participants often described the tension between functioning to support the ABI child and not being able to be there for other family members. Even so, participants expressed notions of "this is what we have to do" even if they knew the situation the family was in was not ideal.

Furthermore, participants reflected on the trend of non-injured children being pressed into greater responsibilities. Mothers described non-injured children being more self-sufficient (e.g. cooking for self or younger siblings, completion of schoolwork, not needing parents) or helping with the ABI child (e.g. monitoring sibling if parents are away, changing diapers). For instance, P8 spoke about how her eldest child of four, who did not have an ABI, became a "parent", especially during the initial crisis, and still acted like a parent years after the ABI event.

> (The eldest) loves and will protect them (ABI injured siblings), but at the same time she gets frustrated with them. Often, she’ll try to almost parent them and it’s like, “It’s not your place to worry what they’re doing right now,” but then that’s kind of the role in a way that she’s kind of had to portray.

Multiple participants addressed changes in roles and responsibilities throughout the family system and how these changes often occurred non-verbally, and how all family members were expected to assist in supporting the changes. For example P11 discussed how her younger non-injured daughters have participated in the care of the ABI child:

> My girls looked up to (ABI child) and suddenly the roles are reversed. So now they’re the ones helping to change her diaper. They’re the ones helping dress her. They’re the ones seeing their sister in a way that they never should have had to see her before.

Participants referenced emotional shifts and meanings connected to the roles and structure of the family. For mothers and families, the participants reported the shifts in expectations and emotions that were the hardest to process. Reactive functioning leads to roles and responsibilities changing, and often, emotional attunement of how these functional changes are impacting the family is absent. The family identity that is disrupted by the ABI event and initially participants reported reactive functional shifts but this method of coping with the ABI stressor does not attend to emotionally being there for family members.

The emotional disconnect in the family creates difficulties in expressing and holding emotion of the family. Participants often would reference their insight of emotions in the family system, though discussing or feeling the emotions intentionally was not a common practice. For many mothers, emotions, for themselves or others, were inconvenient as the mother was focused on the present crisis. For example, P2 told the story of another son coming to the hospital to see his brother in a coma from the ABI:

> So (my son) came around the corner and saw him and just stepped backwards and hit the wall and shrunk down on the floor and just sobbed. And just said, "how do you do this every day?" And I'm like, "I don't know, honey, I just don't really have a choice, you know?" And he didn't come back.

Participants talked about family members, extended family, and friends "disappearing" when the emotions became too much. It was common for mothers to describe experiences where a person withdrew from the ABI child because "it is too hard to see [ABI child] this way."

Reactive functioning can further lead to a removal of or shift in family leisure activities based on the ABI child struggling to participate or having triggers from stimuli. Leisure activities can be an important aspect to family identity and how the family defines spending quality time together. For example, a child who uses a wheelchair limits family leisure activity, such as hiking or boating, or the mental fatigue of the ABI child restricts the duration of activities because the child may need to rest. P4 reflected, "We can't do any big vacations or be gone from home too long. It's too much for [ABI child]." Between the limitations the ABI can place upon the family and the financial strain induced by the ABI, the family is forced to give up activities. Many participants identified leisure activities as influential to their family identity. A family that prioritizes being outdoors together may have to give up that value if the child with ABI is light sensitive and struggles to be outside.

The behavioral problems of the ABI child were exhausting for family members, and participants discussed how they were often reacting to situations created by their child's behavior. Some participants described behaviors of their ABI child flirting with girls by trying to hug them right away or seeking sexual encounters with multiple random men, often 20 years the senior of the ABI child. Participants that dealt with behavioral problems expressed the exhaustion and frustration of managing the behaviors. For example, P2 reflected on her exhaustion with her son's behaviors:

> He's really handsome and you can't look at him and know something's wrong, but once he starts really talking… So, he goes into Starbucks, there's a cute girl, he'll start doing some pushups, take off his shirt, show her his muscles, and get kicked outta there. The cops were called and have a trespass order. He would go back the next day because he didn't do anything wrong, he's gonna just see them again, so he'd get arrested and so he's been arrested for stuff like that probably 40 times. I always had to leave work. There were times I wanted to leave him in jail, so I didn't have to deal with it.

The participants identified that the repetition and frequency of behaviors were a burden. Participants further described pressure upon the family to minimize the behaviors of the ABI child.

Furthermore, participants talked about their need to explain behavior, what an ABI is, and be the primary person to manage the behavior. Tolerance for behavioral problems can run low in other family members, creating a lack of compassion and patience for the parent managing the behaviors. When tolerance for behavioral problems was low, mothers discussed the conflict they experienced between supporting and advocating for the ABI child and not wanting to deal with the behavioral problems anymore. Participants described the tension between supporting the ABI child and isolating the family so not to bother others. P2 stated, "I just don't take him anywhere. I know I should, but it's too much trouble." P5 detailed moving the family to a rural setting to increase space and privacy so her son's delusions would not attract attention.

Even within the family, participants reflected on feeling isolated and needing to explain behavior to other family members. As the family continued to adapt to the ABI, participants described times that other family members would withdraw from helping manage the ABI. The mothers talked about a reactive response from a family member who would just be “over it.” For example P2 discussed this phenomenon,

> You know, everybody deals with it in their own way, I wasn’t upset with him (non-injured child), he just didn’t know how to handle it. It was just way too much for people: The same with his stepdad who had bought him the motorcycle. He (stepdad), people, just at that point were like, “This is so F’ed up. We can’t…” You know… people just slowly trickled away.

The isolation participants experienced due to the ABI event was significant. In the process of helping the ABI child, the mothers focused on the ABI child, leading to ineffective ways to cope and manage the crisis. Additionally, the participants identified how these ways of dealing with the ABI started to fracture the family, and the family struggled to “be there for each other.”

Reconfiguring Family Identity

The second theoretical concept to understand the process of reconstructing family identity after an ABI to a child is *reconfiguring family identity*. Figure 2 captures the transformation of the family in restructuring what it means “to be there for each other” after an ABI to a child. There are three themes that serve as important mechanisms to foster the process of reconfiguring family identity are *intentionality*, *adaptive functioning*, and *emotional processing*.

Intentionality (n = 9; 64%). Intentionality refers to the conscious awareness and deliberate actions to respond appropriately to the changes needed to support the ABI child and the family. The conscious perception of participants about changes revealed the awareness of the family is recognizing that the previous way of being there for each other no longer works and a new family identity is needed in the new context the family lives in. Intentionality is an important process to reestablishing family identity. To be intentional, participants identified the need to be assertive in communication and action to help the family adjust during a time of crisis. In the process of being intentional, mothers were able to address areas that support the family identity *and* were able to attend to the needs of the ABI child. The importance of intentional communication was emphasized by participants. Key elements identified by participants to intentional communication included routine check-ins, awareness of changes, and assertiveness. P6 discussed her intentional communication with her husband:

> My husband and I talk daily. We talk about (ABI child)'s behavior, how we could help her understand it, how to help her have the self-awareness, steps to talk that she could change it. Just shared our frustration over some of the things that were happening. I would support him by asking what was happening in his life with school, jobs, where you like it, whether you don't, and he did the same for me. That support has always been there.

The routine check-in described by this participant illuminates the value of intentional communication, providing space for a discussion on logistics, emotions, new changes, or a personal check-in.

Participants also identified the importance of intentionally reframing the perception of the ABI. Multiple mothers discussed the importance of highlighting new strengths in the ABI child or family or looking for gratitude instead of focusing on deficits or problems from the ABI. This process of reframing helped to access factors of family identity. Reframing is an intentional move in which a person or family must first recognize the initial perspective and decide on the new way of seeing a situation. For example, P7 reflected:

> We need to learn how to talk about this in a very positive way because (ABI child) is getting to the point where she's going to grow up and hear this, and I want her to be able to look at herself in a strong way. Not in a way, you know, we don't dodge hard questions. We talk about the hard stuff. We're open. We're honest.

Participants that spoke about reframing the consequences of an ABI to highlight resilience and strength were not blind to the struggles of an ABI. As the quote above reveals, mothers who embraced intentionality were aware of "the hard stuff" but were focused on creating new meanings and beliefs about the ABI to foster strength and growth.

Furthermore, intentionality includes the awareness of changes or potential and speaking directly into the family about how things will be handled. Participants discussed how beneficial this process was to get the family "on the same page." With so much focus on the ABI child, the rest of the family could be easily placed "on the back burner." Participants identified intentionality as an important mechanism to attend to the entire family. For example, P12 reflected:

> It was in the first couple days after returning home, I took a hold of my husband and I said, "Look, this is what breaks up a marriage and I'm telling you right now, this is not how our story goes, and so you hold onto me and I hold onto you, this is going to be really bad and we're going to get to the other side of it together."

However, mothers reflected that it was difficult to be intentional due to other demands or having other family members not be receptive. Even so, mothers that discussed times of intentionality identified how the process helped the process of reconfiguring family identity. Intentionality is a process that significantly helps with the reconstruction of family identity and assists in adaptative functioning and emotional processing.

Adaptive Functioning (*n* = 9; 64%). Previous examples demonstrated reactive functioning responses, but families can also embrace the changes and be intentional about setting boundaries and limits in how the family participates in activities. As intentionality highlighted the awareness of changes and deliberate actions reframe perceptions or communicate about the changes to family identity, adaptive functioning shows the intentional changes to structure and functioning in the process of reestablishing family identity. Multiple mothers identified ways they deliberately altered the functioning of the family to support the ABI child. For example, P9 discussed her boundary setting with activities:

> We can't do strobe lights, so we'll avoid laser tag. Swimming… I don't really like to go to the pool. I'm not gonna take the kids to a big pool where there's a bunch of other kids. He (ABI child) has a really hard time doing those obstacle course bounce houses. There are even movies we have to avoid, you know, the flashing lights movies. We've actually walked out of movies due to the flashing lights.

The family identity is adjusting to be there for the ABI child. This participant is aware of problematic activities that could create further stressors. The family all avoids these activities for the sake of the ABI child.

However, in the reconfiguring of family identity, the family must learn to adjust for the ABI child but still involve other family members' wants and needs. To accomplish attending to all family members, participants discussed being intentional about planning activities (e.g. going to parks in the morning when there are less people there) or finding activities with options, such as camping, as people could choose to fish, swim, hike, or stay at camp and nap. P1 discussed her intentionality of finding activities for the whole family:

> And we have a cheapy little boat that gets us on the water, we paid outright cash for it, you know it's like, $5,000. But the only… the reason why we got it is because my other kids as a family enjoy it. Even though when (ABI child) has a headache or doesn't feel good, he'll still go out on the boat, try to have a good time. And so, it's cheap entertainment that we don't have to pay thousands of dollars or $50 to go to the movies.

As participants depicted examples of adaptive functioning, a tension was described between attending to ABI sequelae and needs but not allowing the ABI child ultimately to dictate how the family functions. Family identity is reconstructed in the new context of an ABI in a manner that attend to the needs of all family members and recognizes limitations the family must consider.

Adaptive functioning for the family is a systemic process. The family together is learning new roles and responsibilities and reconfiguring how to be there for a family member. A prominent role the family embraced was learning to support the ABI child. Participants talked about their non-injured children learning that video games could not be played during the ABI child's nap or how having too many friends over was overstimulating. Other mothers discussed how the family learned to be attentive to each other to help with the needs of the family (e.g. providing transportation, giving primary care parent a break, helping with chores). Another example is P13 spoke about the family focusing on working through deficits caused by the ABI:

> I think we've all kind of learned when (ABI child) says something we react very quickly to it. We kinda drop everything because just to encourage his speech, you know? So the other day we were going for a walk and (ABI child) wanted to walk by the water. He was saying "water, water, water," because we live near a river. I said, "Honey the park is

> closed." He was not understanding what I was saying and so my 6-year-old daughter, thank God she is there, helped me. "Water broken, water broken." And he goes "Oh. Fix it?" and she says, "They're gonna try, they're gonna try." She didn't jump right in 'cause she thought of a way that he would understand.

This brief story above reveals a focus on the ABI child, but not all focusing is adverse or detrimental to the family. The family, through the guidance of the older sibling, was "there for" the ABI child. The family was able to transform communication and functioning to include the desires of the ABI child into the family. The family has learned how to respond appropriately, the ABI child is attended to, and everyone can move forward in their day.

Emotional Processing (*n* = 6; 42%). The theme emotional processing captures participant narratives of being intentional about acknowledging and processing emotions as a family. These emotional processes need to be expressed systemically so the family can process each member's emotions and perceptions and use them to inform the reestablishment of family identity. Participants described specifically asking about emotions, waiting for the best times for emotions to be expressed, and expressing one's emotions and being open to other family members emotions, even if they were different from their own. Mothers talked about the importance of specifically asking about emotions. For example, P7 spoke about her relationship with her elder son:

> We had a lot of juggling. That was really hard, there was a lot of guilt that I would navigate through, you know, a lot of times we'd sit down with (non-ABI child) and we'd talk to him about how he's feeling and what this was like for him.

It is a deliberate process to check in with emotions and give the family permission to express the emotions. Participants noted that checking in and holding emotion re-enforced family identity, providing ways to support each other. Mothers that described this practice of checking in on emotions found it invaluable, for it offered an opportunity for building relationships and hearing how each family member was processing the ABI event and the ongoing consequences of it.

The different perceptions of multiple family members can lead to multiple meanings and beliefs. Participants identified the difficulty in communicating effectively with other family members and how this difficulty created intense emotions (e.g. anger, frustration, sadness). In addition, mothers described being overwhelmed by not knowing how to process emotions and hold space for multiple meanings. Being overwhelmed can prompt deferred communication, which is waiting for situations or people that can help structure discussions or waiting to be in a situation where there is containment for emotions, such as psychotherapy. For example, P4 discussed communication with her husband:

> I try to talk to my husband about how I see things and then how I feel. It's just in the heat of the moment sometimes things don't go well and, I mean, I react, too. So, you try not to react. It's hard to talk to my husband about it. I have to get him in the right circumstances. Usually I will, if something really bothers me, I'll bring it up a week or two later or wait for sessions with the social worker. He's more open to listening there.

Participants identified how difficult emotional processing could be and how it was necessary. What mothers did reflect upon was the intentionality of engaging in this process, even if it meant needing assistance from outside the family (e.g. therapist, pastor, family friend).

Rehabilitation Services: "Joining the Tribe"

Though rehabilitation services are focused on the ABI child, mothers and the family are influenced by the services rendered. The final research question for this study aimed to capture how rehabilitation services affect self-identity and family identity: When a child receives an

ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive maternal self-identity and family identity? The interviews with participants revealed two themes: (a) *Involving and Validating Mothers in the Treatment Process*, and (b) *Providing Education and Skills*. Table 7 provides a summary of the themes with brief descriptions.

Table 7

Summary of Themes for Rehabilitation Services

Themes	Definition	n (%)
Involving and Validating Mothers in the Treatment Process	• Taking time to attend to the experiences and perspectives of the mothers. Actively bring mothers and family into the treatment process. Need for clear and open communication about treatment plan, with attention to holding hope.	14 (100)
Providing Education and Skills	• Prioritizing education strategies to best support families, such as "planting seeds" regarding potential, general information on ABIs and, guidance accessing services and navigating insurance	12 (86)

The overall name of the heading for this section, "joining the tribe," is a reference to a quote from a participant speaking about helpful professionals. "Joining the tribe" refers to the investment of professionals in the ABI child and the overall family. Participants often talked about feeling close to the child's service team and that the professionals would celebrate and cry with the family through the ups and downs of treating, managing, and adapting to an ABI.

The complexity of an ABI is evident by the multitude of services accessed by the participants of this study. Table 7 details the services participants utilized for their ABI child, mother, or the family. This list of services includes all 15 children that were represented in the study. An average of 6.9 services (SD: 4.21, R: 13) were utilized per family to stabilize and support the ABI.

