A PHENOMENOLOGICAL INQUIRY INTO THE FAMILY MEMBERS' EXPERIENCE OF HAVING AN ADULT MEMBER WITH A TRAUMATIC BRAIN INJURY WITHIN THE FIRST THREE YEARS

By

Erica Lynn Wondolowski

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ABSTRACT

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Traumatic brain injury (TBI) can range in severity from mild to severe, and the side effects of such an injury can produce difficulties with visual-spatial relations, perception, sensory distortions, swallowing, endurance, self-awareness, personality changes, and communication. TBIs constitute approximately 1.7 million of various disabilities acquired annually and of those, approximately 1.6 million individuals will live with TBI sequelae for the remainder of their life. Family members are reported to be the predominant caregivers and/or health care proxies for persons with a TBI rendering it essential that practitioners and researchers understand the family responses to the disability in order to best serve and support both persons with TBI and their families.

The purpose of the present study was to explore how immediate family members describe, and what is the meaning of, the experience of having an adult family member with an acquired TBI within the first three years. Six participants were recruited from a mid-Michigan brain injury rehabilitation facility. Although each experience was unique with regard to how it was felt and encountered, six themes were experienced across all six accounts. Those areas were: (1) an abrupt onset requiring necessary and rapid response, (2) the multiform manifestations of fear, (3) the significant role changes within the family system, (4) the diverse practices for emotional expression and protection, (5) the depth to which grief is experienced, and (6) the immutable alterations to established plans for the future. The current study provides a glimpse into six different experiences of the familial experience of TBI, in addition to interpretations and analyses of those experiences, to inform practitioner interactions and treatment for family members of those persons with a TBI. The experiences shared within the current study aligned with six of seven posited assumptions, in addition to the documented attributions of stress as defined in the ambiguous loss literature. Implications for practitioners and recommendations for future research are discussed.

Keywords: TBI, traumatic brain injury, family, ambiguous loss theory, coping and adaptation, experience, clinical intervention

This dissertation is dedicated first and foremost to my mother, Gina Gianninoto, who without I would have never embarked on this journey. You are always with me in my heart, no matter where I go, as I am with you. This dissertation is also dedicated to the many family members of a person with a traumatic brain injury. May they find and receive the level of help, support, understanding, and care that they need and deserve.

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a colleague, but a dear friend and confidante - thank you for lifting me up when I was down, guiding me when I was lost, laughing with me at the absurdity of life, and for sharing in the incredible and unique rollercoaster of this experience. We truly have a lifelong friendship that has been forged in fire.

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CHAPTER 1

INTRODUCTION

Traumatic brain injury (TBI) is a disabling condition characterized by varying levels of compromised cognitive functioning, impaired memory, and inappropriate affect, among others (Falvo, 2009). TBI can range in severity from mild to severe, and the side effects of such an injury can produce difficulties with visual-spatial relations, perception, sensory distortions, swallowing, endurance, self-awareness, personality changes, and communication (Falvo, 2009). TBIs constitute approximately 1.7 million of the disabilities acquired annually, including those who die as a result of the injury (U.S. Department of Health and Human Services, Centers for Disease Control, National Center for Injury Prevention and Control, 2010). Of those 1.7 million individuals who acquire a TBI, approximately 52,000 pass away, 275,000 are hospitalized, and 1.365 million are treated and released from an emergency department. For the approximately 1.6 million individuals who will live the remainder of their life with a TBI, it is essential that practitioners and researchers understand the family responses to the disability acquisition in order to best serve and support both individuals with TBI and their families. Understanding the familial response is important, as family members are reported to be the predominant caregivers and/or health care proxies for this population (Degeneffe & Burcham, 2008; De Jong, Batavia, & Williams, 1990; Kolakowsky-Hayner, Miner, & Kreutzer, 2001).

Finkelstein, Corso, and Miller (2006) estimated that the annual economic cost of TBI in the United States in the year 2000, including direct medical, rehabilitation, and societal costs, was approximately $60 billion. Gray (2000) reported findings that indicate that improvement may continue for months to years following initial injury, often in the absence of formal rehabilitative care. DePompei and Williams (1994) stated, “Shrinking health care budgets and a growing national commitment to managed care necessitate the empowerment of family and community members so that they can assume roles once played by professionals alone” (p. 79). Therefore, it is critical for individuals living with a TBI to be provided ongoing support and for those family members in the individual’s life to be supported and provided the resources necessary to handle the consequential changes in their loved one, in addition to any care they may need.

Impact of Traumatic Brain Injury on the Family

How the caregiver perceives the impact of the TBI on their loved one is reputed to regulate the degree to which the caregiver believes their loved one has changed (Oddy, 1995). Those persons with a TBI who demonstrate greater overall change are more likely to have a caregiver who perceives considerable burden and manifests greater, problematic mental health symptomology. Multiple researchers have supported the conclusion that certain sequelae and impacted characteristics are more likely to result in greater caregiver burden, overall lower family function and life dissatisfaction. Behavioral, personality, and emotional characteristics are reported to be the most influential, with problems including childishness, lability, adynamia, irritability, and aggression being the most disturbing (Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; Kosciulek, 1995; Kreutzer, 1992; Livingston, Brooks, & Bond, 1985; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978; Thomsen, 1974; Thomsen, 1984). The repercussions of the TBI on the individual family system have been reported to continue to have an impact over 15 years post-injury (Frosch et al., 1997).

Psychiatric morbidity is also posited to be related to the number of unmet needs, and to the total number of complications brought on by the TBI that are perceived by the caregiver (Kreutzer, Gervasio, & Camplair, 1994a; Moules & Chandler, 1999; Nabors, Seacat & Rosenthal, 2002). Caring for an individual with traumatic brain injury has been posited to result in a variety of difficulties, including, but not limited to, stress, affective disturbance, depression, anxiety, psychosomatic disorders, substance abuse, financial difficulties, and poor social performance (Albert, Im, Brenner, Smith, & Waxman, 2002; Flanagan, 1998; Lefebvre & Levert, 2012; Leith, Phillips, & Sample, 2004; Murray, Maslany, & Jeffery, 2006).

Depending upon the severity and the level of impact on functioning, the person with the disability may no longer be able to fulfill the roles s/he operated within, such as husband, wife, child, and employee (Frosh et al., 1997). The loss of this person's roles in the family can result in other family members having to compensate for this absence, by taking it on themselves. In addition to balancing the addition of multiple roles, caregivers may feel "overwhelmed due to the lack of assistance by other significant others, feeling restricted socially and dealing with the reality that their pre-morbid loved one may be permanently different" (Elbaum, 2007, 275; Dell Orto & Power, 2000). Ergh, Rapport, Coleman, and Hanks (2002) reported that those caregivers who did not receive adequate social support felt increasing distress as time since the disability onset accrued. Protective personal and environmental resource factors for caregivers include functional competency, caregiving appraisal, coping, perceived social support, and family needs (Chronister, Chan, Sasson-Gelman, & Chiu, 2010).