Table 8

ABI Services Accessed by Families

Service	*n*	%	Service	*n*	%
Neurologist	14	93	Neurosurgeon	1	7
Emergency Medicine	13	87	Music Therapy	1	7
Occupational Therapy	13	87	Infrared Light Therapy	1	7
Physical Therapy	12	80	Naturopath	1	7
Speech Therapy	11	73	Massage	1	7
General Practice Doctor	9	60	Recreation Therapy	1	7
Psychotherapy	8	53	Vocational Rehab	1	7
Individual Education Plan	7	47	Psychiatric Hospitalization	1	7
Neuropsychological Testing	4	27	Lactation Specialist	1	7
Biofeedback	3	20	Plastic Surgery	1	7
Psychological Testing	3	20	Equine Therapy	1	7
Private Tutor	2	13	Orthopedic Surgeon	1	7
Hypobaric Oxygen Therapy	2	13	Epilepsy Specialist	1	7
Craniosacral Therapy	2	13	Epidemiologist	1	7
Legal Services	2	13	Vision Therapy	1	7
Feeding Specialist	2	13	Supplements	1	7
Developmental Pediatrician	2	13	Stem Cell Treatment	1	7
Psychiatrist	2	13			

The analysis of participants' service experiences revealed only one participant (7%) who had a professional directly discuss self-identity and the changes that could potentially occur following the child's ABI. According to the participants, no professionals addressed changes to the family identity or were attentive to how the family was transitioning. For the participants, it was clear that the ABI child was the professional's main focus. For example, P7 discussed the focus on her daughter with an ABI and the changes she wanted to see:

> These doctors and therapists, they are obviously focused on the child, and that's fully important, but at the same time there needs to be this recognition that the family unit is also an extension of that child, and when the family is getting support they can then support that child even better.

Multiple participants discussed the desires for more professionals to see the family as an extension of the ABI child. Throughout the interview process, participants were focused upon the more negative encounters, with professionals wanting to address changes that were needed to better support ABI families. The participants' desired changes in rehabilitation services will be explored through the themes that emerged from my analysis.

Involving and Validating Mothers in the Treatment Process **(N = 14; 100%)**

Each ABI is completely unique. Due to each injury being so distinct, the treatment and rehabilitation for an ABI are complex. As noted, this is evident in the broad spectrum of services families in the current study accessed. Though professionals have the training and knowledge, participants identified that their experiences and perceptions of their child were often disregarded. Every participant expressed how important it was for them to be involved in the treatment process and to have their experiences validated. Involvement refers to the practical aspects of the treatment process whereas validation is attending to the emotional, cognitive, and perceptual experiences of the mother.

Mothers are often the individuals who have the most insight and awareness into the ABI of their child and their child in general. Many participants spoke about a "mother's intuition" and how professionals either engaged or disregarded the thoughts of the mother. For instance, P2 described her fights with hospital staff about the needs of her son during a hospitalization several years after the ABI event and how the professionals were quick to dismiss her thoughts:

> Listen to the family member. They (professionals) put him in there and he screams, and I know his headache is causing pain. He's crying with urgency, he's just off the wall and the doctors are telling me, your child might have meningitis. I said, "my child does not have meningitis" because the headache and stiff neck is constant. This is my kid's

> medical; this is what he is. They’re no different than what he’s usually had. Call it mother’s instinct, I knew it was something else and I was right.

The complexity of an ABI often created tension between the professionals and the family. Through the perception of the participants, the experience or opinion of mothers or the family were often not highly valued by professionals. Mothers are attuned to aspects of the ABI child which are not readily apparent to professionals, as the mothers are observing and interacting with the ABI child daily. Behaviors or sequelae will not always manifest during appointments, and mothers will have spent the necessary time needed to have observed all sequelae.

Participants brought up their desire for professionals to be intentional about listening to them and talk to them separately, away from their ABI child. This request from participants for individual time with a professional was due to wanting to avoid “awkwardness” from talking in front of their child or fear of the reaction if the mother was to speak openly. To illustrate, P3 asserted:

> I recall a lot of almost condescending comments, you know, “we’re asking him, not you.” He (ABI child) isn’t going to answer appropriately. If you try to answer in front of your child, you’re basically complaining about, your child gets defensive. The doctor saying, “Hey, I’m gonna talk to your mom alone for a minute.” There you can say some things that you probably wouldn’t in front of that person. That would be super helpful.

Multiple participants reflected upon how much they would appreciate professionals setting aside time to talk with mothers, especially without the ABI child present. Mothers can be so important for the overall treatment process. They coordinate appointments, transport the ABI child to the appointments, follow up on things to be accomplished at home, and spend a great deal of time with the ABI child.

Participants explained that professionals taking time to hear what a parent has to say would be beneficial for the treatment process. Time spent with mothers involves them *and* validates them. Validating their perspective also means attending to the emotions and experiences of the parent. Participants reflected on how infrequently professionals would check in with them. The times professionals did listen to participant experiences and held space for emotions was beneficial. For example, P1 discussed her difficulties in helping others understand brain injuries:

> My neighbors are saying that it’s nothing and I kept on talking about…saying to the doctor, you know, people aren’t understanding that. When he would be biking, he’d fall off and shake like a seizure. My doctor said, you know, your neighbors don’t understand it. Nobody gets head injuries. People don’t understand it because they’re not doing this every day.

The doctor for this mother normalized and validated her experience as a mother with an ABI child. Multiple participants reflected that professionals that checked in on the mothers’ well-being or asked about the family were easier to be open with and invest in the professional relationship.

When mothers perceived professionals investing in the ABI child and the family, this experience was validating and important to them. Participants talked about how the validation from professionals towards the family regarding the changes to the ABI child was powerful. For participants, the reflection on changes to the ABI child and the long-term investment in the struggle of rehabilitation was one of the strongest examples of validation. For instance P10 discussed the support the school provided her:

> The school was beyond supportive. When I took him in to drop him off the first day, the principal came up and he said, “anything that (ABI Child) wants or needs, we will make sure it happens.” I was like, “okay, that’s great.” He even had a nap period schedule in his IEP. He had wonderful aids. He had to relearn his ABC’s, his 1-2-3’s, his colors, and stuff like that and that was an eye opener. That was very frustrating for everybody. He graduated on time, in modified situations. He got a standing ovation there, too. It was pretty awesome.

Stories like the quote above were highlighted by participants as experiences that brought hope and joy through the struggle of rehabilitation after an ABI. Mothers found hope and joy in the involvement and validation professionals offered.

The process of involving and validating depends upon communication between mothers and professionals. In the narratives the participants shared, communication served numerous functional purposes, including receiving updates on prognosis, ABI outcomes, referrals to other professionals, and working with insurance. However, the *approach of communication* from professionals to the family was important to the mothers. In the initial ABI event, participants reported the highest degrees of a crisis, especially if there were doubts about the child surviving. Participants often reflected on the poor communication and bedside manner from professionals, such as, nurses being passive-aggressive when mothers tried to voice concerns or professionals “talking down” to mothers and/or not revealing the whole treatment plan to the mothers. For example, P2, when trying to get help for her son in the ICU when many professionals had assumed death was coming, stated:

> It’s my baby, you gotta do something…somethings a problem here. You know, just to not be, just to be, pushed aside. I remember this guy saying to me, “we have other patients in this hospital besides your son.” I wanted to rip his face off.

Participants would reference feeling like they were fighting against professionals who were supposed to be part of treating their child. The conflict, described by mothers, created a lack of trust and resentment towards professionals. To further illustrate, P6 revealed the pressure nurses were giving her to sign her daughter to the organ donor registry. The nurses went so far as to use the mother’s son to accomplish what they wanted. P6 stated, “when my son finally arrived, they (nurses) took him aside and said, ‘You need to convince your mother that she needs to put your sister on an organ donor registry.’ That was highly inappropriate given the circumstances.” This communication pitted the mother against the people who were caring for her child. Participants talked about feeling like they needed to advocate for their child even more due to professionals having a different agenda in treatment.

Participants’ awareness of the different treatment agendas or perspectives revealed how differences in hope were distressing for mothers. The communication of hope was a topic that participants frequently addressed. Participants talked about how professionals and the family (sometimes even within the family) would have different beliefs on hope. The stories participants told revealed this tension in hope was present throughout the treatment, from the initial crisis to ongoing rehabilitation care. Mothers reported that when differences of hope existed between professionals and the family, it broke down communication and information passing between the parties. For instance, P2 reflected on differences of hope between her and her ex-husband, stating, “and his dad said ‘yeah, we need that.’ Like, basically, they went around me to do it (invasive surgery) because I was more optimistic about his recovery than anybody else was.”

The disconnect in hope led to differing priorities that further created conflict. Differences in hope can also occur within the family. Several participants described how this experience led to further experiences of isolation within the family in the midst of a crisis.

***Providing Education and Skills* (n = 12; 86%)**

The education for mothers and families is an ongoing process from the initial crisis to the ongoing rehabilitation services. The consequences of the ABI can vary so drastically that it is difficult for professionals to give the family concrete answers and knowledge about the injury. For instance, the anatomical location of the injury (e.g. frontal lobe, temporal lobe) can cause drastic differences in sequelae and outcomes. Even so, participants reported that their extensive efforts to learn from professionals or their own personal research included knowledge on ABIs, brain development, plasticity, and latest developments in treating an ABI. Participants acknowledged that this information was helpful but identified the deficit in educating mothers about next steps in treatment and giving families a concrete direction in finding services. P6 stated, “Nobody came to me and said. ‘Hey, your daughter could benefit from this.’ I had to ask for it.” Participants reflected that the process of always advocating and being proactive could be exhausting and that they do not have insight into knowing what to ask about.

Though professionals have medical knowledge, mothers spoke about wanting to hear humility from professionals about the gaps in understanding the brain and how, sometimes, things cannot be fixed. To illustrate, P1stated:

> They just stick to the medicals. They’re doing their jobs. They’re not… they’re not telling anyone what to expect. I don’t think they know personally how. I don’t think… I think they’re just trying to fix the problem and they really don’t know how to help with the problems.

When discussing experiences with professionals, mothers referenced how often the professionals seemed focused on “fixing” while often ignoring helping the family in preparing for how to help the ABI child to be successful.

One method of education that participants referenced frequently was having professionals “plant seeds.” Planting seeds refers to the process of naming areas in the future the families may need to consider. By naming them, it starts to give the families knowledge of what to look for in the ABI child. Frequent areas that participants labeled as important to plant seeds were highlighting future needs of the ABI child or family, discussing what to expect, potential helpful services, and emotional/identity processes that may later emerge. To illustrate, P7 spoke on the topic of professionals planting seeds about changes in her self-identity:

> Here’s the thing; I’m certain in the beginning I probably… we probably… wouldn’t have asked for it (discussing identity). We might have been too prideful, or we might have assumed, “our family’s got this, we’re fine.” So I think professionals would do good understanding that at least offering it, it is something that plants a seed in a family’s mind.

Several participants similarly agreed that they were not ready to hear information from professionals due to other circumstances (e.g., emotionally not ready, focused on other areas). Suggestions mothers made to “plant seeds” were to prepare binders with information on ABI, services, and community supports, to have a sit down with a social worker before discharge to discuss finding further services, and for professionals to bring up topics in conversation.

Chapter 5: Discussion

The purpose of this research study was to capture how, after a child experiences an ABI (Acquired Brain Injury), mothers reconstruct self-identity, how families reconfigure family identity, and how rehabilitation services can support the changes to self- and family identity. An ABI can have multiple consequences for mothers and families, and these changes will impact both self-identity and family identity. Given the importance of supporting mothers and families after a child receives an ABI (Ownsworth, 2014; Wade et al., 2011), a conceptual framework of how reconstruction of self-identity and family identity occurs was needed. It is evident that self-identity and family identity will be impacted after an ABI to a child; however, the process through which reconstruction occurs is not fully understood. Furthermore, researchers have no yet investigated changes in self-identity, primarily among individuals with an ABI (Ownsworth, 2014; Ylvisaker et al., 2008), or specific areas of self-identity that are influenced by a child receiving an ABI (Gelech & Desjardins, 2011; Godwin et al., 2014). Including the perceptions of mothers and considering the family as a system provides a more thorough conceptualization of self-identity and family identity reconstruction after an ABI.

In this study, I sought to answer the following research questions: 1) How do mothers of a child who has received an ABI construe and reconstruct their self-identity? 2) How do mothers reestablish family identity, after a child has experienced an ABI? 3) When a child receives an ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive maternal self-identity and family identity? To answer these questions, I interviewed 14 mothers who have a child with a formally diagnosed ABI and analyzed the data using constructivist grounded theory methodology (Charmaz, 2014) to develop conceptual models in how mothers and families reconstrue self-identity and family identity. Contextual Model of Family Stress was the guiding theory throughout the research process of my dissertation.

ABI Context

The findings of this study clarified how influential the context of the ABI can be upon self-identity and family identity. In this section, I highlight the severity of the ABI, consequences of the ABI, and secondary trauma experienced by mothers due to the ABI. Previous research has revealed a positive correlation between the severity of the ABI and more significant consequences and sequelae (e.g., behavioral problems, learning difficulties, emotional dysregulation; O'Neil et al., 2013). Furthermore, a more severe ABI is connected to more intensive services and more drastic changes for the child and the family system (Ownsworth, 2014; Rolland, 2018). These changes influence self-identity and family identity, as identity is interpreted through the context of the ABI.

Behaviors are an example of a consequence of the ABI that influences both self-identity and family identity. Though all effects from an ABI will impact the entire family, the child's behaviors seem to require more of an investment from the mother to manage as mothers strive to keep the child with the ABI safe. For example, one participant's 17-year-old daughter routinely sneaked out of the house to meet up with high school boys and older men she met online for sex. The mother explained that the police could do nothing, so the burden of regulating behavior rested upon the participant and her husband. As this example illustrates, the behavioral consequences of an ABI can profoundly affect both mothers and family. To mitigate the negative consequences of the ABI child's behaviors, participants referenced restricting activities or public outings to avoid potentially negative interactions. Participants often discussed times that their ABI child behaviors would be internalized and influenced self-identity. For example, several mothers discussed how they felt personally responsible for managing their ABI child's behaviors. This responsibility to manage behavior reflects the external self-identity and the external forces (i.e., child' behavior, perceived perceptions of others) influencing the meaning of being a mother.

Through the lens of the CMFS (Boss et al., 2017), the internal contexts of philosophy and psychology are crucial in the process of making meaning about the ABI child's behavior and mothers' self-identity. Some participants seemed to internalize their child's behaviors, such as being embarrassed for inappropriate social exchanges or feeling it is their responsibility to stop all behavioral outbursts at a family gathering. The process of mothers internalizing their child's behavior demonstrates how external factors influence self-identity. When positioned in external self-identity, mothers' response to problematic behaviors can be to over-explain behaviors or become increasingly more isolated to minimize ABI child interactions outside of the family.

Other consequences from an ABI, such as the ABI child having light sensitivity or mental exhaustion, often restrict family activities, leisure time, and the overall structure and set up of the home. This can impact both self- and family identity. Multiple participants identified ways in which their family spends time together was important for their family identity. For some families, the living room was transformed into a hospital room as that was the only space to provide care for the ABI child. Other families limited their non-injured children from having friends over, as the noise and increased activity could be problematic for the child with an ABI. As these examples show, it is necessary to consider the consequences of the ABI, as they dramatically influence internal and external contexts of the family. The shifts in family internal and external contexts impact family identity, and the awareness of the prioritization of the ABI is noticeable throughout the family. For example, Figure 2 demonstrates the disrupted family identity occurs through the unexpected ABI event. In this disrupted state, a family's access to hospitals (external context) or shifts in family structure (internal context) will impact family identity and the reestablishment of family identity.

A final aspect of the ABI context to consider, in terms of self- and family identity, is the intensity of long-term care. Some ABIs, due to brain plasticity and rehabilitation services, can allow the individual to recover and live independently with minimal supports, whereas some persons with ABIs require 24/7 care and support. The amount of time, resources, and energy that mothers and families must invest can drastically disrupt self-identity and family identity. The care needed by ABI children is a spectrum, as illustrated by the participants of this study. For example, one mother's main task was to collaborate with school officials and therapists as the child was increasingly improving. On the opposite end of the spectrum, one mother's daughter was bedridden and needed assistance in all things. The intensity of care in the long term versus short term is an essential variable to consider for researchers and professionals when examining self-identity and family identity. From the perspective of CMFS (Boss et al., 2017), long-term intensive care can perpetuate the crisis the family is experiencing. Furthermore, families with limited resources may focus their time and energy on caregiving tasks and be unable to make sense of the ABI stressor and meanings from this experience. The exploration into the ABI context highlights crucial internal and external contextual factors associated with the process of reconstructing self-identity and family identity after a child receives an ABI.

Self-Identity

The fact that self-identity shifts for mothers after a child or adolescent receives an ABI is supported by previous research (Gelech & Desjardins, 2011; Tam et al., 2015). Alhough self-identity changes are recognized, researchers have not examined the process of self-identity reconstruction after an ABI. In this study, I sought to answer the following research question related to self-identity: How do mothers of a child who has received an ABI construe and reconstruct their self-identity? Through constructivist grounded theory (Charmaz, 2014) analysis, three theoretical concepts and ten associated themes emerged from the analysis. The three theoretical concepts were: 1) *pre-ABI event self-identity: perceptions of continuity and sameness*, 2) *external self-identity* and 3) *internal self-identity*.

As Figure 1 demonstrates, the theoretical concepts are interconnected and part of the process of reconstruing and reconstructing self-identity. Shifting between external and internal self-identity will occur, especially when crises emerge. External self-identity is focused upon the factors that lead to the crisis and managing functioning in response to initial and subsequent crises. When this occurs, self-identity becomes subsumed by the tasks necessary to manage the crisis. Internal self-identity allows people to have conscious awareness of the factors that are important to their self-identity and how these factors need to change to help support them through the crisis. To further explore the dynamics between internal and external self-identity, drawing a parallel to the concepts of internal and external locus of control is helpful (Rotter, 1954). Locus of control refers to the degree to which people believe they (i.e., internal locus of control) have control over their lives, rather than forces they cannot control (i.e., external locus of control; Rotter, 1954). Similarly, the dichotomy of internal and external self-identity highlights the degree to which the mothers can identify and utilize aspects of self-identity located within themselves, as opposed to external forces or factors determining self-identity.

Pre-ABI Event Self-Identity

Participants clearly distinguished between who they were before and after the ABI event. This research therefore confirms findings by Godwin et al. (2014) that family members have an awareness of the “old us” and the “new us.” This knowledge of the pre-ABI identity and post-ABI identity is necessary for the reconstruction of self-identity. The awareness of the pre-ABI event self-identity identifies the aspects of self-identity that have been altered due to the ABI event. Some participants from this study discussed liking their old self better than who they are now. These meanings and perceptions about self-identity need to be carefully considered by the individual to assist in the self-identity reconstruction. The perceptions or meanings about self-identity will often be influenced by whether a person’s self-identity is positioned externally or internally.

The concepts of *situational meaning* and *global meaning,* developed by Claudio et al. (2016), provide further insight. As their findings suggest, the more inconsistent situational meaning is with global meanings, the more distress a person experiences (Claudio et al., 2016). Similarly, the more drastic the shifts between pre-ABI event and post-ABI event in self-identity, the greater potential distress mothers will experience in their self-identity. For example, the mother who radically shifted her life to become the full-time caregiver for her daughter who is bedridden experienced much more stress in her self-identity than another mother whose described minimal appointments and coordinating with the school to obtain the extra support the child needs.

External Self-Identity

The theoretical concept of *external self-identity* captures how a mother’s identity is absorbed into the ABI child and all of the functional aspects associated with supporting the child. In external self-identity, the mother’s self-identity is defined and formed by external factors. The external factors become the way the mother perceives her self-identity. The ABI event was the catalyst to shifting to external self-identity; the focus on the ABI child reveals how the identity continues to be positioned outside of the mother. This external shift in self-identity demonstrates how important the ABI to a child is to the mother’s identity construction.

From the theoretical perspective of CMFS (Boss et al., 2017), the ABI event is a crisis and the family must adapt to manage the needs of the crisis. Participants discussed how their attention and that of the family revolved around the child with an ABI. Mothers mentioned sacrificing their careers and spending less time with spouse/partner or caring for other children, so that they might be with the injured child and invest in the child’s medical and rehabilitation treatment. The focus on the ABI is useful and often necessary during the initial crisis, which can involve life-flights to a Trauma I hospital center, lengthy hospitalizations, and coordination of complex treatment regimens and services.

There are other contexts that prolong the need for the ABI child to be the focus of the mother. Witnessing the injury event, ongoing ambiguity with legal processes, or near-death experiences in the hospital increase the complexity of processing the crisis event. Witnessing the injury event can elicit powerful emotions (e.g., guilt, resentment, shock) that keep mothers stuck in that moment. Legal processes can take a long time, and mothers feel their ability to “move on” is connected to the legal process. The intensity of these external factors makes the external self-identity more prominent.

If external self-identity continues, the focus on the ABI child can remain in place. Since ABIs are lifelong injuries, the continued assistance and supports the ABI child’s needs can perpetuate external functioning and prolong the experience of the family being in crisis. External self-identity provides a restrictive view with which to interpret the ABI event and the ongoing rehabilitation process. Remaining in crisis was evident in several participants; for example, one mother, whose daughter was assaulted and strangled and due to the lack of oxygen and is now bedridden, provides 24/7 care at home. For this participant, every minute of the day and every aspect of the family revolves around the ABI child. There was an awareness of these dynamics, but the mother often spoke of having no choice or other alternatives.

Furthermore, the experience of an ongoing crisis can extend the ABI event. The nature of an ABI can introduce new complications or medical issues over time. Several participants described additional hospitalizations or a need for increased outpatient services to manage new difficulties. This experience can be re-traumatizing and the mother’s self-identity can remain or revert to being external, absorbed in the needs of the ABI child and functioning primarily to support that child’s needs. Even if there is no medical emergency or need, the focus on the ABI child can remain present years after the ABI event due to other factors, such as behaviors or learning difficulties, requiring attention to manage and support in order to enhance the child’s functioning. This ongoing vigilance can perpetuate the sense of crisis. The experience of being in crisis bears the hallmarks of external self-identity, demonstrating that the external forces are the primary factors affecting how the self is experienced and perceived. The focus on the ABI child is the main cause of mothers’ self-identity to be positioned outside themselves. Caregiving tasks taken on by mothers reveal how difficulties obtaining necessary services and supports can contribute to mothers remaining in external self-identity. A lack of support, guidance, or access to services can increase the pressure for mothers to make sure their children are receiving treatment and care. External self-identity attends to functional aspects, and these practical aspects determine the self-identity.

Self-identity is defined as the unique and persistent qualities and characteristics of self as experienced and perceived through the person’s conscious awareness of inner sameness and continuity (Allport, 1961). The external self-identity can create a split between the pre-ABI event self-identity and the post-ABI event self-identity. In external self-identity, the post-ABI event self-identity is absorbed in the ABI child. For example, a mother spoke of being “super mom” – involved in PTA, parenting groups, and volunteering at school – and giving it all up to take care of her child with an ABI. Other participants described little integration between the pre- and post-ABI self-identity. The difficultly in integrating pre- and post-ABI self-identity seemed to heighten the awareness of how much was lost in self-identity. Participants seemed to process the change between pre-ABI event and post-ABI by the recognition of what was lost (e.g., career, hobbies, being a “super mom”) and what life involved now (e.g., coordinating appointments, being on the phone with insurance representatives). The descriptions of external self-identity portray a focus on functioning and self-identity being perceived through this lens.

A powerful source of external influence upon self-identity was the perceptions of others. The descriptions from participants parallel the philosophical reflections of Jean-Paul Sartre (1984), who discussed how others can impose and determine who we are by projecting identities upon us. Several participants discussed receiving “looks” or passive aggressive comments from other family members or strangers when the child with an ABI displayed problematic behaviors. Additionally, overt expectations, comments, or perceived emotions from others have a strong effect on defining self-identity. The projections from others and the interactions with others can lead to further internalization of behaviors from the ABI child.

Through the theoretical perspective of the CMFS (Boss et al., 2017), these external forces influence how the mother perceives and makes meanings about the ABI (crisis event). The functional and structural changes to the family become a primary way of processing the crisis, which has become a way of understanding self-identity. The internal context of psychology and philosophy is present as the mother has perceptions of the ABI event. Still, the perception is often restricted, not allowing the mother to fully access thoughts and emotions and pushing her to focus more on functional aspects to manage the crisis.

Thoits' (1991) concept, identity-threatening, adds to the understanding of external self-identity. The changes to a mother's sense of self-identity due to the ABI to a child can disrupt previously salient aspects of self-identity. Following the argument Thoits (1991) posits, the disruption to more salient aspects of a mother's self-identity should be more psychologically distressing to the mother. The psychological distress of due to a disruption in self-identity was present in the result of the study. Mothers discussed leaving careers or having their perception and expectation of motherhood altered due to the ABI to a child. For many participants, having a career or a specific meaning in being a mom were salient aspects to self-identity, and the shifts due to the ABI created identity distress.

The sacrifices that mothers reported from this study (i.e., giving up jobs, more involved in caregiving tasks, primary person to regulate ABI child's behavior) support previous research (Heisler & Ellis, 2008; Leiter et al., 2004). Multiple participants reflected on the unspoken transition of roles and the expectations that were placed upon them to live out the social role of mother. This parallels the research of Leiter et al. (2004) revealing the assumptions placed mothers with disabled children, who are expected to move into the caregiving role, often with little to no discussion about this role transition. In the midst of a crisis, the external influences (i.e., spouse, professionals, friends, societal expectations) on informing what it means to be a mother with a child who has an ABI are strong.

The theme *emotionally overwhelmed* further exemplifies the external positioning of the ABI. As the results demonstrated, participants who were primarily defined by external self-identity described avoiding or numbing their emotions. Self-identity is focused upon the ABI child, and to attend to their own emotions would take away from the mother's focus on the child. The findings revealed a clear narrative that emotions were not helpful to assisting in the functional aspects of adapting after an ABI.

External self-identity positions mothers to have their self-identity understood and processed through contextual and external factors. When the crisis initially occurs, the positioning of self-identity externally can help stabilize functional factors. However, the long-term effects of having self-identity positioned externally can lead to maladaptive coping skills and can reduce the sense of control and confidence in themselves and how they engage the world around them.

Internal Self-Identity

The theoretical concept of *internal self-identity* highlights how the mother's self-identity can be positioned from within. Though external factors and context will influence mothers, they are aware of internal forces and are conscious of the sameness and continuity that has transcended the ABI crisis and the subsequent consequences of their child's injury. The focus of external self-identity is on another individual, functioning, or at times, merely surviving the ABI crisis. The shift from external to internal self-identity ontologically grounds a person. Ontology, which refers to the study of being, particularly focuses on the concept of *becoming* (Heidegger, 1962), and it fits well with describing internal self-identity. Internal self-identity assists a person in the process of becoming; it is the ongoing process of changing to or moving towards defining oneself from within. For example, a person does not simply become a mother and then stagnate with that definition. Instead, being a mother is an ongoing process of change as new contexts, relationships, and perceptions will inform this process of *becoming* a mother.

The concept of internal self-identity highlights Thoits's (1991) idea of identity enhancing experiences. Thoits (1991) posits that identity is impacted by experiences and events and by the appraisals of events and the meanings of particular stressors. This process can lead to *identity threatening* (previous discussed) and *identity-enhancing* experiences. It is clear an ABI to a child is horrific and always undesirable; even so, the ABI event can provide mothers the experience of enhancing their self-identity. Some mothers perceived the ABI to their child as an "new way to be mom," and this manner of appraising and making meaning of the ABI event and its consequences reveal an enhancement to the self-identity role of mother. The social role of mother is continuing to grow and transform to match the needs of the family. The meaning and expectations of being a mother are able to be defined internally while also incorporating external influences.

Choi et al. (2005) highlighted how women transitioning into motherhood for the first time often felt unprepared and how their expectations were based on myths and projections from society and other social examples. Research on mothering and disabled children found that mothers felt unprepared *and* isolated, not having friends who understand or a community to have support (Leiter et al., 2004; Muthukrishna & Ebrahim, 2014). Similarly, all of the mothers in the current study described how unprepared they were to transition into the role of being a mother to a child with an ABI. However, the mothers of this study often felt isolated and alone, as there were few or no examples of what it means to be a mother to a child with an ABI. The narratives of the mothers reveal a desire to be present, attentive, and the best mother possible, and many mothers had no idea what this look liked in the new ABI context. When mothers did connect with social media groups, it was often a great relief to find other mothers in similar experiences who were all able to support and learn from each other. Learning to be a mother of an ABI child was an ongoing process informed by the ABI context and the process of making meaning of the changes to the role of mother.

This continual adaptation to respond to the ongoing demands fits with the literature on stress adaptation and resilience (Boss, 2006; Boss, 2014; Patterson, 2002). Boss et al. (2017) posits resilience focus guidelines for helping families such as finding meaning, reconstructing identity, and discovering hope. By helping mothers and families to create meaning and find hope provides increased opportunities to coping processes and moving forward (Boss 2006; Boss et al., 2017). The meanings and appraisals that lead to self-identity enhancement can be a source of resilience through the ABI event and the long-term consequences from the ABI to a child. The concepts of identity-enhancement and resilience provide the context for what is necessary for the process of *becoming* to occur for mothers.

Internal self-identity can facilitate the process of becoming, whereas external self-identity factors on exterior factors that can halt adaptation and resilience. The CMFS identifies the importance of the internal contexts of a person that they can control (Boss et al., 2017). These internal aspects, which include the structural (e.g., boundaries, role assignments), psychological (e.g., perceptions, cognitive process, emotions), and philosophical (e.g., values, beliefs) contexts of the family are invaluable to the ongoing process of one’s internal self-identity becoming. The internal contexts of an individual are elements that *can be changed and controlled.* Due to this agency, the person can remain active in the process of becoming and, borrowing a term from narrative therapy (White & Epston, 1990), thicken their identity.

The theme *transcendent sense of self* revealed that participants who could identify an aspect of their self that had remained present and intact throughout the time and experiences of the ABI coped better with the ABI. For example, one mother disclosed she had always wanted to be a mother, and even after the ABI to her child, that desire to be a mother remained. Wanting to be a mother transcended the effects of the ABI, and the mother had the support of this continuity and sameness through the transitions associated with her child’s injury. The transcendent sense of self is not stagnant. The meanings of transcendent aspects must evolve and change to make meaning with and function in the new context that is present. For the mother who always identified as wanting to be a mother, her desire to be a mother remained, but the meaning and perception of what it meant to be a mother transformed due to the new external changes associated with her child’s ABI. The mother in this example was active in the process of becoming a mother, letting the latest external information (i.e., ABI context, new demands) inform the meaning making process about aspects of the mother’s identity that transcend time. This participant exhibited control and allowed her previous meanings about motherhood to change to fit in the new context. Furthermore, the mother is *responding* to external contexts but is actively engaged in processing what being a mother means to her now.

The transcendent sense of self can further mitigate the stress a mother experiences from the consequences of an ABI to a child. The aspect of self-identity that transcends the ABI event provides identity enhancement (Thoits, 1991). The new contexts and experiences a mother’s self-identity encounters after an ABI to a child grant an opportunity for growth to self-identity. Though the ABI is a stressor, a mother positioned in internal self-identity fosters an appraisal of the ABI stress and the meanings that are beneficial for resilience. A mother’s identification of transcendent aspects of self highlights an internal resource that is familiar and useful to the mother, and the mother can adapt this part of her self-identity to meet the ongoing demands from the ABI stressor. Through the CMFS lens, the mother is reconstructing old meanings, perceptions, and structures to adapt to the new context of the ABI stressor. What a mother perceives about the ABI, the sense she makes from these perceptions, and how that affect the mother going forward are part of the stress adaptation process (Boss, 2006). To increase resilience, mothers need to balance hope with despair, learn to normalize ambivalence, and adjust mastery to fit the new context (Boss et al., 2017).