Multiple researchers have provided evidence that family needs continue to go unmet for several years following hospital discharge (Albert, et al., 2002; Stebbins & Leung, 1998). Family needs expanded from focused acute medical and professional support during the first two years following onset to an expanded range of needs, including community supports, financial resources, caregiver supports, and health information (Kosciulek, 1995; Stebbins & Leung, 1998). Reported needs include understanding treatment, pain management, and financial resources, including insurance. Other concerns include finding and evaluating providers, hospital discharge support, employer support for the family caregivers, and life planning assistance (Lefebvre & Levert, 2012; McLennan, Starko Anderson, and Pain, 1996; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; Sinnakaruppan & Williams, 2001). Leith, et al. (2004) proposed that the family often has informational, networking, and support needs highly similar to the individual with the traumatic brain injury.

Brooks (1991) posited that the family members will be impacted equally to that of the member with the brain injury, if not more so. As it is highly likely that the family's ability to cope emotionally and practically directly impacts the person with the brain injury, research in this area is pertinent (Dausch & Saliman, 2009; Oddy & Herbert, 2003). Several predictive variables have been explored, including Kosciulek's (1994) family tension management and positive appraisal variables, affect/behavior variable (Kosciulek & Lustig, 1998), family schema and adaptation (Kosciulek, 1997b), and family type (Kosciulek, 1995).

Three coping dimensions for the families of a person with a brain injury are identified in the literature. These dimensions are individual-to-family versus family-to-community coping, family-respite versus head-injury focused coping, and cognitive versus behavioral coping (Kosciulek, 1994; Kosciulek, 1997b). A later replication and extension study identified two dimensions by which the family copes with head injury: social support versus cognitive coping, and head-injury-focused coping versus family tension management (Kosciulek, 1997b). Poor adaptation was partly attributed to a lack of long-term resources available for family members

(Kosciulek & Pichette, 1996). Often, support for the family ends when the family member with the brain injury leaves acute care and is released to the family for ongoing, home-based care, resulting in a struggle to adapt successfully to having a family member with a traumatic brain injury (Kosciulek & Pichette, 1996).

Statement and Significance of the Problem

In September 2010, my mother acquired a TBI, after collapsing and aspirating in her home where she lived alone. She spent over a month in a medically induced coma, being sustained through a variety of tubes and machines. As the doctors lowered her dosage of sedating medications and my mother began to awaken from the coma, it was immediately apparent just how markedly different her personality was in comparison to before her accident. A glazed look had become the default appearance of my mother's face. When she looked at you, it felt as though she was looking through you. Her words, if she could find any to say, were jumbled and often used inaccurately. Prior to her accident, my mother always knew what she wanted to say and had no problem saying it, to anyone. Now, driven by what can only be perceived as frustration from being trapped in a body that does not work to her liking, my mother was displaying signs of aggression and acting out violently. In the year following her TBI acquisition, my mother would scream, cry, get very frustrated, and on one occasion, she even blackened my eye and spat in my face.

My mother eventually was able to find certain words and phrases that she could use accurately. Her responses could not always be relied upon, however, because she developed a tendency of parroting, or repeating what you had said, and of providing the answer she thought you wanted to hear. Four years since the accident, my mother believes she is 21 years old and that she is still married to my father. Both are untrue. She experiences periods where she may or may not remember the names of her loved ones. While her long-term memory has been significantly impacted, her short-term memory is nearly non-existent. If I leave the room for more than 20 minutes, my mother forgets I was even there, and she welcomes me into her room as if she had not seen me in ages.

With my mother's TBI acquisition, I mourned and grieved the loss of my mother. I thought about how this woman would never be able to help me plan for a wedding or tell me what pregnancy and childbirth may be like. She would never be the grandmother that she had looked forward to being; making cookies with her grandchildren and watching them grow. As I mourned, and as friends around me experienced the death of their respective loved ones, I often heard, "You are so lucky. Your mom is still here." I was irate; she was not still here. She was the shell of who she once was and I can never ask her to tell me about my childhood or the story of how my parents met. She looked like my mother and sounded like my mother, but was not my mother. Trapped within the ambiguity of the situation, I knew that I could not be the only family member who has felt this way. Given that not every case of TBI is as significant or severe as that of my mother, and therefore will not replicate similar sentiments, for those of us who are in comparable situations, I believe that there are a number of shared themes in the experience of having a loved one with a severe TBI. It is because of my personal account and the belief that I am not alone in my experiences that this study has taken root.

Purpose of the Study

Given that family members are significantly affected by TBI, it is imperative for TBI service systems and brain injury rehabilitation programs to provide resources and support as the family members adjust to the change in personal roles within the family system, and to the new person before them. In collecting data related to the family members' experience of having a family member who has acquired a TBI later in life, it may be possible to identify similar themes across accounts. The purpose of this phenomenological study was to describe the initial experience, and what is the meaning of, the experience of having an adult family member with an acquired Traumatic Brain Injury (TBI) within the first three years. The family experience of having an adult member with a TBI was defined as those initial experiences, cognitions, and reactions that occurred within three years of the disability onset. The application of ambiguous loss theory to the experiences shared in this study was assessed. By identifying an appropriate theory, practitioners and researchers may be able to develop evidence-based practices or grief models that work successfully with the family of a person with a disability.

Research Question

Given the significant impact of TBI on the family, additional data is needed to guide state and national TBI rehabilitation service systems, specific traumatic brain injury rehabilitation programs, and individual practitioners so that they may more effectively meet family coping and adjustment needs. As such, using a qualitative, phenomenological approach, the purpose of the proposed study is to collect, summarize, and report data from the perspective of individual family members on their initial experiences of having an adult family member with an acquired TBI. The research question used to address this purpose was: How do immediate family members describe, and what is the meaning of, the experience of having an adult family member with an acquired TBI within the first three years

CHAPTER 2

LITERATURE REVIEW

Traumatic brain injury (TBI) is a disabling condition characterized by varying levels of compromised cognitive functioning, impaired memory, and inappropriate affect (Falvo, 2009). TBI can be acquired by individuals of all ages, often resulting in some degree of assisted living need or compensatory skill execution. Side effects of a TBI can produce difficulties with visual-spatial relations, perception, sensory distortions, swallowing, endurance, self-awareness, personality changes, and communication (Falvo, 2009).

TBI has been described as a “signature injury” of the recent wars and battles, with as many as 22% of military personnel returning home with a brain injury (Stein & McAllister, 2009, p. 3; Terrio et al., 2009). Unique to the military sub-population is the high co-morbidity between the TBI and mental health symptoms and issues such as post-traumatic stress disorder (PTSD), anxiety, suicidality, and substance abuse (Hoge, Auchterlonie, & Milliken, 2006; McNulty, 2005; Jacobson et al., 2008). TBI injury is not solely encountered by military personnel, however.

Traumatic brain injuries constitute approximately 1.7 million of the disabilities acquired annually (U.S. Department of Health and Human Services, 2010). Of those, about 52,000 die, 275,000 are hospitalized, and 1.365 million are treated and released from an emergency department. Most of the 1.365 million individuals living in the general public are doing so with the assistance and care of family (DePompei & Williams, 1994). It is necessary, then, to fully understand the impact of TBI on the family to better serve both family members and the individual with the TBI.

The purpose of this phenomenological study was to describe the initial experience of having an adult family member with an acquired TBI. An understanding of the nature of TBI, in addition to the overall impact of TBI on the family system was necessary prior to this study's data collection and analysis of families' initial reactions to the disability. Therefore, the literature review addresses the following areas of impact: a) the psychosocial impact of TBI on the family, b) family needs following injury, c) coping and adaptation processes executed by the family following TBI acquisition, and d) an overview of the concept of family integrated care. Information pertaining to Ambiguous Loss Theory (Boss, 1987; Boss, 1999) is presented at various stages in the literature to provide a potential theoretical basis for familial reactions.