The theme *being an active agent* was a prominent resilience factor in the promotion of internal self-identity. Participants discussed several ways of being an active agent. One method was to choose to feel and experience emotions. Multiple participants reflected on the importance they place on feeling emotions, often setting boundaries around how long they would, for example, let themselves cry. This demonstration of resilience is connected to the mothers' internal contexts, as the beliefs (philosophical context) or perceptions about emotions and the crisis (psychological context) influenced their decision to be active and present in feeling their emotions. Participants also discussed being an active agent by choosing to wrestle with ambiguous loss, existential questions, purpose, and perceptions of the ABI event and its consequences. These were, and continue to be, difficult topics to ponder. Many mothers reported having questions such as: *Why did this happen to my child? Why would God allow this to happen?* As discussed with external self-identity, these thoughts, emotions, and questions were often repressed or denied, as mothers reported: "not having time for that." However, internal self-identity provides a grounded sense of self-identity that can tolerate and process these uncomfortable questions, emotions, and perceptions. The identity is grounded because external factors do not define it. Instead, self-identity is set within a person, giving that person the freedom to choose, act, and become who the person wants to be.

The groundedness of internal self-identity and its usefulness in responding effectively to the ABI stressor demonstrate the importance of this process in the individual and family adaptation. Boss (2006) addresses the importance of attending to perceptions family members and the meanings being made from these perceptions. These new created meanings are important in helping mothers with an ABI child and the family to understand and cope with the stressor event and its consequences. Similarly, Patterson (2002) highlights the adaptation processes - how meanings and capabilities manage demands from a crisis. For individuals and the family, these processes are necessary to mitigate the stress for the ABI to a child. An internal self-identity, which promotes being an active agent, fosters agency in perceiving the ABI crisis in a manner that promotes and identifies capabilities and resources.

The theme *light bulb moments* refers to a phenomenon multiple participants identified as a catalyst for change from an internal to external self-identity. A light bulb moment is a sudden shift in perspectives, an instant where one can suddenly think in a new way or alter behavior. Participants told stories about perceiving themselves as victims to circumstance or simply focusing on managing the new stressors due to the ABI, and then, something occurred that allowed them to suddenly reframe their thoughts. This spontaneous reframing induced mothers to change and make the desires they daydreamed about a reality. Though participants struggled to identify how these light bulb moments came to be, the transition from external to internal self-identity was significant.

Family Identity

In this study, I sought to answer the research question: How do mothers reestablish family identity, after a child has received an ABI? Through the constructivist grounded theory (Charmaz, 2014) analysis, three theoretical concepts emerged from the data: 1) *Family Identity: "There for Each Other,"* 2) *Disruptive Event*, and 3) *Reconfiguring Family Identity*. These theoretical concepts provide the framework for understanding how an ABI to a child impacts the family identity.

Family Identity: “There for Each Other”

Participants described, in various ways, how family and family identity were shaped by the importance of family members being “there for each other.” This statement included ideas of unconditional love, support, and always helping each other. Beyond the roles, rules, and responsibilities, this theoretical concept was an underlying meaning that directed the family. Being “there for each other” is a core foundation of family identity. There is a transcendent quality to the theme that contextual factors cannot change; being “there for each other” is the means to interpret the new internal and external contextual information that each family encounters.

What became clear is that participants had an established understanding of who is in the family and who is not. It was also evident in the narratives of participants who would be “there for each other.” The notion of knowing who is in and who is outside of a family system parallels the CMFS (Boss et al., 2017). The internal context of structure, according to the CMFS (Boss et al., 2017), refers to roles, family membership, and rules about who is in and who is out of the family. The structure of family identity is about knowing who the family supports and helps through struggles. However, the beliefs and values of the family influence the interpretation of the family identity and determine the membership of the family.

Disruptive Event: ABI to Child

An ABI to a child is disruptive to the family. It is not an expected life event, and the family quickly has to adjust functioning, communication, and processing the changes as a family system. The unexpected nature of an ABI leads to nonnormative demands that can trigger a chain of risks (Patterson, 2002). Other literature on nonnormative events to a child can increase the risk to the family (Wallander & Varni, 1998) and increase problems or consequences to the child (Ownsworth, 2014). The changes in the family result in increased boundary ambiguity, ambiguous loss, and changes to the family's internal contexts. The changes in internal contexts is disruptive as previous perceptions, family structures and routines, and meanings/beliefs are interrupted and are not as effective in the new ABI context (Boss et al., 2017). Family struggle to adapt and find resilience in the disruptive event of the ABI event, which can lead to rigid unhelpful meanings and maladaptive coping mechanisms. Furthermore, the family identity of being "there for each other" under pre-ABI event meanings no longer works as it once did. The family identity is disrupted, not in meaning, but in practice. Being "there for each other" functioned, felt, and looked different prior to the ABI.

Participants spoke of this awareness of ambiguous loss. In fact, out of all of the jargon terms and concepts of research, ambiguous loss was the concept most commonly known among participants in this study. According to Boss's (2002) distinction between ambiguous loss and boundary ambiguity, "ambiguous loss is the stressor situation (located heuristically under the A factor in CMFS), boundary ambiguity is the perceptual response to that stressor (located heuristically under the C factor in CMFS)" (p. 86). The stressor situation is the ABI to the child and the child physically being present but psychologically absent or different. This phenomenon is well documented in the literature (Kreutzer et al., 2016; Ownsworth, 2014; Ownsworth, 2004). Each family was aware of changes that were difficult to process because of the perceptions of the ambiguous loss.

Boundary ambiguity, the perceptual response to ambiguous loss, was prevalent as the ABI redefined the family. For many participants, the ABI event was so disruptive that rapid changes to functioning, roles, and responsibilities were made in response to the ABI. For example, one mother left older non-injured children with neighbors so the mother could stay at the hospital with the injured child. At times, this separation in the family lasted months at a time, with one parent at the hospital or functioning as the primary caregiver for the ABI child and the other working and maintaining the home. Another example is families giving up leisure activities because the child with an ABI could not participate. Through the contextual changes that participants described, it became clear that who was inside or outside of the family became ambiguous. Categorically, the family could identify members, but it was evident that there were emotional disconnects between family members and in some families, leaving certain members feeling abandoned.

In these situations, the family identity was not fulfilling its mission of *being there* for all members of the family. It became apparent in the data that a hierarchy of needs was established within the family identity, with the family first and foremost being there for the ABI child. This movement in the family identity seemed to be unspoken. Even so, the data also revealed that family members were often irritated by or resentful of the privileges, attention, time, and resources that went into the care and support of the ABI child. Because an ABI is a disruptive event which also disrupts family identity, the family may engage in maladaptive functioning. During the initial crisis, reactive functioning is necessary but cannot be a long-term pattern. However, multiple participants revealed that reactive functioning continued well after the ABI event, perpetuating poor communication patterns, blunted emotional expression, and repressed meanings.

Participants revealed that often individuals in the family all have different meanings about the changes brought on by the ABI. Reiss (1981) emphasized that the meanings about the

ABI events are more than just agreement among family members. Rather, the sharing of meanings, thoughts, and emotions between family members is crucial in maintaining and structuring the family system (Patterson, 2002). The disruption in family identity and structural aspects of the family creates an environment in which families struggle to hold and maintain the various perceptions and meanings. With multiple perceptions and meanings, participants reported family members engaging in a wide range of coping strategies. For example, a father may use denial coping to defend against the painful experience of loss, while the mother is engaged in preparedness coping, trying to take action against future catastrophes (Boss et al., 2017). The differences between the coping strategies creates a conflict that is against the family identity.

Reconfiguring Family Identity

Significant changes to functional, structural, and perceptual aspects of the family after an ABI impact family identity. As explored in the previous section, the disruptive event of an ABI does not alter the core of the family identity; rather, the family needs to reconfigure how to be “there for each other.” The family implicitly shares in the co-constructive collaborative process to incorporate the perspectives, emotions, thoughts, and meanings of each family member (Reiss, 1981). One person in a family system cannot independently take on the process of reconfiguring family identity. Participants who spoke of collaborative efforts among the family members demonstrated the process of reconstructing family identity.

The collaborative sharing of meanings within the family revealed by the mothers in this study parallel what Patterson and Garwick (1994) suggest, that families construct meaning on three levels: (a) about the specific stressor, (b) about family identity, and (c) about the family’s view of the world. For the first level, about the specific stressor (i.e., the ABI), participants discussed the various perceptions and meanings about the ABI and how it has impacted the family structure and functioning. The second level, family identity, was addressed by participants and seemed to occur in families in explicit (e.g., intentionally discussing changes to family, asking family members about their emotions) and implicit (e.g., non-injured child angry at parent due to ABI child getting more time and resources) ways. The third level, the family's view of the world, was also relevant in the narratives of participants. For some participants, the world became a dangerous place, and the family became isolated. Other participants described a transformation in values or beliefs that enhanced family adaptation and resilience.

The process of how, in the context of having a family member with an ABI, the family collaborated and reconfigured family identity to be there for each other occurred through intentional decisions and behaviors. The theme of *intentionality* highlights the importance of recognizing the need to directly address the changes to the family. This direct approach illuminates for the family the needs to redefine together how to be there for each other in the midst of stressors coming into the family system. Intentionality also reveals an awareness within the family that new stressors must be managed. Participants revealed that often they, their partners, or sometimes even a child would directly voice an area of concern due to the new stressors. The findings revealed three strategies with which families practiced intentionality: *adaptive functioning*, *open communication*, and *emotional expression*.

Adaptive functioning was the family's deliberate action to consciously respond to the changes associated with an ABI. The initial crisis has the family responding reactively, which is appropriate during the crisis. However, families that intentionally recognized changes and worked together to implement a new structure to the family system demonstrated resilience or adaptive functioning. Family members need to recognize changes that have happened within the family system and discern new ways to function under the influence of the ABI. The perception of the stressor helped inform the changes that needed to be implemented by the family structure.

Boss et al. (2017) illustrates how perceptions, meanings, and how the meanings affect the family going forward are seen as factors that mediate how families with an ABI child navigate and overcome adversity and challenges. Adaptive functioning reflects this mediating process between meanings and resources. Positive meanings and perceptions (i.e., commitment to family, family love and support through all things) lead to positive outcomes. The family joins together to support each other through the crisis and ongoing transitions after an ABI. Furthermore, the resources available to the family matter, as mothers with more financial resources did not discuss employment stressors or financial concerns compared to other mothers in this study.

Many times, the structures of a family reacting to the ABI and a family that is responding through adaptive functioning may look relatively similar. For example, the family stops participating in activities that have large crowds or noises due to the mental fatigue it causes to the ABI child. However, the manner in which this functioning is reached does matter. The participant that described getting a boat modeled adaptive functioning by attending to the needs of the ABI child while seeking activities that will be fun for other members of the family.

A parallel intentional process with adaptive functioning is *open communication*. As addressed in the previous section, restricted or repressed communication is common in families after an ABI. Even so, participants discussed their intentionality with being open in communication among family members. For example, one participant shared the story that once she heard of her son's hospitalization, she grabbed her husband and said, "we will not be a couple that falls apart. We will cling to each other." The participant recognized the stress that could happen to her marriage and family, and before the family was immersed in the disruption of the ABI, she set an expectation for her marriage.

Open communication allowed the practical and contextual dialogue that was necessary as the family adapted to the ABI context to be effective. Open communication challenged coping strategies of forbearance and denial, as the direct open communication brought dynamics, perceptions, and emotions affected by the ABI to light. Open communication is a vital mechanism in the reconfiguring family identity process. Open communication provided the space for the members of a family to express perceptions, meanings, and beliefs that had been influenced by the ABI. Through these discussions, the family could collaborate together to redefine values and beliefs and reconstruct the new way that it means to “be there for each other” in the family.

Open communication prompts authenticity within the family. Authentic *emotional expression* can be repressed for the sake of getting the family through the crisis of the ABI. Participants spoke of not having time for their partner’s emotions because there was too much going on to deal with them. Open communication is an invitation for emotional expression. Some participants reported having intentional conversations with non-injured children or their partner about their feelings. Even if a person does not participate in this conversation, it opens the door for emotions to be expressed. Boss (2006) highlights the importance of shared meaning among family members. A family member’s emotional experience from a ABI event is important to their perception of the stressor and how meaning is being made. By expressing emotion, family are able to revise attachment and find meaning about the ABI as a system (Boss et al., 2017).

Furthermore, emotional expression demonstrates to the family system that it can handle the emotions from individual family members rooted in their experiences and perceptions from the disruptive event of the ABI. Many of the coping strategies Boss et al. (2017) presented are methods for the family to relieve the tension and distress from a stressor. Many of these coping strategies are designed to protect the family from further distress. The intentionality of expressing emotions is a counterintuitive process, bringing the family right into the distressing emotions from the ABI context. The encounter of emotions continues to help the family process the ABI event, deepening the perceptions and meanings that the family is creating. By having the emotions of each individual member expressed, the family is able to process the emotions together. The family can experience the potentially different emotional states of each person.

Rehabilitation Services: “Joining the Tribe”

The data revealed two themes related to implications for professional practice: 1) *involving and validating mothers in the treatment process*, and 2) *providing education and skills*. These themes emerged to answer the research question: When a child receives an ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive maternal self-identity and family identity? In short, the results revealed minimal dialogue between professionals and mothers on self-identity and family identity. Some mothers did mention professionals asking about the family in small talk or checking on the emotions of the mother. However, even though previous literature stated the importance of attending to identity (Ownsworth, 2014; Wilson, 2011), the results of this study reveal that discussing self-identity or family identity is negligible in clinical settings. Nevertheless, the themes from my analysis demonstrate ways for professionals to work with mothers and families in a manner that will promote and support the reconstruction of self-identity and family identity.

During an interview, a participant referenced a doctor “joining her tribe,” and the phrase struck me. It captured a desire of participants to have professionals join them in the process of providing support and ongoing services for the child with an ABI. “Joining” promotes the idea that professionals invest in the ABI child and the family. The investment mothers articulated was to be authentically present and emotionally engaged and to demonstrate genuine care for the ABI child. For many mothers, it is not enough for professionals to fulfill medical or rehabilitation duties; the personal encounter is necessary. One mother spoke of the comfort and support of having a neurologist cry tears of joy with her while discussing the improvements the ABI child was displaying.

Joining the tribe brings the professional into community with the entire family. Participants revealed that professionals would rarely inquire how mothers and the family are doing. Even more striking is that among the 14 participants, only one had a professional talk to her about changes in her self-identity, and no professional addressed family identity. Though research demonstrates the importance of the family and mothers in the rehabilitation process (Woods et al., 2013; Zuna et al., 2016), this process is not supporting the mothers or family as well as it could. Building a community of families and professionals will help conversations about self-identity and family identity be more authentic and organic. Self-identity and family identity are about who a person or family is; a family-professional relationship is needed to explore the dynamics of these changing identities.

Involving and Validating Mothers in the Treatment Process

Research has demonstrated the importance of including the parents and the rest of the family in the rehabilitation process after an ABI (Robert et al., 2014; Woods et al., 2013). The family and mothers are invested in the care of the ABI child and interact with the child much more than the professionals providing services do. Unfortunately, many participants spoke of being silenced or pushed aside by professionals as they focused solely upon the ABI child. The experience of mothers being pushed aside led to resentment, prompting restrictions in communication to the detriment of the child with an ABI.

Medical and rehabilitation professionals need to be aware of their position of power in the treatment process. The professionals are knowledgeable of their field and should be directing the rehabilitation process and assessing needs. However, mothers, though lacking that type of expertise, perceive themselves as being the most aware of and involved in the child’s life and believe that what they have to say matters. This tension between professional and mother can lead to conflict if not managed well. Having professionals actively involve mothers in developing treatment plans and strategies creates a relationship that will be beneficial for the ABI child and the family.

Involving mothers in the treatment or rehabilitation process soothes emotions and increases their sense of control in understanding and managing the ABI sequelae. Furthermore, when mothers were included in the treatment process, participants reported more willingness to listen and follow through with the homework, recommendations, or education that a professional provided.

The validation of mothers’ experiences, thoughts, and emotions is necessary for the success of the treatment process. Participants told stories of the initial crisis event, struggles managing ABI sequelae, or their overall perceptions of the family after the ABI that were still eliciting thoughts and emotions. It was evident that participants needed to talk and process the changes that had occurred throughout the family system. Professionals taking the time to validate mothers’ experiences, making efforts to support the ABI child, and normalizing the challenges associated with an ABI can assist mothers in continuing to engage in the treatment process rather than becoming burnt out or isolated from the professionals working with the ABI child.

Often mothers reported feeling left out of medical decisions when their child was in the ICU or of PTs or OTs not giving the mothers homework for the child with ABI. When mothers pushed for answers or dialogue but did not receive it, they often described their feelings of shame and anger. Lack of communication to inform mothers about what is occurring often leads them to view professionals as persons to fight against, rather than as members of the treatment team.

A vital time for effective communication is during the initial crisis, especially if the child is in the ICU with an ambiguous survival prognosis. Participants described both the desire to hear the truth of what is happening *and* the need for hope to be present. Holding the tension between the truth and hope can be difficult, but it is absolutely necessary for mothers and families. The need to provide truth and hope extends continuously from the initial crisis through the entire rehabilitation process. Many participants, years after the ABI event, held on to hope that their child could improve and were consistently investigating new therapies or treatments.

An additional mode of communication that participants desired to see in professionals was humility. Research demonstrates the complexity of an ABI, the spectrum of sequelae from the injury, and the different trajectories of healing that could occur (Babikian & Asarnow, 2009; Levin, 2012, Ownsworth, 2014). For some mothers, having a professional admit to not knowing or not having an answer was beneficial. Not having all the answers models being able to sit in ambiguity and work through it. With ABIs, typically there are no definitive recovery timelines or pathways; rather, progress and needed strategies and adaptations are likely to unfold with time.

Providing Education and Skills

A theme that emerged from the analysis was participants appreciating or desiring more education and skills to manage and support their child after the ABI. Education on ABIs, brain anatomy, or brain development is helpful, but education needs to extend beyond these topics. Many mothers are thrown into the role of being the social worker for their child, learning how to locate and access services. Additionally, mothers must work extensively with insurance companies to advocate for services and payments. Facilitating these dialogues with services or insurance companies can be time consuming, and often mothers do not know the details of these systems that would make navigation easier.

Multiple participants discussed the disconnect across services needed at different times, especially when moving from hospitalizations to outpatient services. Providing mothers with education through conversations with social workers, information pamphlets, or a list of resources to assist in the adjustment from hospitalization would be beneficial. Beyond education on accessing services and negotiating with insurance, participants spoke about their desire to have more information about how the ABI will impact the family. Provide this education could involve identifying research outlining experiences, thoughts, and emotions of mothers and families to help normalize the experience the family is having. Additionally, multiple participants described the value and importance of support groups, especially the online community. Sharing information about these groups and equipping mothers and families with the knowledge to access support groups would be beneficial.

Furthermore, participants discussed the importance of planting seeds, having a conversation or providing information that would be beneficial in the future, even if not useful in the present moment. During and after the initial crisis, mothers and families may not be ready to hear how an ABI can impact self-identity and family identity. Education can help instill anticipatory knowledge and plant seeds of information that the family could tap later when it would be more helpful for them. Every mother and family will process their feelings and needs at different rates and will have a diverse range of responses stemming from the ABI injury.

Finally, mothers and families need to learn certain skills. Participants reported that professional services did well in teaching mothers caregiving skills when the consequences of the ABI left the child needing extensive support. However, training on skills for managing behavioral difficulties, emotional regulation after a brain injury, or delusions were also needed. Participants reported they did not receive referrals to other professionals who could help them manage and learn how to support their child. Moreover, even when mothers were connected with professionals, such as a psychotherapist in family therapy, the therapist often did not have the training needed to fully understand ABIs and typical sequelae of the injury. Mothers often felt they spent that time educating others, and the experience was not beneficial.

Study Limitations

There are several limitations to this research. The participants were all mothers and were the primary person responsible for the child or adolescent with an ABI. No fathers were interviewed; the participants in the current study described fathers as the parent who fulfilled other roles, especially employment to provide income for the family. As a result, I was limited to getting perspectives only from the parent who is the most involved and invested in the life and care of the ABI child or adolescent.

Further limitations to this study include racial homogeneity, as all participants identified as white with no cultural diversity. Conducting similar research with participants from other racial or cultural backgrounds is essential to identifying whether there are differences or similarities in reconstructing self-identity and family identity after a childhood ABI. Additionally, definitions of self-identity and family identity could vary across diverse groups of families. The results of this research study do not capture the experience or perspectives of a diverse world.

Similarly, no participants in this study were from low income families. The average annual income was $35,001 or more. Participants did not stress or focus on financial struggles or worries during the interviews. Not having representation of families with a low socioeconomic status limits the generalizability of the findings to that group. The economic burden of an ABI can be substantial in many ways (e.g. cost of care, sacrificing work), and understanding how this stress could impact the reconstruction of family or self-identity is important.

Another limitation of this study was acceptance of all ABIs as an inclusion criterion. Specifically, looking at ABIs that need intensive emergency medical care or ABIs with specific sequelae (e.g., behavioral outbursts, emotional dysregulation) may provide a more in-depth understanding of self-identity and family identity. Including all ABIs provides a more generalized view of ABI and self-identity and family identity. The final limitation is that I only received the mothers’ experiences and perspective of encounters with rehabilitation professionals. Including perspectives of fathers, other caregivers, non-injured children, or the ABI child would produce a richer narrative to encounters with rehabilitation professionals.

Implications and Recommendations for Research

While the findings of this investigation extend current research by providing a conceptual model related to the reconstruction of self-identity and family identity, further research is needed to refine the model. The current findings point to the value of exploring and identifying additional resilience and protective factors that help mothers remain in or transition to internal self-identity. Specifically, participants talked about either light bulb moments or intentionally checking in with another family member, which provided helpful information for the process of reconstructing self-identity or family identity. Further investigation of when and why triggers occurred or what prompted checking in will inform research and clinical practice supporting the return to an internal self-identity after an ABI crisis event. Future research could continue this work by obtaining more specific information on each factor, through use of deep interview techniques that probe maternal reactions to ABI situations. Detailed descriptions would provide a comprehensive account of each factor and how participants utilized these to reconstruct self-identity or family identity.

In addition, this research highlighted how certain sequalae resulting from an ABI (e.g., behavioral problems, promiscuity, delusions) are more distressing to mothers than others (e.g., physical scars or learning difficulties) Mothers often referenced feeling isolated in managing their ABI child's behavior. Future research could investigate the specific needs of the family in the context, for example, of how the ABI occurred or behaviors exhibited by the ABI child, and how to better support mothers and the family in managing such sequalae. For example, a mixed-methods study, in which the researcher gathered open-ended descriptions of distressing sequalae of an ABI, followed by a large-scale survey to gather frequency data on particular sequalae, could enable connecting sequalae to self-identity and family identity outcomes. Such a study could uncover improved ways to support families and identify specific sequalae that exacerbate distress for mothers and families.

Further research is also necessary on how factors such as race, ethnicity, or religion influence the process of reconstructing self-identity and family identity. Participants from this study who identified themselves as Christian often referenced their spirituality as a source of strength and used their religion as a lens for meaning-making about the ABI. Extending current research by specifically investigating how various social locations (e.g., race, culture, religion, gender, age) influence the perception of an ABI event and the process of reconstruing self-identity and family identity would provide useful information for professionals working with diverse groups about nuances influencing these identity reconstruction processes.

There is a need for research on the effectiveness of programs, interventions, and assessments designed to support the reconstruction of self-identity and family identity after a childhood ABI. Literature reveals that rehabilitation treatment largely addresses functional gains or skill-based progress, and more programmatic emphasis is needed to address identity issues (Wilson, 2011). A challenging aspect of self-identity and family identity is that intervening to promote identity reconstruction can be abstract and difficult to address in a step-by-step practical manner. Even so, self-identity and family identity are essential to maternal and family adaptation after a child or adolescent receives an ABI. Further studies could investigate perspectives from clinicians and other professionals who work with individuals and families affected by an ABI to ascertain whether and how they address identity and their comfort with discussing such topics. The findings could point to development of needed interventions tailored to different types of professionals.

Additionally, the development and evaluation of assessments, interventions, and programs to address aspects of identity would be beneficial. These could serve as an aid for professionals and help make discussions regarding self-identity and family identity more concrete. For example, researchers could develop a brief questionnaire to assess external vs. internal self-identity. The development of these clinical tools and supports would provide more options in exploring supporting self-identity and family identity.

Clinical Implications

The theoretical concepts and heuristic models that emerged from this research study have significant implications for clinical practice. First, participants voiced the desire for professionals to check in with the mother and the family about recent events, challenges, and emotions. The job descriptions and professional socialization of many professionals who work with ABIs are, by nature, focused upon the individual with the ABI. It is equally essential for all professionals to take a few minutes to check in with the well-being of the mother and the family. This simple encounter can prompt deeper reflection into self-identity and family identity, which may have been ignored due to the focus on functional and practical responsibilities and needs.

Another recommendation is for professionals to consult with mothers about their observations about progress and perspectives on needs of the ABI child. Mothers can be a helpful resource in treatment for children and adolescents with an ABI that often is underutilized. Specifically, including the mothers and family in developing and modifying treatment plans can be accomplished by listening and validating their perspectives and thoughts. Listening and validating build a collaborative process that will be best for the treatment and rehabilitation of the child with ABI. Furthermore, this collaboration can use the perspectives of the mother and family to guide treatment goals, and the family will be more invested in the goals feeling greater ownership in goals development. In turn, these outcomes can promote better self- and family identity reconstruction.

Specifically, psychotherapy will provide more opportunities for exploration into self-identity and family identity. Therapists working with these mothers should be intentional about attending to changes, distress, or confusion in self-identity and family identity. Therapists can use several approaches to establish a relationship and environment that allow mothers and families to process self-identity and family identity:

- Provide holding and containment. Holding and containment are concepts from object relations (Scharff & Scharff, 1991) which address the responsibility of the therapist to provide an environment that offers safety and comfort and to contain the emotions and thoughts that emerge during a session. Being emotionally overwhelmed is common for mothers and families dealing with ABI, so therapists need to provide a sense of security that emotions will not be overwhelming. They need to enable the mother or family to have a new experience in expressing emotion in a safe way.
- Give hope. While focusing on addressing struggles and necessary adjustments when a child has an ABI, bringing hope into these conversations is crucial. When a focus on a specific behavior is consuming a session, the therapist can step back and identify the progress the mother or family has made in the context of the big picture of treatment. Providing a realistic level of hope allows the mother and family to become aware that the current situation can change. Ending sessions optimistically or identifying hope will help the mother and family leave the session feeling encouraged to practice strategies discussed in the session.
- Summarize tangential thoughts. The experience of a crisis, such as an ABI to a child, can lead to tangential thinking due to the experience of being overwhelmed. Tangential thought processes can distract mothers and the overall family from addressing more proximal issues and concerns to help with adaptation to the ABI stressor. A therapist can help mothers and families with tangential thoughts by slowing down the process of therapy, using open-ended

questions to clarify statements, and summarizing what mothers or other family members have said.

- Verbalize and label emotions. During sessions, the therapist can identify emotions that were verbalized or became present during therapy. Identifying emotions provides a language and terms to describe an experience. Mothers can correct the therapist if the verbalized emotion is not correct. This will help mothers feel more knowledgeable about their experiences and reactions.

Tools and interventions to assist in the exploration of self-identity and family identity are available for therapists to use, including identity charts, motivational interviewing, open-ended questions exploring identity, and Johari’s Window (Luft & Ingham, 1955). These tools allow for various ways to explore, expand, and gain insight into self-identity and family identity. It would be necessary for the therapist to assess the pre-ABI event and post-ABI event identity perceptions. This assessment would highlight particular areas of self- or family identity that a person needs to address in the process of reconstructing self-identity and family identity.

Therapists need to be creative and flexible in exploring self-identity and family identity. Some clients may discuss their emerging sense of self-identity in conversation, while others may need to visualize the changes they are experiencing. For example, some mothers may struggle to express through verbal dialogue how they have changed due to their child receiving an ABI. Using identity maps to draw out aspects of identity and visualize the conversation can be helpful in structuring the conversation. A therapist working with mothers or families affected by a child or adolescent with an ABI should be aware of as many tools as possible to assist clients in exploring self-identity and family identity.

Though eight of the participants reported utilizing psychotherapeutic services, doing so was not a priority for many participants. For mothers existing in external self-identity, psychotherapy for themselves would be difficult to accept, as psychotherapy for a mother is not directly focused on the ABI child. Therapists need to be attentive to this perspective and align treatment goals to support the rehabilitation of the ABI child. For example, to connect a mother's psychotherapy to their ABI child, a therapist could provide psychoeducation about the importance of mothers in fostering environments with emotional stability, good communication, and effective conflict resolution, and how these environments produce better outcomes for the child with an ABI. This reframe can allow mothers to see the value of investing in psychotherapy to better support the ABI child and the family.

Furthermore, mothers reflected how it is exhausting to retell the ABI narrative repeatedly; they feel like they are always educating others about ABIs. When mothers feel pressure to educate others, especially when the person is a professional who should be helping the mother, they become drained. They are spending time that should be for their own benefit on a task that should be undertaken by others. Psychotherapists, and all professionals, need to be diligent in educating themselves about ABIs before agreeing to work with families experiencing this situation. Knowing about ABIs conveys to mothers that their experience is the focal point and they are receivers of needed assistance, not trainers of others. Then mothers are not responsible for educating the professional about ABI details that arise in their stories. Also, psychotherapists can approach therapy through a solution-focused lens, which implies not requiring the mother or family to retell the ABI narrative. Therapy can then address goals identified by the mother or family, and the ABI narrative will emerge when necessary.

Finally, professionals working with treating and rehabilitating a family experiencing ABI need to prioritize collaboration with other practitioners. Collaboration reduces the burden on mothers and provides the best treatment, as professionals are working together in shared treatment goals. This allows each professional to focus on what they were trained for and have confidence that other areas of rehabilitation are being addressed by other team members.

Conclusion

The purpose of this study was to explore the reconstruction of self-identity and family identity after a child experiences ABI and investigate how rehabilitation services support identity shifts of the mothers and the family. Informed by interviews with mothers, I developed conceptual frameworks relevant to the reconstruing of self-identity and family identity. These frameworks illustrate maternal experiences after a child receives an ABI, revealing protective factors, barriers, and differing coping mechanisms that mothers and families utilize to manage the shifting of self-identity or family identity. The results of this study provide a detailed understanding of family processes resulting from a child’s ABI and of interventions for assisting these families. They also point to directions for future research that would expand knowledge on the range of ABI-related experiences and responses as well as identify additional services and supports for these families.

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Appendix A

Parental Self-Identity and Family Identity after a Child Acquires an ABI

SCREENING/RECRUITMENT FORM FOR PARTICIPANTS

Name: ____

Telephone: ____

Email: ____

Contact Log: ____

____

____

Agreed to Participate? ____________ Yes ____________ No

Date/Time of Interview: ________________________________

Date Consent Sent? ________________________________

Hi <<SUBJECT NAME>>, this is Jameson Natwick from the **Parental Self-Identity and Family Identity after a Child Acquires an ABI** research study. How are you today?

I am calling in reference to the email/message I received about possibly participating in an interview. I was calling to tell you a little more about the study and to see if you might be interested in participating. Is now a convenient time for us to talk?"

(If no) Okay. Can I call back at a later time?