Impact of Traumatic Brain Injury on the Family

Illustrations of personality change in the individual with a TBI include the blunting of emotions, a loss of inhibition, inflexible concrete thinking and irritability. The blunting of emotions, although having some benefits such as appearing less anxious than one may actually feel, can be detrimental to interpersonal relationships. Such a change may be perceived by others as a lack of caring or desire. Disinhibition, resulting from cognitive consequences of the TBI, is particularly troublesome for the family as it may contribute to the individual engaging in actions that may be risky or life threatening, without concern. Inflexible concrete thinking and irritability can also be difficult for family members to understand and adjust to, as it often results in the person with a TBI becoming highly agitated if demands are not met or things do not occur, as they believe they should (Oddy, 1995). Lezak (1978) proposed five areas of personality change that most likely generate conflict within the family system and between individual members: impaired social perceptiveness, impaired control and self-regulation, stimulus-bound behavior, emotional alterations, and inability to profit from experience.

As previously discussed, a majority of the 1.365 million individuals living in the general public are doing so with the assistance and care of family (DePompei & Williams, 1994), indicating that caregiver literature may have high applicability to family members of a person with a TBI. How the caregiver perceives the impact of the TBI on these areas in their loved one is reputed to regulate the degree to which the caregiver believes their loved one has changed (Oddy, 1995). Persons with traumatic brain injuries who demonstrate greater overall change are more likely to have a caregiver who feels increased burden and manifests greater mental health symptomology. Flanagan (1998) postulated that in addition to post-injury deficits and changes, the kin relationship between the caregiver and the person with the TBI, as well as the ability of the family system to cope with the crisis-imposed stresses, could determine the extent to which that family system is affected by the TBI. Furthermore, the trajectory of the illness and rehabilitation of the individual with the TBI is reported to influence the level of hope experienced and overall functioning enacted by the family system and individual members (Brooks, 1991; Duff, 2002; Knight, Devereux, & Godfrey, 1998). Other research, however, contradicts the aforementioned findings. For example, Kreutzer, et al. (1994a) postulated that neither injury severity nor functional outcome is significantly related to caregiver distress or overall family functioning.

Many researchers have provided support for the conclusion that certain sequelae and impacted characteristics are more likely to result in greater caregiver burden, overall family function, and life satisfaction. Behavioral, personality, and emotional characteristics are reported to be the most influential, with problems including childishness, lability, adynamia, irritability, and aggression being most disturbing (Brooks, et al., 1987; Kosciulek, 1995; Kreutzer, 1992; Livingston, et al., 1985; McKinlay, et al., 1981; Oddy, et al., 1978; Thomsen, 1974; Thomsen, 1984). Other research has provided insight regarding the impact of cognitive problems within the person with the TBI, and the subsequent influence on the caregiving experience. Issues pertaining to memory, concentration, problem-solving difficulties, and executive functioning are argued to have an inverse relation to caregiver life satisfaction (Ergh, et al., 2003; Kneafsey & Gawthorpe, 2004; Ponsford, Olver, Ponsford, & Nelms, 2003; Semlyen, Summers & Barnes, 1998). The repercussions of the TBI on the family system have been reported to continue to have an impact over 15 years post-injury (Frosch et al., 1997).

Psychosocial effects of traumatic brain injury on the family. Caregiver emotional distress begins upon injury onset and is exacerbated when the individual with the TBI is discharged from acute care. The exacerbation of distress is reported to occur due to uncertainty of the future, the level of anticipated necessary caregiving, overall condition prognosis, and the perceived coping ability of the caregiver (O'Callaghan, McAllister, & Wilson, 2011; Turner et al., 2007). Psychiatric morbidity is postulated by several researchers to be related to the number of unmet needs, and the total number of complications brought on by the TBI as perceived by the caregiver (Kreutzer, et al., 1994a; Moules & Chandler, 1999; Nabors, et al., 2002).

Caring for an individual with a TBI has been reported to result in a variety of difficulties, including, but not limited to stress, affective disturbance, depression, anxiety, psychosomatic disorders, substance abuse, financial difficulties, and poor social performance (Albert, et al., 2002; Flanagan, 1998; Lefebvre & Levert, 2012; Leith, et al., 2004; Murray, et al., 2006). Research postulates that between 31%-45% of relative caregivers of individuals with a TBI report clinically significant anxiety, and 21%-32% report clinically significant depression (Flanagan, 1998; Kreutzer, et al., 1994b; Perlesz, Kinsella, & Crowe, 2000; Ponsford, et al., 2003). Semlyen, et al. (1998) emphasized that in addition to depression, irritability, stress and anxiety, that:

> There also is evidence that this increased stress contributes to a relatively high incidence of physical, emotional, and psychosomatic disorders among caregivers, and several investigators have reported the frequent use of tranquilizers, sleep medication, and alcohol to help caregivers cope with the effects of the person's injury. (p. 53)

By 12 months post-injury, families begin to establish a clear picture of the situation they are faced with and an idea of what the future will look like. The daily, ongoing life of the family members and the caregiver has been forever changed (Ponsford, et al., 2003; Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989; Thomsen, 1984).

Role changes. Depending on the severity and the level of impact on functioning in the individual with the TBI, the person with the disability may no longer be able to fulfill the role s/he operated within, such as husband, wife, child, and/or employee (Frosh et al., 1997). The loss of this person's role in the family may result in other family members having to compensate for this absence by absorbing it themselves. The impact on caregivers may result in the lowering of overall life satisfaction, an increase in perceived caregiver burden, and the perception that the individual with the TBI has a greater number of behavioral consequences from the injury (Frosch et al., 1997; Kosciulek & Lustig, 1998; Man, 2002). In addition to balancing the addition of multiple roles, caregivers may feel "overwhelmed due to the lack of assistance by other significant others, feeling restricted socially and dealing with the reality that their pre-morbid loved one may be permanently different" (Elbaum, 2007, p. 275; Dell Orto & Power, 2000).

Social support. As it pertains to the psychosocial impact of having a family member with a TBI, multiple researchers have concluded that when social support needs have been met, perceived burden levels of caregivers are lowered, and the quality of life, mastery, and overall satisfaction improves (Chronister, et al., 2010; Dell Orto & Power, 2000; Elbaum, 2007; Frosch et al., 1997). Conversely, it has been reported that those caregivers who do not receive adequate social support feel increasing distress as time since disability onset accrued (Ergh et al., 2002). Protective personal and environmental resource factors for caregivers include functional competency, caregiving appraisal, coping, perceived social support, and family needs (Chronister, et al., 2010).