> *(If yes)* Great! I'll call back later to talk with you about the ABI and Identity study you were interested in.
>
> *(If no)* Okay. Sorry for any inconvenience. Have a nice day.

(If yes) Great. First, in order to participate in the study, I need to make sure that you are…

> A parent/primary caregiver of a child who has been diagnosed with an acquired brain injury under the age of 18?

____________ Yes ____________ No

It has been between more than one year since the event of the injury to the child.

____________ Yes ____________ No

The child diagnosed with the acquired brain injury is still living.

____________ Yes ____________ No

(If yes to all three, proceed below. If not, inform them that they are not eligible to participate and thank them for their time and interest in the study).

Thank you for answering those questions. The purpose of the study is to learn about how a ABI to a child can influence the identity of parents/caregivers of the child and the identity of the family. The study would consist of me meeting with you, in person, over the phone, or Zoom, at the time that would work for your schedule and answering some questions regarding your experiences. Your participation should take around 2 hours of your time and you will receive a 40-dollar gift card to Amazon for your time.

Do you have any questions about this information? (*If yes, answer the questions. If not, continue).*

Based on what I've told you, would you be interested in participating?

If yes, note this above and continue below.
If not, thank them for their time and interest in the study.

If yes, say, "Great, now let's find a time to do the interview.

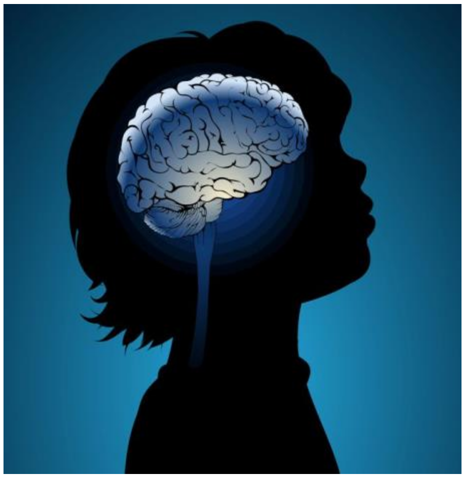
*After scheduling the interview for a two-hour block, say the following, "*To confirm, I have our interview down for DATE at TIME at the LOCATION/on Zoom/over the phone determined by the participant. The day before the established time for the interview I'll email you a reminder. In that email I will confirm the time and location we will meet. Also, I will attach a copy of the consent form for you to review before we meet. When we meet in person, I will bring a hard copy of the consent form for you to review again and then sign. If you have any questions after looking over the consent form, please let me know.

Do you have any further questions at this time? *If yes, answer them.*

*If not or when the questions have been answered, say, "*Great, we're looking forward to seeing you soon. Have a good day/evening. Goodbye."

Appendix B

Parental Self-Identity and Family Identity after a Child Acquires an ABI



You are invited to participate in a research study about how being a parent or primary caregiver of a child with Acquired Brain Injury (ABI) can affect the parent's identity and the family's identity

To participate in the study, you must have a child who was diagnosed with a ABI who under the age of 18 at the time of the injury and the injury occurred more than one year ago.

Being in the study involves completing two brief questionnaires and doing a one-on-one interview. The study can be completed in person, over Zoom, or over the phone at a time that is convenient for you. Your participation should take about 1-2 hours, and to compensate your time you will be given a $40 gift card to Amazon.

If you are interested in being part of this research study or would like more information, please contact:

Jameson Natwick, MS, LMFT
Doctoral Candidate
Department of Human Development and Family Science, Virginia Tech
jnatwick@vt.edu or (507)327-2115

Participation is voluntary and confidential. Participants may withdraw from the study at any time. Risks associated with participation are minimal but may include feelings of discomfort with sharing one's views. Results may be published.

This study is approved by the Virginia Tech IRB, #19-295. 540-231-3732; irb@vt.edu]

Appendix C

Parental Self-Identity and Family Identity after a Child Acquires an ABI

RECRUITMENT EMAIL

Subject Line: Parental Identity and Family Identity after a Child Acquires an ABI – Virginia Tech Research Study

Dear _________________,

I am writing to let you know about an opportunity to inform others to participate in a research study about how a child with an Acquired Brain Injury (ABI) can influence the identity of parents. My name is Jameson Natwick, I am a doctoral candidate in the Department of Human Development and Family Science at Virginia Tech. You have been identified as an individual who is connected to working with parents or primary caregivers of a child with an ABI, and the research team would appreciate if you would share with parents the purpose of this study.

The study would consist of meeting with me in person at the time and location that would be convenient for the participant or to schedule a time to meet over Zoom, a HIPPA compliant video conferencing platform or over the phone. Participants will be asked to complete two brief questionnaires about themselves and their experiences and then participate in a one-on-one interview with me. The interview will involve a discussion about how the ABI to the participant's child has impacted how the parent views himself or herself and changes to the family after the ABI. Participation in this study should take about 2 hours. Parents who participate in this study will receive a $40 gift card to Amazon for their time. This study is approved by the Virginia Tech Institutional Review Board [IRB #19-295; 540-231-3732; irb@vt.edu].

Individuals who would like to participate in this study or have questions, please contact me by phone at (507)327-2115 or by email at jnatwick@vt.edu.

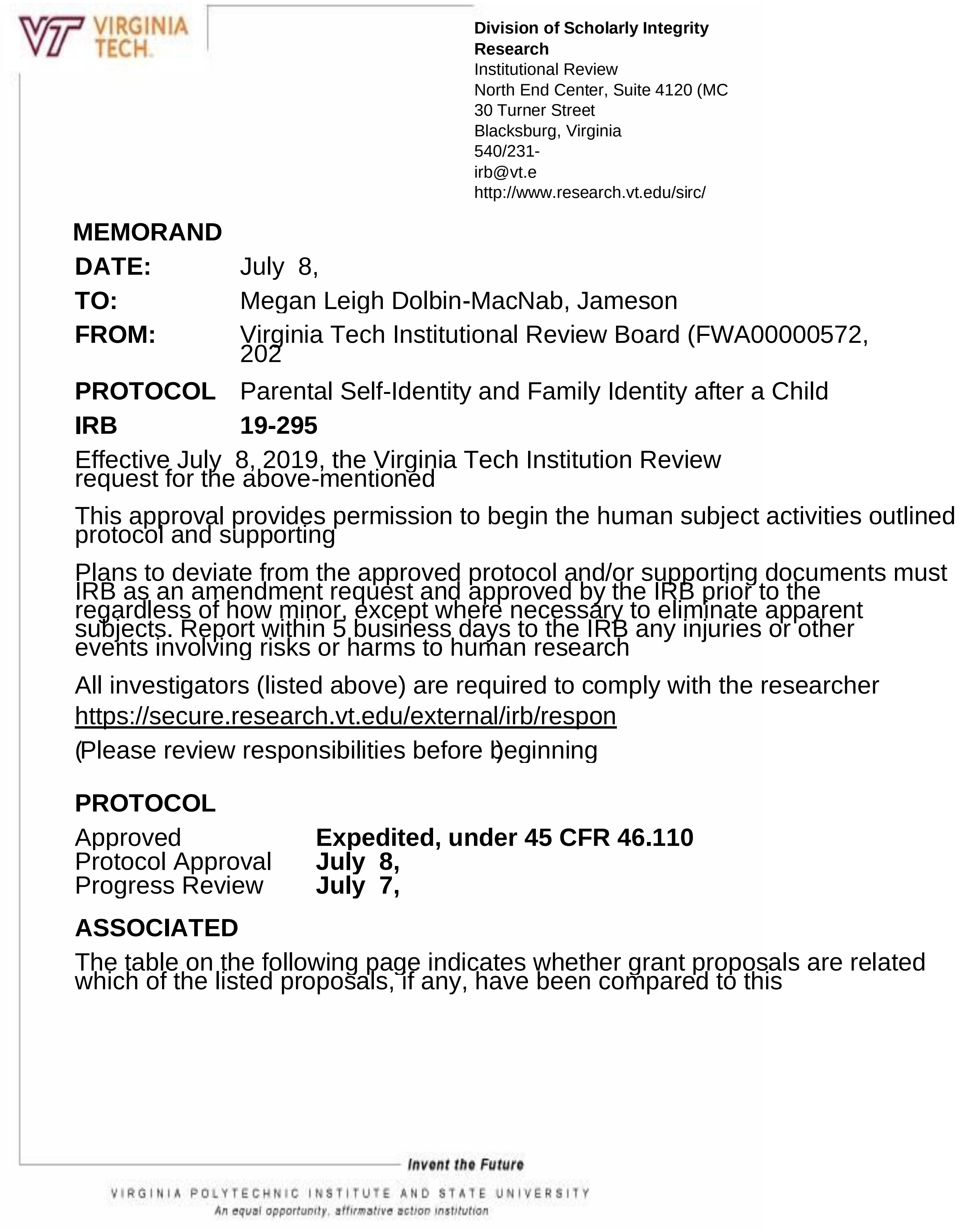
If you know of any parents who have a child that was under the age of 18 when they received an ABI and it has been at least one year since the event who may be interested in participating, please tell them about this study. For your convenience, I have attached a flyer for you to this email, please feel free to give parents who you feel could participant in this study the attached flyer.

Thank you for considering this research opportunity.

Sincerely,
Jameson Natwick
Doctoral Candidate
Department of Human Development and Family Science
Virginia Tech

Appendix D

IRB Approval Letter and Amendment Approval Letters



Division of Scholarly Integrity
Research
Institutional Review
North End Center, Suite 4120 (MC
30 Turner Street
Blacksburg, Virginia
540/231-
irb@vt.e
http://www.research.vt.edu/sirc/

MEMORAND

DATE:	July 8,
TO:	Megan Leigh Dolbin-MacNab, Jameson
FROM:	Virginia Tech Institutional Review Board (FWA00000572, 202
PROTOCOL	Parental Self-Identity and Family Identity after a Child
IRB	**19-295**

Effective July 8, 2019, the Virginia Tech Institution Review request for the above-mentioned

This approval provides permission to begin the human subject activities outlined protocol and supporting

Plans to deviate from the approved protocol and/or supporting documents must IRB as an amendment request and approved by the IRB prior to the regardless of how minor, except where necessary to eliminate apparent subjects. Report within 5 business days to the IRB any injuries or other events involving risks or harms to human research

All investigators (listed above) are required to comply with the researcher

https://secure.research.vt.edu/external/irb/respon

(Please review responsibilities before beginning)

PROTOCOL

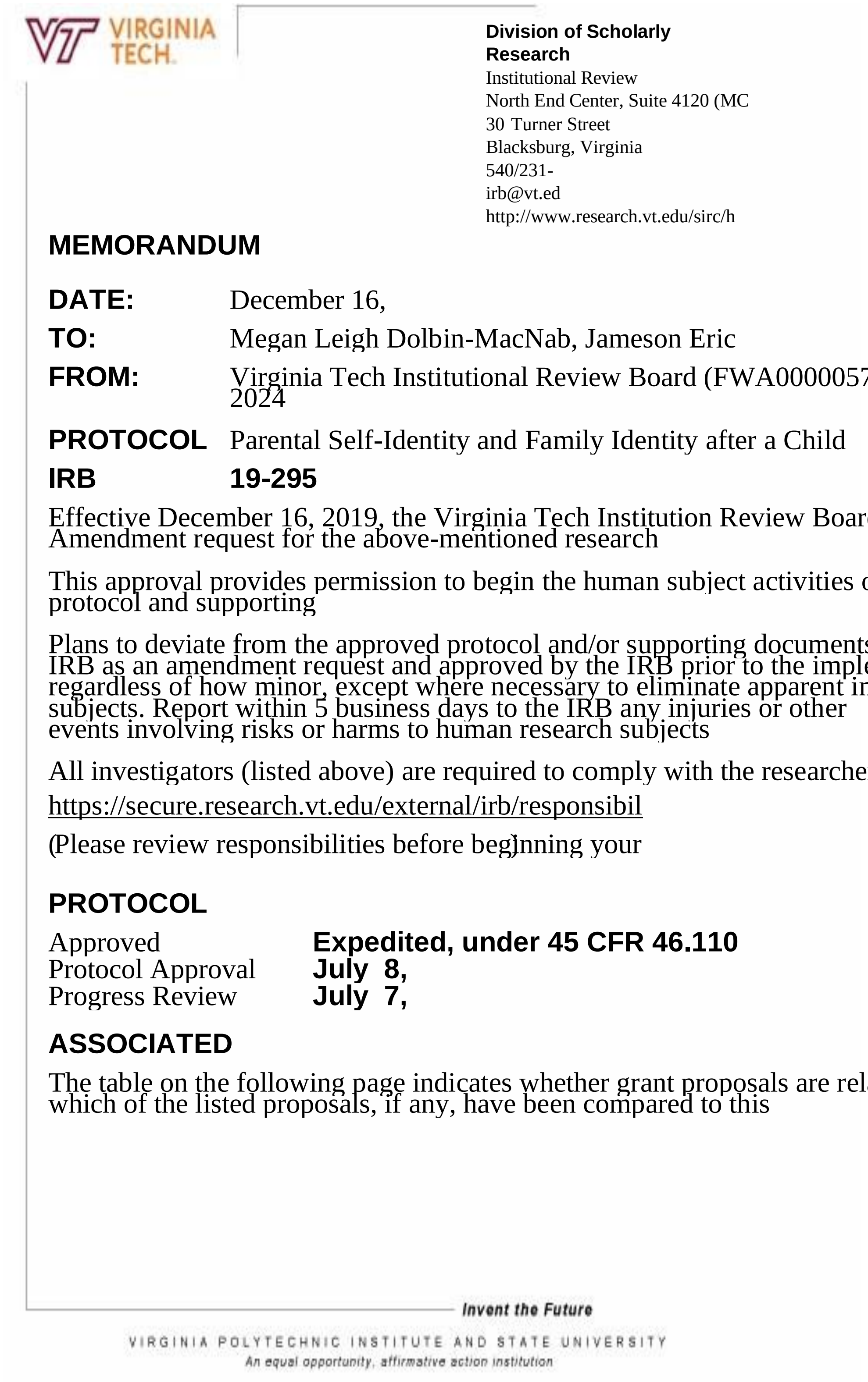
Approved	**Expedited, under 45 CFR 46.110**
Protocol Approval	**July 8,**
Progress Review	**July 7,**

ASSOCIATED

The table on the following page indicates whether grant proposals are related which of the listed proposals, if any, have been compared to this

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution



Division of Scholarly
Research
Institutional Review
North End Center, Suite 4120 (MC
30 Turner Street
Blacksburg, Virginia
540/231-
irb@vt.ed
http://www.research.vt.edu/sirc/h

MEMORANDUM

DATE: December 16,

TO: Megan Leigh Dolbin-MacNab, Jameson Eric

FROM: Virginia Tech Institutional Review Board (FWA00000572,
2024

PROTOCOL Parental Self-Identity and Family Identity after a Child

IRB **19-295**

Effective December 16, 2019, the Virginia Tech Institution Review Board
Amendment request for the above-mentioned research

This approval provides permission to begin the human subject activities outlined in the
protocol and supporting

Plans to deviate from the approved protocol and/or supporting documents must be
IRB as an amendment request and approved by the IRB prior to the implementation of
regardless of how minor, except where necessary to eliminate apparent immediate
subjects. Report within 5 business days to the IRB any injuries or other
events involving risks or harms to human research subjects

All investigators (listed above) are required to comply with the researcher

https://secure.research.vt.edu/external/irb/responsibil

(Please review responsibilities before beginning your)

PROTOCOL

Approved	**Expedited, under 45 CFR 46.110**
Protocol Approval	**July 8,**
Progress Review	**July 7,**

ASSOCIATED

The table on the following page indicates whether grant proposals are related to this
which of the listed proposals, if any, have been compared to this

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
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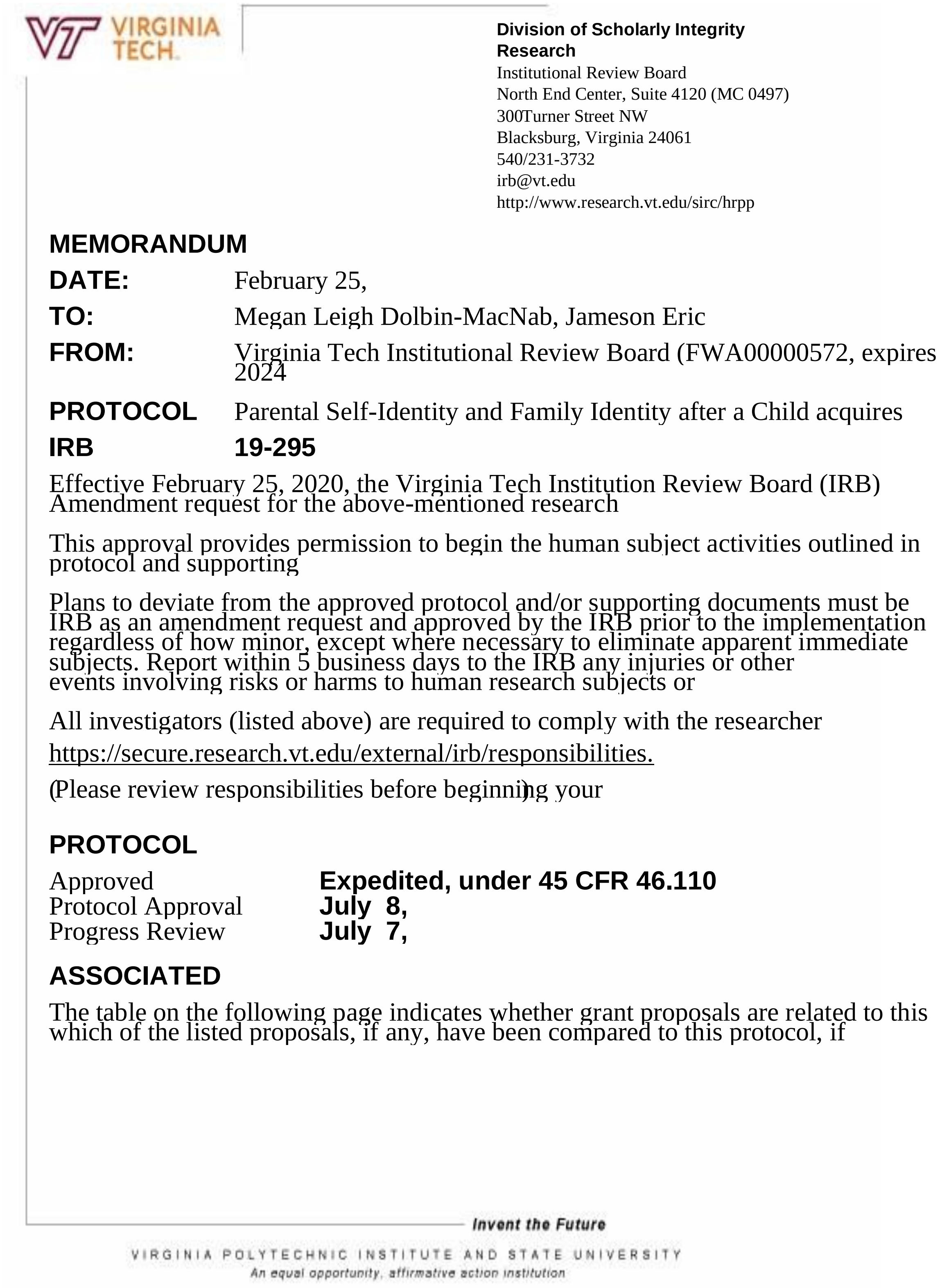

Division of Scholarly Integrity
Research
Institutional Review Board
North End Center, Suite 4120 (MC 0497)
300Turner Street NW
Blacksburg, Virginia 24061
540/231-3732
irb@vt.edu
http://www.research.vt.edu/sirc/hrpp

MEMORANDUM

DATE: February 25,

TO: Megan Leigh Dolbin-MacNab, Jameson Eric

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires 2024

PROTOCOL Parental Self-Identity and Family Identity after a Child acquires

IRB **19-295**

Effective February 25, 2020, the Virginia Tech Institution Review Board (IRB) Amendment request for the above-mentioned research

This approval provides permission to begin the human subject activities outlined in protocol and supporting

Plans to deviate from the approved protocol and/or supporting documents must be IRB as an amendment request and approved by the IRB prior to the implementation regardless of how minor, except where necessary to eliminate apparent immediate subjects. Report within 5 business days to the IRB any injuries or other events involving risks or harms to human research subjects or

All investigators (listed above) are required to comply with the researcher

https://secure.research.vt.edu/external/irb/responsibilities.

(Please review responsibilities before beginning your)

PROTOCOL

Approved **Expedited, under 45 CFR 46.110**
Protocol Approval **July 8,**
Progress Review **July 7,**

ASSOCIATED

The table on the following page indicates whether grant proposals are related to this which of the listed proposals, if any, have been compared to this protocol, if

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution

Appendix E

Research Participant Consent Form

Title:	Parental Self-Identity and Family Identity after a Child Acquires an ABI
Protocol No.:	#19-295
Sponsor:	Virginia Tech
Investigator:	Megan Dolbin-MacNab, PhD, LMFT Family Therapy Center of Virginia Tech (0515) 840 University City Blvd., Suite 1 Blacksburg, VA 24060 USA
Co-Investigator	Jameson Natwick, MS, LMFT 16308 123rd PL NE Bothell, WA 98011
Daytime Phone Number:	(507) 327-2115 - Jameson Natwick

You are being asked for your consent to take part in a research study. This document describes the key information that we believe most people need to decide whether to take part in this research.

What should I know about this research?

- Someone will explain this research to you verbally. This form also explains the research to you.
- Taking part in this research is voluntary. Whether you take part in this research up to you.
- If you choose not to take part in this research, it won't be held against you. There will be no penalty or loss of benefits to which you are otherwise entitled.
- You can decide to take part in this research now and then decide to drop out later. If that happens, it won't be held against you.
- You are not required to answer all of the researcher's questions. If you choose not to answer a specific question, it won't be held against you.
- If there is anything that you don't understand about this research, you should let the researcher know so that they can answer your questions.
- If you have questions about what it means to be part of this research, you should ask all of your questions before you decide to take part in the research.

How long will I be in this research?
It is expected that it will take approximately 2 hours to participate in this research.

Why is this research being done?
The purpose of this research is to learn about how a parent understands them self and how their family is affected by an Acquired Brain Injury (ABI) to a child. Information from this study will be used to help to inform rehabilitation services. This research study seeks approximately 15 parents/primary caregivers

of a child, under the age of 18 when the ABI was acquired and it has been at least one year since the event that lead to the ABI.

What happens to me if I agree to take part in this research?
If you decide to take part in this research, first you will schedule with Jameson a time and place to meet for the procedures of the study or will schedule a time to meet with Jameson over the online conference platform, Zoom, or over a phone call. Then, you will meet with the researcher at the scheduled time and location, in person, over Zoom or a phone call, to complete two questionnaires, one asking general information about yourself and other asking about your experiences as a parent who has a child with an ABI. To complete the questionnaires, the participant will have the questions read to them by Jameson and will respond verbally to answer the questionnaires. After completing the questionnaires, you will participate in an interview, that will be audio-recorded, about how having a child with a ABI has influenced the way you see yourself and your family, and your experiences with rehabilitation services. Participation in the whole study will take approximately 2 hours to complete.

What are my responsibilities if I take part in this research?
If you take part in this research, you will be responsible for:

- Working with the research team to find a time and private location, such as your home or another place of your choosing, to complete the procedures for this study.
- Completing two questionnaires, one about demographic information and the other about your experiences as a parent who has a child with an ABI.
- Taking part in an audio-recorded interview with the researcher.

Could being in this research hurt me?
The most important risks or discomforts that you may expect from taking part in this research include emotional or psychological discomfort associated with discussing your personal perspectives and experiences. The risks for your participation in this study are minimal.

Will being in this research benefit me?
Possible benefits that you or others may expect from taking part in this research include gaining further insight into how the ABI to your child has affected you and your family. The researcher cannot guarantee any benefits for participating in this study.

Will it cost me money to take part in this research?
There is no cost for you to participate in this research.

What other choices do I have besides taking part in this research?
Instead of being in this research, your choices include not taking part in this research. This research is not designed to diagnose, treat, or prevent any diseases.

What happens to the information collected for this research?
All information for this study will be collected and stored securely in the researcher’s office. The audio recording of the interview will be transcribed. When this is completed, we will remove your name and other identifying information and give your interview a code number. Once that happens, it will not be possible to link your responses to the interview questions to your name. We will keep the transcription of the interview but will destroy the audio-recording after 3 years. The questionnaires you complete will get a code number. The key to match up information will be stored securely and separately from other data and will destroy it at the end of the study.

In addition, identifiers might be removed from the identifiable private information and, after such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you.

The results of this study may be published. However, your name and other identifying information will remain confidential in all publications.

We protect your information from disclosure to others to the extent required by law. We cannot promise complete secrecy, particularly if you share information about child or elder abuse/neglect or possible harm to yourself or others.

Who can answer my question about this research?
If you have questions, concerns, or complaints, or think this research has hurt you, talk to Jameson Natwick (507) 327-2115.

This research is being overseen by the Virginia Tech Institutional Review Board (IRB) and by Dr. Dolbin-MacNab, a professor at Virginia Tech. An IRB is a group of people who perform an independent review of research studies. You may talk to them at 540-231-3732 or email them at irb@vt.edu if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

What if I am injured because of taking part in this research?
If you are injured or experience emotional distress because of being in this research, contact the researcher immediately. The researcher will refer you to appropriate medical services or community supports. You are responsible for any costs associated with getting medical services or community support as a result of taking part in this research.

Can I be removed from this research without my approval?
The person in charge of this research can remove you from this research without your approval. Possible reasons for removal include not following researcher instructions or showing signs of serious physical or emotional distress.

Will I be paid for taking part in this research?
You receive a $40 gift card to Amazon for your participation. You will get the gift card as long as you begin the study, therefore if you need to drop out part way through you will still be compensated for your time.

Summary of Results
Will you want to receive a summary of the final results of the research, which will be sent to you via email?

☐ **Yes** ☐ **No**

Statement of Consent:

☐

Your signature documents your consent to take part in this research.

Verbal consent given for Zoom/phone call participant.

Signature of adult subject capable of consent	Date
Signature of person obtaining consent	Date

Appendix F

Demographic Questionnaire

1. Age:__________
2. Gender:__________
3. Race/Ethnicity:_________________
4. What is your current Marital Status:
    - ☐ Single
    - ☐ Married
    - ☐ Dating
    - ☐ Divorced
    - ☐ Separated
    - ☐ Widowed
5. Highest Level of Education
    - ☐ Less than a high school diploma
    - ☐ High school diploma or GED
    - ☐ Some college
    - ☐ Associates Degree
    - ☐ Bachelor's Degree
    - ☐ Master's Degree
    - ☐ Doctoral Degree
    - ☐ Other:______________
6. What is your yearly household income before taxes?
    - ☐ $0 - $10, 000
    - ☐ $10,001 – $20,000
    - ☐ $20,001 – $35,000
    - ☐ $35,001 – $50,000
    - ☐ $50,001 – $65,000
    - ☐ 65,001 – $80,000
    - ☐ $80,001 – $100,000
    - ☐ More than $100,000
7. Current Employment:
    - ☐ Full-time
    - ☐ Part-time
    - ☐ Not Working
    - ☐ Unemployed
8. Age your child received the ABI:_______________________________________
9. Current age of child with an ABI:____
10. When did the diagnosis of ABI occur?___________________________________
11. Cause of ABI:____
12. Number of children in the home:_______________________________________
13. (If applicable) Severity of ABI to your child (Circle one):

Mild Moderate Severe

Appendix G

Family Impact Questionnaire

Being a parent can be difficult, and children have different effects on the family. We would like to know what impact your child has had on the family compared to the impact other children his/her age have on their families. The following questions attempt to understand children's impact on different areas of family functioning. Please check the category that best describes your situation in terms of how things have been in general for you with reference to the child who has acquired an ABI.

Your Feelings and attitudes about your child	Not at all	Somewhat	Much	Very Much
COMPARE TO CHILD AND PARENTS WITH CHILDREN THE SAME AGE AS MY CHILD…				
1. My child is more stressful.				
2. I enjoy the time I spend with my child more.				
3. My child brings out feelings of frustration and anger more.				
4. My child brings out feelings of happiness and pride more.				
5. When I am with my child, I feel less effective and competent as a parent.				
6. It is easier for me to play and have fun with my child.				
7. My child's behavior bothers me more.				
8. My child makes me feel more loved.				
9. I feel like I am working alone in trying to deal with my child's behavior.				
10. My child makes me feel more energetic.				
11. I feel like I could be a better with my child.				
12. My child makes me feel more confident as a parent.				
13. I feel like I should have better control over his/her behavior.				

14. My child does what I tell him/her to do most of the time.				
If you are married complete the following section. THE IMPACT OF YOUR CHILD ON YOUR MARITAL RELATIONSHIP	Not at all	Somewhat	Much	Very Much
1. My spouse and I disagree more about how to raise this child.				
2. My spouse is more supportive of the way I deal with my child’s behavior.				
3. This child pits my spouse and me against each other more.				
4. Raising this child has brought my spouse and me closer together.				
5. My child causes more disagreements between my spouse and me.				
6. My spouse is less supportive of the way I deal with my child’s behavior.				
7. Raising this child has pushed my spouse and me farther apart.				

Appendix H

Interview Protocol

Research Questions	Interview Questions
Background Information	1. When did your child acquire an ABI? 2. How did the ABI occur? • Who was present? Responsible for watching the child? • The severity of ABI? • Hospitalization? If so, how long? 3. Describe changes you have noticed in your child after he/she received an ABI? • What symptoms have you observed? • Questions into the multiple domains of symptoms (e.g. cognitive, behavioral, physical, etc.) • What changes have you observed over time? - Evolution of symptoms - Pre to post ABI • Describe any changes in the severity of symptoms you have noticed - Evolution of symptoms - Pre and post ABI 4. Describe how the ABI impacted you and your family. Ask about the impact on… • Marriage • Relationship with injured child • Relationship with uninjured child (if applicable) • Career • Parenting/Discipline • Friends • Extended family members 5. How do you think would your life be different if your child did not receive an ABI?
Research Question 1. How do parents of a child who has received an ABI construe and reconstruct their self-identity?	1. How would you describe yourself to a stranger? Additional Prompts: • Who are you? • What makes you you? • What things really matter to you in life?

	2. How has having a child with an ABI impacted the way you view yourself? • Yourself as a person, a parent, a partner, in your career? • What parts of yourself have been most influenced? • What stories do you have to illustrate your experience of how you view yourself and how it has been influenced by having a child with an ABI? 3. How would you define the term “self-identity”? 4. How would you define your self-identity in a word or sentence? 5. Since your child acquired an ABI, have you noticed any ways you've changed for the better? In what ways? • What prompted that kind of change in yourself? • How has the way you thought about the ABI influenced your growth? • Were other people or other resources helpful in making you grow in that way? How were they helpful? • Were there any things that got in the way of your growth, or made it harder or take longer? 6. Since your child acquired an ABI, have you noticed any ways you've changed that you don't like too much or which hadn't changed? Tell me about that. • What do you think caused or influenced these changes? • How have you handled the parts of you you don’t like too much? • How have these changes impacted the way you view yourself? • How others view you? 7. What has stayed the same about you since the ABI to your child? 8. Considering the ways you’ve changed that you like and don’t like so much, do you think you’re a different person now that your child had an ABI? • In what ways? • How do you feel about the “new you”? • How do you think others feel about the “new you”?