Ambiguity. The physical, cognitive and emotional losses following a TBI can be devastating to the family system (Muir, Rosenthal, & Diehl, 1990). Subtle changes in areas such as sense of humor, compulsive behavior, or use of manners can make the survivor with the TBI appear as a stranger in their own home (Oddy, 1995). In support of Oddy (1995), Muir, et al. (1990) reported:

> In some cases, the survivor's family members report that fundamental aspects of the survivor's personality have changes [sic], that the person they could depend on to fulfill their expectations and needs no longer exists. In other words, that the person they knew and loved is 'dead'. (p. 436)

The extensive loss of control over a situation, including ambiguity, may block the coping and grieving process of the family, often resulting in greater depression, anxiety, and family conflict symptomology (Boss, 1999; Duff, 2002). The ambiguous nature of a TBI can feed feelings of anxiety and confusion in the family, making them cautious about sharing concerns about death and loss to others outside of the experience. Such a situation hinders the family members' ability to adapt and cope with the sudden onset of the TBI in a loved one (Walsh, 2006). Consequently, "family members may be tormented, hoping for the best while fearing the worst", and developing problematic clinical symptomology (Walsh, 2006, p. 201; Boss, 1999).

The point at which an individual enters acute care for the TBI can be devastating to the family who are also present at this time. Dependent upon the severity of the injury, there may be several life sustaining technologies utilized, as well as physicians and other care team members who are instructing the family that their loved one may not survive the injury (Oddy, 1995). For many families early on in the TBI acquisition process, there are two possible outcomes: death or living. Living, however, is automatically interpreted as a full recovery from the injury and a return to the person the individual was prior to acquisition. Although this is most often not the case, it is one of the leading factors associated with the reported extended grieving processes (Oddy, 1995). The perception of the individual with a TBI as "a stranger" or as being "no longer the same person" is a common sentiment and experience shared by family members, often brought about by subtle changes in the personality of the individual with the TBI (Del Orto & Power, 2000; Oddy & Herbert, 2008).

Romano (1972) reported that personality death is far greater of a loss than physical death. With physical death, the individual is no longer present in the day-to-day world. With personality death however, as often occurs with TBI, the uncertainty of whether the person will recover and reassume their prior personality and role often leaves family members in a state of constant or extended grief (Lezak, 1978; Oddy, 1995; Oddy & Herbert, 2008). Uncertainty of recovery is postulated to be related to the "trajectory of illness and the eventual cognitive, physical, and behavioural outcomes that resulted from the injury" (Duff, 2002, p. 15). Man

(2002) reported that family reactions and pursuit toward coping with a TBI mirrors that which would be seen as a normal process by a family that is facing the death or trauma of a loved one.

Kűbler-Ross' (1969) model of grieving has previously been applied to families of people with a TBI (Elbaum, 2007; Lehr, 1990), despite the physical death associated with the original model. Application of this model has also been recently disputed, as the original model is linear. Research has hypothesized that the stages may be experienced by family members of individuals with a TBI out of order, many at once, or not at all (Degeneffe, 2001; Williams, 1993). It becomes important, then, to identify a grief model that families of individuals with a TBI work through. In doing so, clinical practitioners can begin to better serve family members during acute care, and to provide greater long-term support following discharge.

*Applicability of ambiguous loss theory***.** Ambiguous loss theory, conceptually based in family stress theory (Boss, 1987), is defined by Boss (1999) as "an incomplete and uncertain loss" (p. 3). According to this theory, loss can occur in two different ways: The family member can be physically present but psychologically absent, or physically absent and psychologically present. Without resolve, families may find that the loss could very likely control daily events, in addition to shaping the long-term experience of every member within the family. Boss (2006) concluded that ambiguous loss is the "most stressful kind of loss because it defies resolutions and creates long-term confusion about who is in or out of a particular couple or family" (p. xvii). Three of the seven assumptions that are presented by Boss (2007) are that ambiguous loss theory assumes that a) a psychological family exists, and that this perceived construction of one's family may differ from the physical or legal family structure; b) with situations of ambiguous loss, truth is unattainable and thus relative; and c) there is a natural resiliency in families.

At the core of ambiguous loss theory, the family system finds itself compromised. Due to the decline in functioning of the particular member, others are required to work hard in roles where they might not feel as competent, resulting in the confusion of family dynamics, roles, and responsibilities (Von Suhr, 2003). The impact that ambiguous loss has perseverates throughout every aspect of a family member's life: physical, cognitive, behavioral, and emotional (Boss, 1999; Weiner, 1999). Physical symptoms include fatigue, headaches, and sleep disruption, while cognitive issues manifest as an ongoing preoccupation with the loss and its surrounding circumstance, forgetfulness, and worry. Behavioral impacts include persistently remaining quiet, hypervigilance, dependence, avoidance, and overall withdrawal from daily activities. Lastly, emotional complications from ambiguous loss include loneliness, anger, irritability, anxiety, depression, or apathy (Betz & Thorngren, 2006; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Boss, 1999; Boss, 2002; Weiner, 1999).

Betz and Thorngren (2006) acknowledged that this phenomenon might result in family members going through cycles of hope and disappointment, stating, "The unpredictable nature of an uncertain future leaves family members in a reactive position. The family may feel tremendous guilt and may be unable to make decisions, fearing that the wrong choice will be made" (p. 361). Ambiguous loss is characterized by factors that inherently impede the grieving processes due to intangible or uncertain resolution to the loss, and freeze family dynamics until a clarity, which never comes, is attained (Betz & Thorngren, 2006; Boss, 1999; Boss, 2002; Boss, 2004). The concept of being frozen in grief can lead to the manifestation of “prolonged, pathological grief states” in family members (Von Suhr, 2003, p. 49). Other key facets of ambiguous loss include the cyclical raising of hopes and subsequent disappointment, which may lead to a psychically numb state, a withdrawal from social support systems, and family member exhaustion, with support burnout due to the ongoing nature of the loss (Harris & Gorman, 2011).

Brain injuries may result in cognitive and physical impairments in addition to a disruption in self-image and interpersonal relationships. Research on populations who have a TBI, have shown that boundary ambiguity develops as a result of such disruptions (Landau & Hissett, 2008). Kean (2010) reported that when speaking to family members of individuals who have a TBI, most utilize the past tense when discussing their loved ones. It is believed that as the families try to adjust to life with a family member who has a TBI, their "use of the past tense without it ever being consciously acknowledged as loss at that time" emerges (Kean, 2010, p. 70).

Previous applications of ambiguous loss theory to persons with a disability have reported significant support for its use. Patrick-Ott and Ladd (2010) reported the presence of the ambiguous loss phenomena when studying parents of children who had been born with a disability, stating that "feelings of loss and disappointment are revisited throughout the child's life span as the child grows, matures, and yet is unable to master age-appropriate developmental milestones or experiences" (p. 76). Many disabilities are difficult to diagnose, and those that are diagnosed often have no cure, leaving the disability and the individuals involved with a high level of ambiguity. In fact, it has been reported that "the deluge of ambiguity often becomes as debilitating as the illness itself. Innumerable diagnostic tests meant to clarify one's prognosis make people feel as though they're riding an emotional roller coaster between hope and hopelessness" (Boss & Couden, 2002, p. 1352).

As applied to family members of those who have Alzheimer’s or Dementia, the changes from being characteristically “normal” functioning towards deeper progression into the condition results in feelings of frustration and distress (Blieszner et al., 2007; Boss, 2004; Boss & Kaplan, 2003). What is often observed in adult children of individuals with these two disabilities is a fluctuation between accepting and rejecting the caregiving role, primarily due to the confusion surrounding new responsibilities and roles within the family construct. According to ambiguous loss theory, this confusion can result in frozen grief and, subsequently, “behavioral and psychological helplessness” (Boss, 2004, p. 211). It is important to note, however, that these postulations and findings may vary by cultural and societal standards. In a preliminary study conducted by Boss (2004) with Ojibway Indian women who were caring for a family elder, negative descriptors were seldom used in regard to the elder’s dementia. The Native women objected to the words such as “burden” or “stressful”, instead viewing the situation as part of the circle of life.

Ambiguous loss theory is particularly well suited for application to the familial response to a TBI within the family unit, due to the unique and irreconcilable nature of the condition. As has been seen with TBI and ambiguous loss theory respectively, the ambiguity surrounding the given situation’s loss may interfere with adaptation, and can produce depression and conflict (Betz & Thorngren, 2006; Blieszner, et al., 2007; Boss, 1999; Boss, 2002; Weiner, 1999). Despite many parallels that have been drawn between this theory and the condition of TBI, this particular pairing of the two has gone practically unstudied. Rather, the literature has focused more on other conditions with a compromised cognitive component such as Alzheimer's and Dementia.

High levels of distress in the families of individuals with a TBI have been present as far as 15 years post injury, due in part to an inability to reconcile grief (Florian & Katz, 1991; Koskinen, 1998). Family members may find themselves beleaguered, hoping for the best (complete recovery) while fearing the worst (death) (Walsh, 2006). As with ambiguous loss theory and TBI, independently, the ability to meet societal criteria for grief appropriateness is often not achieved. Such a situation leaves family and friends of the person who has acquired the TBI in a constant state of grief, compounded by forced isolation brought about by society implying that their grief is not warranted (Del Orto & Power, 2000; Harvey, 2000; Harvey, 2002; Kozloff, 1987; Oddy & Herbert, 2008; Sacks, 1970; Walsh, 2006). Furthermore, levels of expressed emotion have been reported to remain contingent on the caregivers' perceptions of social support, and the degree to which the burden of caring can be shared with others (Flanagan, 1998). Boss (1999) stated that:

> Ambiguous loss can cause personal family problems, not because of flaws in the psyches of those experiencing the loss, but because of situations beyond their control or outside constraints that block the coping and grieving process…the greater the ambiguity surrounding one's loss, the more difficult it is to master it and the greater one's depression, anxiety, and family conflict. (p. 7)

Groups available for spouses and family members of individuals with a TBI can provide ongoing support to those individuals who society may casually label as too quick to grieve. In acknowledging the profound effect that a TBI can have on the family system and on the individual who acquired it, support groups validate the emotions and extended grief that is often associated with this injury (Harvey, 2000).

Different caregiver relationships. Due to the frequently changing friendship dichotomies following a TBI, most often the immediate family becomes the primary and sole resource for the person with the TBI (Muir, et al., 1990). Degeneffe (2001) posits that family members often provide care for loved ones with a TBI out of obligation and necessity rather than voluntary choice. The sense of duty or commitment that reportedly exists within the confines of a kindred relationship can serve as a predictor for increased depressive symptomology (Kreutzer, et al., 1994a). Despite research postulating that the caregiver of male individuals with a TBI will experience greater negative burden (Knight, et al., 1998), conflicting studies report that families of females with TBI are associated with greater family distress (Gan, Campbell, Gemeinhardt, & McFadden, 2006).

Research has further proposed that needs vary depending upon the role that each family member assumes within the family system. Parents of the individual with the TBI are more likely to endorse greater met needs when the individual is perceived to have more physical problems, whereas spouses are less likely to endorse met needs when physical problems are perceived (Devany Serio, Kreutzer, & Gervasio, 1995). More specifically, spouses are especially impacted by behavior and cognition problems of the individual with the TBI (Devany Serio, et al., 1995).Family members' perception of the loved one's neurobehavioral status has been reported as a good predictor of family needs.

Several studies have examined the differences and similarities between caring for a spouse and caring for a child with a TBI. Spouses of individuals with a TBI have been reported to show significantly greater symptomology of depression, anxiety, and psychoticism (Kreutzer, et al., 1994b). Perlesz, Kinsella, and Crowe (1999) conclude that:

> A number of variables have been found to have a significant impact on marital strain or spouse distress: financial hardship, severity of injury, psychosocial maladjustment of the patient; restrictiveness in the day to day physical functioning of the patient; the person with TBI being a father of young children, lack of support in physically caring for an injured spouse, loss of a peer based, supportive relationship, less marital cohesion and increased marital conflict, and role changes. (p. 20)

Overall, a majority of the literature is in agreement that spouses, specifically wives of individuals with a TBI, are more significantly impacted by the TBI in a spouse than mothers who care for children with a TBI (Lezak, 1978; Lezak, 1988; Livingston, et al., 1985). Despite wives showing significantly greater levels of anger and less satisfaction with family life, parents of individuals with a TBI expressed significantly more pessimism and concern for the future of their children (Knight, et al., 1998; Perlesz, et al., 2000).

Being a sibling to a person with a TBI also lends to the cultivation of negative symptomology and feelings of burden. Whether adult or under the legal age of 18, most siblings hold highly pessimistic views on the attainability of successful rehabilitation for their brother or sister (Degeneffe & Olney, 2008). Cynical views on their sibling's potential reportedly results in a significant level of anxiety and distress. Understandably, siblings of individuals with a TBI tend to perceive their families as functioning at a significantly lower level than those siblings of individuals without a TBI (Gan, et al., 2006). Most sibling literature, however, concludes that the needs of, and impact on, siblings mirror that which have been reported for other family caregivers such as those discussed above (Degeneffe & Olney, 2008).

Due to the level of dependence that a child has on their parents, the impact on children of a person with a TBI is profound. Urbach and Culbert (1991) posit that sequelae that are most problematic include "memory loss, confusion, cognitive impairment…behavioral disturbance and personality change" (p. 31). Children may feel as though they have lost a person they considered a role model and look to the other parent, or a surrogate if the parent is unavailable, to assume some of the injured parent's role in their life (Urbach & Culbert, 1991). Socially, the child may develop argumentativeness, anger, or a passive-aggressive demeanor (Pessar, et al., 1993; Urbach & Culbert, 1991). Pessar et al. (1993) postulate that the age of the child at time of TBI onset aids in determining the extent to which the child my experience struggles with the parent who has the TBI. Such difficulties may include displays of "being less loving toward the injured parent, not wanting to spend time with the injured parent and not bringing friends home" (Pessar, et al., 1993, p. 238).

Several other factors have been researched that pertain to the impact of TBI on caregiver burden and overall caregiver quality of life. Those with lower number of years of education and, subsequently, those caregivers with lower household incomes are postulated to have an increased perception of caregiver burden related to the cognitive, affective, and behavioral impairment of the person with the TBI (Nabors, et al., 2002, 1046). Age of the caregiver is also asserted to be a mitigating factor on caregiver satisfaction and burden. That is, younger caregivers, report fewer needs that they feel have been met (Mitchley, Gray & Pentland, 1996; Moore, Stambrook, Peters, & Lubusko, 1991; Nabors, et al., 2002).