Research Question 2. How do parents reestablish family identity, after a child has experienced an ABI?	1. How would you describe your family and what your family is all about to a stranger? 2. In a sentence or two, what does it mean to be family? 3. How would you define “Family Identity”? 4. What is your family identity? 5. What has stayed the same about you since the ABI to your child? 6. Consider the ways your family has changed after the ABI to your child. What do you like and what are areas that you do not like so much? • What caused or influenced these changes? • How have you handled the parts of your family you do not like so much? 7. How does your family talk about the changes? • Who starts the conversations about the changes? • In what context do these conversations occur? • Do members of your family see other family members differently? 8. How would you describe your family before/after ______ received a ABI? • Prompts: - Family routines - Communication - Leisure activities - Family roles - Conflict - Family values 9. What challenges have you encountered in how other family members understand what it means to be family since your child had an ABI? • Prompts: - Extended family - Friends - Co-workers/Boss 10. What has been your role in helping your family adjust since your child had an ABI?

	• What has been the role of other family members? 11. How have things like religion/spirituality, friends, other family members, or professionals helped you define your family? • How have they interfered? • How have they helped your family grow? 12. How do you think the outside world sees your family? • How do you feel about the way your is viewed? • Do you or your family behave differently when in public? 13. Since your child had an ABI, have you needed to adjust to the way the outside world views your family? • In what ways? • How have you done that? • How have you felt about the adjustments? 14. What challenges has your family encountered in adjusting to the way the outside world views your family? • How have you overcome these challenges?
Research Question 3. When a child receives an ABI, what services and clinical supports are needed to promote and support the reconstruction of a positive parent self-identity and family identity?	1. What rehabilitation services did you access for your child or family immediately after the injury? • Are services still being used by the family? Which ones? • What needs did your child and your family have? - Immediately after ABI? - Currently? • Are there new, ongoing, or previously unmet needs? • What services are you using now? 2. What services have been most helpful? Least helpful? In helping your child, you, and your family? • Why has it been helpful/unhelpful? - Professionalism: Respectful, caring, understand needs, etc. - Policies and Procedures: - Fees, paperwork, how the clinic is run, etc. - Outcome(s) of service(s)

        - What did you learn from services? What skills did you/your child/your family gain?

3. To what extent did professionals talk to you about how you're feeling about yourself and your family, about how the outside world might view your family now or react to your child and your family?
    - What was most helpful?
        - For you?
        - For your family?
    - Did professionals do anything that was damaging to your thoughts about yourself or your family?
    - What could services do in helping parents think about themselves as a parent of a child with an ABI?
    - What could services do better in helping families with someone who had an ABI manage how others look at them and help families look at themselves?

4. Is having services or professionals discuss self-identity or family identity even something that you would want them to bring up?
    - Why or why not?
    - What types of services would feel more comfortable for you to discuss your sense of self and your family's identity?
        - Context: Medical setting, therapy, etc.
    - What qualities in professionals would help you discuss self-identity and family identity?

5. What recommendations would you give to other families who have a child with an ABI to how the injury has influenced self-identity and family identity?
    - Prompts
        - What would you tell another parent who has a child with an ABI about how to view his/her self?
        - What advice would you give another families in adjusting to how the family has changed and sees itself and how the outside world can look at the family differently?
        - Seeking services, utilizing services, voicing needs of child, self, or family

6. What recommendations would you give to practitioners?
    - Prompts

	- What they should ask or do regarding self-identity or family identity? - What they should not ask or do about self-identity and family identity? - How to talk about specific topics - How to ask about self-identity and family identity

Appendix I

Member Checking Procedures

(Email to set up Member Checking Process)

Dear [Participant's name],

This is Jameson Natwick from the Parental Self-Identity and Family Identity after a Child Acquires an ABI study. I want to thank you again for your participation in the interview process. Your participant in the study has been very helpful and I could not have gotten the findings without you.

I am reaching out to you again to see if you would participate in the member checking interview. Member checking interview is a process in which I will provide a one-page summary of the results of the study from all XX participants. After you review the findings, we would have a member checking interview on the phone about your thoughts of the results. If you are interested, I am hoping to schedule a time when we would be able to speak briefly on the phone about the results of the study. This conversation will take about 15 minutes of your time and will not be audio recorded. Prior to our member checking interview on the phone, I will email a summary of the results from the study and the consent form for the member checking interview for you to review. During our member checking interview, I will be interested in your thoughts about the findings, if I missed anything, or if a finding does not match your experience. If you are interested, what would be the best time and phone number to reach you? Please let me know if you have any questions. I look forward to hearing from you.

(If participant is no longer interested)

Dear [Participant's name],

I appreciate your time and I apologize for any inconvenience my emails may have caused. I thank you again for your participation in this research study and I hope you have a nice day.

(If participant is interested)

Dear [Participant's name],

Thank you for your willingness to speak with me again.

(If participant gave times to talk). Given the times that you suggested, let us plan on having our member checking interview on *Date* and *Time*. I will plan on calling you at this time. To confirm, I will be calling (XXX)XXX-XXXX. Attached to this email is a summary of the results of the study from all the interviews I have conducted and a consent form. Please review the results and the consent form before our member checking interview. I will be asking you about if the findings match your experience as a parent, if you disagree, or if there is anything I missed

in the findings. Your contributions are very important in making sure that this research study is capturing the experience of parents. Please review the results of the study before we talk on *Date* and *Time*. Please let me know if you have any questions.

Member Checking Questions

Interviewer: Thank you again for being willing to participate in the member checking interview. First, I want to quickly read through the member checking interview consent form, answer any questions you may have about this process, and obtain your verbal consent to participate in the member checking interview.

(Read through consent form, answer any questions and get verbal consent)

Thank you. Before asking you questions, do you have any questions before we begin? *(if no, begin; if yes, answer questions)*

1. What are your initial thoughts about the findings summary that you were provided?
2. How are the results I provided to you similar to your experience of being a parent of a child with an ABI?
3. What findings do you disagree with, find confusing, or do not match your experience?
4. What findings to do think I may have misunderstood what the parents were talking about?
5. After reviewing the results, are there any corrections that you would want to make?
6. Is there additional information that you would add to the results?

Appendix J

MEMBER CHECKING INTERVIEW CONSENT FORM

Title:	Parental Self-Identity and Family Identity after a Child Acquires an ABI
Protocol No.:	#19-295
Sponsor:	Virginia Tech
Investigator:	Megan Dolbin-MacNab, PhD, LMFT Family Therapy Center of Virginia Tech (0515) 840 University City Blvd., Suite 1 Blacksburg, VA 24060 USA
Co-Investigator	Jameson Natwick, MS, LMFT 16308 123rd PL NE Bothell, WA 98011
Daytime Phone Number:	(507) 327-2115 - Jameson Natwick

You are being asked for your consent to take part in the member checking interview. This document describes the key information that we believe most people need to decide whether to take part in this research.

What should I know about this research?

- Someone will explain this research to you verbally. This form also explains the research to you.
- Taking part in this research is voluntary. Whether you take part in this research up to you.
- If you choose not to take part in this research, it won't be held against you. There will be no penalty or loss of benefits to which you are otherwise entitled.
- You can decide to take part in this research now and then decide to drop out later. If that happens, it won't be held against you.
- You are not required to answer all of the researcher's questions. If you choose not to answer a specific question, it won't be held against you.
- If there is anything that you don't understand about this research, you should let the researcher know so that they can answer your questions.
- If you have questions about what it means to be part of this research, you should ask all of your questions before you decide to take part in the research.

How long will I be in this research?
It is expected that it will take 15-30 minutes to complete the member checking interview.

Why is this research being done?
The member checking interview is utilized in research to ensure the results of a study are valid and match the experience of the participants who participated in the original interview by having a brief interview between you and the research team. Since you participated in the interview for the research study "Parental Self-Identity and Family identity after a Child Acquires an ABI" the research team wants

to check to make sure that the results match your experience and the researchers fully understood what you meant during the interview. The research team is wanting to get all participants of the "Parental Self-Identity and Family identity after a Child Acquires an ABI" research study to participate in the member checking interview.

What happens to me if I agree to take part in this research?
If you decide to take part of the member checking interview, first you will schedule a time with Jameson to conduct the interview over the phone. Once this time is scheduled for the interview, you will receive an one-page summary of the findings of the study from all the participants and the consent form for you to review before talking with Jameson. Then, you will have the member checking interview with Jameson over the phone about whether you agree, disagree, or feel the research team missed something in the findings. The phone conversation will take 15-30 minutes. This interview is NOT audio recorded.

What are my responsibilities if I take part in this research?
If you take part in this research, you will be responsible for:

- Working with the research team to find a time to complete the procedures for the member checking interview.
- Reviewing the one-page-summary of the findings and the consent form.

Could being in this research hurt me?
The most important risks or discomforts that you may expect from taking part in this research include emotional or psychological discomfort associated with discussing your personal perspectives and experiences. The risks for your participation in this study are minimal.

Will being in this research benefit me?
Possible benefits that you or others may expect from taking part in this research include gaining further insight into how the ABI to your child has affected you and your family. The researcher cannot guarantee any benefits for participating in this study.

Will it cost me money to take part in this research?
There is no cost for you to participate in this research.

What other choices do I have besides taking part in this research?
Instead of being in this research, your choices include not taking part in this research. This research is not designed to diagnose, treat, or prevent any diseases.

What happens to the information collected for this research?
All information for this study will be collected and stored securely in the researcher's office. This interview is not audio recorded. Notes will be taken during the interview. The form the notes will be taken on will not include your name or other identifying information.

The results of this study may be published. However, your name and other identifying information will remain confidential in all publications.

We protect your information from disclosure to others to the extent required by law. We cannot promise complete secrecy, particularly if you share information about child or elder abuse/neglect or possible harm to yourself or others.

Who can answer my question about this research?

If you have questions, concerns, or complaints, or think this research has hurt you, talk to Jameson Natwick (507) 327-2115.

This research is being overseen by the Virginia Tech Institutional Review Board (IRB) and by Dr. Dolbin-MacNab, a professor at Virginia Tech. An IRB is a group of people who perform an independent review of research studies. You may talk to them at 540-231-3732 or email them at irb@vt.edu if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

What if I am injured because of taking part in this research?

If you are injured or experience emotional distress because of being in this research, contact the researcher immediately. The researcher will refer you to appropriate medical services or community supports. You are responsible for any costs associated with getting medical services or community support as a result of taking part in this research.

Can I be removed from this research without my approval?

The person in charge of this research can remove you from this research without your approval. Possible reasons for removal include not following researcher instructions or showing signs of serious physical or emotional distress.

Will I be paid for taking part in this research?

You receive not compensation for partaking in the member checking interview.

Verbal Consent will be obtained

Verbal Consent Obtained?

☐ Yes ☐ No

Appendix K

Rev Information Security & Privacy Program Overview

Introduction

The following document provides an overview of Rev's Information Security & Privacy program. We advise reviewing this document in its entirety as an overview. Our complete Information Security package can be provided upon request.

Rev.com's advanced platform is a multi-tenant, multi-user, on-demand service providing unbeatable quality, speed, and value to clients and freelancers alike. Rev.com may be securely accessed 24x7 through any Internet-connected computer with a standard browser, an application program interface (API), or mobile applications.

Objectives

Security is a critical part of our business. With our security & privacy program, we strive to achieve the following goals:

1. Ensure that customer data is encrypted and inaccessible to other customers and the public.
2. Ensure that customer data is accessible to staff only to the extent necessary to perform the required work.
3. Prevent loss or corruption of customer data.
4. Maintain a redundant infrastructure with 99.9% uptime.
5. Provide timely notifications in the unlikely event of a downtime, data corruption or loss.
6. Provide continuous training for our staff on proper operation of our systems and best practices for security and privacy.

Our security policies and procedures are reviewed on an ongoing basis by the Rev security committee, which is also responsible for enforcement. All our staff have signed confidentiality agreements.

Information Security

Rev.com uses appropriate technical, organizational and administrative security measures to protect any information in its records from loss, misuse, and unauthorized access, disclosure, alteration and destruction. Rev.com uses NIST guidelines and Center for Internet Security Cybersecurity Best Practices as a foundation for its information security program including information security policies and incident response.

Privacy

Please see the Rev.com Privacy Policy (https://www.rev.com/about/privacy) for details of how Rev.com treats personal information and complies with privacy regulations.

Secure Infrastructure

All Rev.com services are hosted by Amazon Web Services (AWS). AWS maintains strict physical access policies that utilize sophisticated physical access control mechanisms. Environmental controls such as uninterruptable power and non-destructive fire suppression are integrated elements of all data centers. Rev.com uses multiple geographically distributed data centers as part of a comprehensive disaster recovery strategy, and uses the CIS Amazon Web Services Benchmarks (https://aws.amazon.com/quickstart/architecture/compliance-cis-benchmark/) as a guide for best practices. AWS provides DDOS services.

Software Development Lifecycle

As a cloud service company, Rev.com releases software frequently and regularly so that clients may benefit from on-going development of new service and security capabilities. Rev.com follows a defined SDLC (Software Development Lifecycle) that includes the application of security-by-design principles. Rev operates using an agile development methodology under which software development teams and management are tasked with ensuring that the SDLC method and design principles are followed.

Secure Service Operations

Access to production infrastructure is managed on a least privileges basis and is limited to the Rev.com operations team. Background checks are performed and security training is provided to ensure the background and skills of the operations staff are consistent with the information security policy and work instructions. Sensitive product service data stored in service databases never leaves the production system and access is controlled according to least privilege principles.

Firewalls rules are maintained so that production systems can only be accessed for maintenance from defined Rev.com locations using secured access mechanisms. Systems are maintained in a hardened state with defined baselines for all host and network equipment.

All changes to systems are tracked and managed according to well-established change management policies and procedures. The patch level of third-party software on systems in regularly updated to eliminate potential vulnerabilities.

Breach Detection and Response

Rev.com utilizes network intrusion detection and host integrity management tools to continuously monitor the state of the system. Availability of the system is also continuously monitored using external monitoring tools. System logs are aggregated and archived centrally, facilitating both continuous analysis for suspicious access patterns and future forensic analysis. Regular external vulnerability scanning is also performed.

In the event of a breach, Rev.com has the ability to isolate components of the system to contain the breach and maintain ongoing operations. Rev.com's incident response team is at the ready to notify customers of security or service impacting events according to defined notification policies in the Incident Response Plan.

Security Package Contents

Our Information Security package includes:

1. Rev Information Security Overview (this document)
2. Rev Privacy Policy
3. Rev Terms of Service
4. Rev GDPR Overview
5. Rev Policies
    a. Encryption Policy
    b. Third-Party Connection Policy
    c. Retention Policy
    d. Network Security Policy
    e. Incident Response Policy
    f. Wireless Access Policy
    g. Password Policy
    h. Network Access and Authentication Policy
    i. Mobile Device Policy
    j. Email Policy

    k. Acceptable Use Policy
    l. Physical Security Policy
    m. Backup Policy
    n. VPN Policy
    o. Remote Access Policy
    p. Outsourcing Policy
    q. Guest Access Policy
    r. Data Classification Policy
    s. Confidential Data Policy
    t. Web Application Security Policy
    u. Remote Access Policy

6. Rev Procedures (select examples, Rev retains additional confidential procedures)
    a. Incident Activity Log Template
    b. Incident Tracking Form
    c. Rev Data Handling 3rd party request procedure
    d. Privacy & Information Security Policy training (high-level example, Rev also requires completion of a 3rd party training platform)
7. Rev Data & Security Architecture
    a. Rev Data Flow diagram
    b. Rev Data Subprocessors
    c. Rev Data Flow folder – supporting details
8. Rev Qualifications, Certifications and Tests
    a. National Institute of Standards and Technology - Cybersecurity Guidelines
    b. PCI Compliance certificate
    c. Rev PCI Scan Report

Available on request (our standard legal documents):

1. Rev Master Service Agreement (MSA)
2. Rev Service Level Agreement (SLA)
3. Rev Non-Disclosure Agreement (NDA)
4. Rev Data Protection Addendum (DPA)
5. Rev Service Agreement