Multicultural implications. Investigation into the multicultural impact on caregiving for individuals with a TBI has been scarce in the literature. Initial research in this area, conducted by Sander et al. (2007), reported that caregivers who are either Black or Hispanic have reported lower income, lower education attainment, as well as caring for an extended family member when compared to White, non-Hispanic caregivers. Furthermore, Black and Hispanic caregivers are more likely to report subscribing to traditional caregiver ideology such as family and cultural traditions. Such engagement has been postulated to have greater association with the development of distressful symptomology due, possibly, to the adoption of added responsibilities (Nabor, et al., 2002; Sander et al., 2007). The reported relationship does not hold true for White, non-Hispanic caregivers. Lastly, non-White caregivers utilize emotion-focused coping skills at a greater rate than White, non-Hispanic caregivers do. Despite this difference in utilization, the two groups do not differ on measures of emotional distress (Sander, et al., 2007).

Positive consequences. Although most symptomology or sequelae following TBI are considered negative, Wells, Dywan, and Dumas (2005) hypothesized that the act of caregiving and the adoption of the caregiving role may result in a surge of positive feelings within the caregiver. This finding is attributed to the possibility that “families feel good about being able to provide care to their injured family members despite the added stresses associated with caregiving” (p. 1113). It is hypothesized that feelings of satisfaction occur independently of those feelings of dissatisfaction or challenge that may also arise. Perlesz, et al. (2000) report that between 51%-80% of primary carers perceive family satisfaction with no associated feelings of psychological distress. A TBI may result in positive changes, which leave the family system more satisfied, such as with perceived positive personality change (Adams, 1996; Fahy, Irving, & Millac, 1967).

Family needs following traumatic brain injury. Bond, Draeger, Mandleco, and Donnelly (2003) concluded that the family has needs within four areas while their family member is engaged in in-patient care: the need to know, the need for consistent information, the need for involvement in care, and the need to make sense of the experience. The need to know specifically refers to the readily available access that the family has to medical staff and the degree to which they believe the staff are being truthful in what answers they provide (Lefebvre & Levert, 2012). Due to the many different medical professionals that the family may meet during an in-patient stay, the information they receive may vary by person. Therefore, there is a strong desire for consistent information pertaining to their family member with the head injury. A strong desire has also been expressed by families to be involved in their loved one's care. Not only can the family attest to changes in the loved one, but they can also assist with care to lessen the burden on orderlies and nurses. Lastly, the experience of a TBI in a loved one can arouse significant emotional distress. The aforementioned themes compound this distress while the family attempts to make sense of the situation that they are as a result of the injury. In responding to the needs surrounding information delivery, practitioners should seek to reduce emotional distress.

The literature has provided evidence that family needs continue to go unmet for several years following hospital discharge (Albert, et al., 2002; Stebbins & Leung, 1998). Family needs expand from focused acute medical and professional supports during the first two years, to a vast range of needs that includes community supports, financial resources, caregiver supports, and health information (Kosciulek, 1995; Stebbins & Leung, 1998). McLennan, et al. (1996) reported that families' largest need is for information concerning understanding the treatment, drugs administered, and pain management both while the member with the TBI is in the hospital and once they are discharged. While the family member is being treated in-patient, families express a high concern with financial resources, including insurance. These learning needs and financial concerns continue to be expressed six or more weeks following hospital discharge (McLennan, et al., 1996; Murray, et al., 2006). Other reported needs include finding and evaluating providers, hospital discharge support, employer support for the family caregiver, and life planning assistance (Lefebvre & Levert, 2012; Rotondi, et al., 2007; Sinnakaruppan & Williams, 2001).

Attention to the needs of the family is crucial for family development, coping, and adaptation. It has been proposed that the family often has informational, networking, and support needs highly similar to the individual with the TBI (Leith, et al., 2004). Focus is traditionally on the individual with the injury, often leaving family members to perceive significantly unmet needs, both during and following hospital treatment. Sinnakaruppan and Williams (2001) postulated that this position often results in family members perceiving a lower overall quality of life and greater psychiatric morbidity.

Family coping and adaptation to traumatic brain injury. It has been reported that over half of all family carers exhibit high levels of strain associated with caring for a family member with a TBI (Mitchley, et al., 1996). As previously discussed, having a person who has a TBI in the family can affect the family system emotionally, socially, and financially. As it is highly likely that the family's ability to cope emotionally and practically to the individual with the head injury directly impacts the brain-injured person, research in this area is pertinent (Dausch & Saliman, 2009; Oddy & Herbert, 2003).

Oddy and Herbert (2008) reported that not only do family members become increasingly socially isolated following TBI onset, but also that individual member response can vary based upon gender as well as the particular role they serve in the family system. Purportedly male caregivers tend to appear more emotionally detached and often take on the position of advocating and organizing services rather than be directly involved with day-to-day care. Previous research has also concluded that male caregivers are more likely to report their distress in terms of anger and fatigue, and they experience these emotions more so when caring for a female member with a TBI (Gervasio & Kreutzer, 1997; Perlesz, et al., 1999). As it pertains to roles played within the system, parents of the person with the TBI tend to worry greatly about what will happen to the adult child when they are no longer able to care for him/her (Knight, et al., 1998), whereas spouses or partners are more concerned with the change in role from equal partner to parent (Gosling & Oddy, 1999). Drastic change in roles contributes in part to the high divorce rate for couples that include a person with a TBI, which reportedly range from 30% (Stilwell, Hawley, & Stilwell, 1997) to 50% (Wood & Yurdakul, 1997), and increase with the time since injury (Oddy & Herbert, 2008).

Families use several successful coping and adaptation methods. Kosciulek (1994) identified two predictive variables of family adaptation to head injury: family tension management and positive appraisal. Family tension management refers to the ability of the family to identify when there is building pressure as a result of the newfound roles, and to react appropriately. Examples of appropriate reactions include taking time for oneself away from the person with the TBI and openly expressing one’s feelings. Positive appraisal involves the family redefining stressful events related to the member with TBI as manageable. In doing so, the family is less likely to catastrophize the situation, and is more likely to successfully adapt to their new way of life (Kosciulek, 1997b; Kosciulek, McCubbin, & McCubbin, 1993). Later, the variable of affect/behavior was identified as a predictor of family adaptation in that “the accumulation of demands on a family system resulting from the brain injured member’s affective and behavioral functioning, or family stress, was related to general family system functioning, or family adaptation” (Kosciulek & Lustig, 1998, p. 11). Families found to be balanced across scales of cohesion and adaptability are reported to exhibit greater overall functioning and more positive communication skills than those families who are identified as an extreme type (Kosciulek, 1996).

Family functioning prior to the onset of TBI aids in the identification of certain qualities of the family baseline interactions and functioning, which have been reported to be predictors of adaptation (DePompei & Williams, 1994; Elbaum, 2007; Kosciulek, 1997b). Kosciulek (1997b) postulated the existence of a relationship between family schema and family adaptation. Family schema refers to the family’s set of beliefs, goals, priorities, values, and expectations in relationship to each member and the greater society. Similar to the positive appraisal variable discussed above (Kosciulek, 1994), if a family does not value ideologies such as connectedness and the value of a human being with a disability, they are less likely to adapt positively to the presenting situation.

Family types have also been researched as this reportedly aids in the explanation of family functioning in lieu of stressful life events. Kosciulek (1995) reported that there are five family types relevant to TBI: unpatterned, fragile, pliant, regenerative, and vulnerable. The unpatterned family type places little emphasis on family interaction and may appear unconnected. Furthermore, this type is also characterized by highly independent family members, erratic discipline patterns and a low level of familial loyalty. Fragile families also lack familial loyalty and closeness, and are further characterized by poor communication and are resistant to compromise or change. It is reported that this type may experience most, if not all, of the difficulties associated with having a family member with a TBI. The pliant family type functions generally well, with the exception of communication difficulties. Such difficulties include providing double messages and conveying criticism, subsequently influencing the family's ability to adapt and to be viewed as a team. Regenerative family types appear to function effectively to the chronic stress produced from having a member with a TBI. Coping skills utilized by this type may include cultivating trust and maintaining calm in the wake of adversity, subsequently leading to a sense of unity. Lastly, vulnerable families display a considerable amount of conflict stemming from poor information exchange, strong emotional response to the injury and stress produced by it within the family, and task assignment problems. Vulnerable families have been suggested to utilize negative coping skills such as blaming others, and getting outwardly upset (McCubbin & McCubbin, 1989).

Three coping dimensions for families of an individual with a TBI are identified in the literature. The dimensions are individual-to-family versus family-to-community coping, family-respite versus head-injury focused coping, and cognitive versus behavioral coping (Kosciulek, 1994; Kosciulek, 1997b). The first dimension pertains to the ability of the family to move beyond the family system and access the resources available in the community. The second dimension speaks to the ability of family members to care for himself or herself throughout the process of caring for the individual with the brain injury. The cognitive versus behavioral coping dimension refers to the family members' ability not only to reframe the injury, but also to engage in behaviors that reflect this reframe.

A later replication and extension study identified two dimensions by which the family copes with head injury: social support versus cognitive coping, and head-injury-focused coping versus family tension management (Kosciulek, 1997b). Collective data from the two studies promote the idea that families use a variety of coping strategies when addressing issues surrounding the member with a TBI. Through this suite of research, coping strategies have been posited to vary, depending on the region in which they are learned and executed.

Poor adaptation can partly be attributed to a lack of long-term resources available for family members (Kosciulek & Pichette, 1996). Often, support for the family ends when the person with the TBI leaves acute care and is released to the family for ongoing, home-based care, resulting in a struggle to successfully adapt to this change in the family system (Kosciulek & Pichette, 1996). Maladaptive responses, including rumination and negative self-re-evaluation, are also prevalent with family members of a person with a TBI (Mitchley, et al., 1996).

The relationships that the family has with the rest of the care team can directly influence the adaptation process (Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005). As discussed earlier, many traditionally trained medical professionals have not had the experience or the preparation for working collaboratively with the family. There is a strong argument found within the literature, however, that emphasizes the need to see past convention and to adapt to the processes which best serve the patient and the family. Not only can this change in approach produce greater rehabilitation outcomes for the patient, but research has reported that it also provides the family with the resources to “find solutions for managing their issues of concern” aiding in the overall adaptation process (Sohlberg, et al., 2001, p. 505).

Family integrated care. Research has reported that the acknowledgement of support system involvement is not the only step necessary for a successful partnership between the familial support system and practitioners. Redpath et al. (2010) stated that the way in which the individual acquired the TBI could result in prejudicial attitudes and stigma from practitioners. That is, if practitioners believe the individual to have had a role in the acquisition of their TBI, whether through risky behaviors or alcohol or other drug use, they are more likely to express negative attitudes. The authors further explain this by also identifying a negative correlation between helping behaviors and prejudicial attitudes; as prejudicial attitudes increase, practitioners are less likely to have helpful intentions toward that individual. Although these findings vary based on profession and number of years in the profession, they evoke concern when seeking universal quality care for all persons who acquire a TBI.

These prejudicial attitudes also play a role when it comes to the time needed for practitioners to engage in rehabilitation referral decision making. Foster, Tilse, & Fleming (2004) reported that practitioners consider both clinical and non-clinical factors concurrently when engaging in the process of decision-making. Of note specifically are functional status, age, and family involvement. Most clinicians report physical and cognitive functioning as the primary consideration when deciding upon post-acute referral; however, the age at acquisition also factors into what recommendation is provided. The older the individual was when they acquired their TBI, the less likely they are to be referred to post-acute rehabilitation services. Clinicians cited co-morbidities, less chance of spontaneous rehabilitation, and lowered resiliency as reasons for this trend (Foster, et al., 2004). The presence and ability of family members to serve as caregivers and advocates also impact the decision making process, with many clinicians being more apt to release their patients into family care if they feel they are willing and that the burden of this care will not be too cumbersome.

Collaborative partnerships between practitioners and family members have recently emerged in the literature as the direction in which palliative care should continue to develop a foundation. Involving the family in treatment planning and the provision process has been reported to have a significant impact on the rehabilitation process; hospital stays are shortened, the client's level of comfort is maximized, and the chance of relapse is reduced (Horwitz, Horwitz, Orsini, Antoine, & Hill, 1998; Lawlor & Mattingly, 1998). The inclusion of family members in the care team provides an advocate for the client, in addition to individuals who can speak to the client's biopsychosocial history, preferences, habits, and other pertinent information to the treatment planning process, and, as caregivers, an active partner in care provision. The inclusion of family in the care team has further been reported to enhance the comfort of the person with the TBI, as well as reduce stress and worry, due to the family being more supportive and satisfied with the care the client is receiving (Horwitz, et al., 1998). Groswasser (1995) postulated that without family involvement, it is near impossible to rehabilitate those individuals with a severe TBI.

Previous models for collaborative care were identified in two distinct studies. A social work liaison program was proposed by Albert, et al. (2002), where increased access to information and referral resources, as well as counseling, specifically for family members who care for an individual with a TBI, were made available via telephone contact with social workers,. Resources were made available to family members at and following discharge from acute hospital care. Results were promising, indicating that caregivers who received these services were more likely to report significantly less burden and greater satisfaction and mastery with caregiving tasks.

Moore Sohlberg et al. (2001) also proposed a preliminary model for collaborative care, which includes three overlapping phases: the initial interview, goal selection, and the monitoring of change. In the first phase, practitioners are encouraged to learn about the family and to become familiar with their unique situation. The research in this phase underscores the importance of strong interpersonal communication skills, and how these skills are necessary for success in the following two phases as well. In the goal selection phase, families are empowered to discuss issues, strengths, and observations that they have encountered and how family life has been affected by the injury. The practitioners then utilize these reports and the family members as experts on the person with the TBI, in collaboration with their professional knowledge, to generate options regarding which areas to target in the rehabilitative care process. The final stage, monitoring change, is characterized by utilizing the family and the person with the TBI to implement any strategies developed in the previous stage and to monitor any changes, struggles or successes that occur as a result of the strategy implementation. Weekly meetings with the care team are recommended to evaluate the progress made and to develop new strategies if necessary.

In order to address concerns related to caregiver burden, such as lack of educational opportunities, DePompei and Williams (1994) reported that families need to be uncompromisingly accepted on the care team, and to be provided with meaningful interactions while on that team. As team members, families can serve in several capacities: information providers, active participants, advocates, expert communication partners, and vision developers. Active involvement in the case management process throughout the life cycle also aids in the minimization of poor adaptation to caring for an individual with a TBI. It is important that the medical staff have an “understanding of why family members react as they do and of the possibility and causes of friction between staff and families” to inform behaviors and actions they may take which could jeopardize the partnership (Oddy & Herbert, 2008, p. 443). Further, due to institutional environment and the traditional manner in which practice is informed, it is important that both medical professionals and family members realize that this collaboration will be difficult at first to formulate, and that they may need to adjust the ways in which they proceed with family integrated care (Lawlor & Mattingly, 1998; Sohlberg, McLaughlin, Todis, Larsen, & Glang, 2001). In order to successfully make this adjustment, a redefinition of practice may need to be developed and implemented.

With post-acute care needs not being met by community resources, it becomes ever important to utilize the individual’s support system, often comprised of family members, friends, and/or other loved ones. These resources often serve as direct service providers, evaluators, and caregivers; however, these functions continue to go under or unutilized by practitioners. Turner et al. (2007) concluded that the family plays a significant role in the transition process of individuals with TBI from the hospital back into the home and general community. Acknowledging the rehabilitation literature, which strongly supports the integration of family and/or support system involvement into the rehabilitation process of individuals with a TBI, it is then imperative to analyze how such an injury can affect the family unit and possibly mediate later involvement.

CHAPTER 3

METHOD

Research Design

The purpose of this study was to collect, summarize, and report data from the perspective of individual family members regarding their experiences of having an adult family member with an acquired TBI, within three years of acquisition. The following research question was developed and applied to address this purpose: How do immediate family members describe, and what is the meaning of, the experience of having an adult family member with an acquired TBI within the first three years? This question was addressed using a phenomenological qualitative design that consisted of interviews, field notes, and informally collected demographic information. The underlying theme of phenomenology is people making meaning of their experiences; this meaning is contained within their stories (Moustakas, 1994). The aim of the interview was to bring out the individual and shared meanings by having family members share their personal experiences following their family member's TBI acquisition. This methodology was chosen because the research question sought to identify the meaning that was derived from each individual experience.

According to Creswell (2013), phenomenological research "describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon" (p. 76). Creswell further described phenomenological research as capturing "what all participants have in common as they experience a phenomenon….to reduce individual experiences with a phenomenon to a description of the universal essence" (p. 76). Given the significant impact of TBI on a family, additional data are needed to guide state and national TBI rehabilitation service systems, specific traumatic brain injury rehabilitation programs, and individual practitioners, so that they may more effectively meet family coping and adjustment needs.

Participants. The experience of interest in this study was that of having an adult family member acquire a Traumatic Brain Injury (TBI). Due to the exploration of experience, a phenomenological approach was used. The literature in phenomenological methodology cites 7-8 as the optimal number of participants in a study (Moustakas, 1994; van Manen, 1990), although sample sizes have ranged from one (Dukes, 1984) to 325 (Polkinghorne, 1989) in previous research. Phenomenological research involves studying a small number of participants through extensive and prolonged engagement, in order to identify patterns and relationships of meaning (Creswell, 2013; Moustakas, 1994). Given the depth of the interviews, a large amount of data may be collected without need for a larger number of people to be involved, if the participants talk at length about their experiences. This study sought to capture the essence of what family members experienced within three years of another immediate family acquiring a TBI through the interviews of six individuals.

Six participants, representing four families, were recruited from a mid-Michigan brain injury rehabilitation facility. Two mother/daughter dyads were included in the within the total number of six family members. Criterion sampling was used to ensure that all participants have experienced the phenomenon being studied (Creswell, 2013). Criteria for participant inclusion in this study included: (a) the individual had an immediate, adult, family member who recently (within 3 years) experienced a TBI; (b) the individual was at least 18 years of age at the time of the study; and (c) the individual had routine contact with the family member who has a TBI, both prior to and following acquisition. A 3-year inclusion window was applied in an attempt to control for the development of coping mechanisms and the influence of counseling on the raw emotion of the experience. For the purpose of this study, the definition of acquired brain injury used in Gan et al. (2006) was applied:

> a) damage to the brain which occurs after birth and is not related to: i) a congenital disorder, ii) a developmental disability, or iii) a process which progressively damages the brain (i.e. Pick's disease, Alzheimer's disease, multiple sclerosis); and
>
> b) the damage may be caused: i) traumatically (i.e. motor vehicle collision, fall, assault, sports injury) or ii) through a medical problem or disease process which causes damage to the brain (i.e. anoxia, aneurysm and vascular malformations, brain tumours, encephalitis, meningitis, stroke with cognitive disabilities). (p. 589)

Lastly, the adapted Romano (1989) definition of family states that "…ties of kinship (i.e. parent, children, extended family of origin); marriage (i.e. spouse, ex-spouse, family of procreation)" (as cited in Brooks, 1991, p. 156) was utilized to identify family members. Let it be noted that the present study left out Romano's (1989) partial definition of family, which included "sustained intimacy (i.e. close friends, lovers, and so forth)" (as cited in Brooks, 1991, p. 156).

Procedure. The present study required approval by the administration of the Michigan State University Social, Behavioral, and Education Institutional Review Board (SIRB). Following approval, the researcher reached out to a mid-Michigan brain injury rehabilitation facility. The researcher, having previously gained permission to advertise in the facility, proceeded with advertising and presented the study twice to a support group ran by the facility. A local chapter of the Brain Injury Association (BIA) also allowed the researcher to present the study and recruit for participants at a support group meeting. While attending the support group meetings, the primary investigator provided a brief presentation of the study and explanation related to study procedures and objectives, in addition to sharing her personal experience of having a family member with a TBI. She answered questions pertaining to the study, provided contact information, and discussed concerns. Copies of the *Research Participant Information and Consent Form* (Appendix A) and a copy of one or more of three different recruitment flyers were provided to individuals for their information. The researcher asked that those participants who were interested either sign up for the study prior to leaving the meeting or contacted her via the information located on the recruitment flyers or *Information and Consent Form*.

Once participants were identified, the researcher arranged to hold the interviews in appropriate environments where the individual participant felt encouraged to share their personal story. An appropriate location was determined based on proximity of the setting to the participant, how comfortable each participant felt in a location, noise and other distractions of the surrounding environment, and level of privacy and ability to keep confidentiality within the environment. Appropriate meeting locations included a conference room at the mid-Michigan brain injury rehabilitation facility and a meeting room on the campus of where one participant went to school. Two interviews were held by phone due to distance being an issue and the inability to coordinate schedules. Upon beginning in-person interviews, the researcher discussed the informed consent procedure with the participants, by verbally describing the purpose of the study, participant rights, and confidentiality. The researcher clarified that the recounting of this experience has the potential to evoke strong emotions and may be uncomfortable, and that resources are available should the participant wish to seek counseling. The researcher then explained that the conversations would be confidential within normal limits, and that any reference of intent to self-harm or abuse/neglect of the adult in care would be reported in accordance to the law. The *Research Participant Information and Consent Form* (Appendix A) was given to the participant for them to read. A copy of the information form was provided to all in-person interview participants. Upon the participant's understanding and consenting to participate, the researcher began the interview. For phone interviews, *Research Participant Information and Consent Form* (Appendix A) was read verbatim to the individual and subsequently mailed via post mail for their records.

In-depth interviews were held with each participant at the arranged time, date, and location. Each interview lasted between 40-60 minutes, dependent on the participant. The purpose of each interview was to (1) ensure the participant meets the study's inclusion criteria, (2) explain informed consent, (3) establish rapport, (4) gather information regarding each individual experience, and (5) provide a small gift card for a local grocery store as incentive for their participation. All interviews were audiotape recorded. In addition, a field log was kept and written by the researcher throughout the data gathering process, in order to document key phrases that each participant said. The field log was also used to provide a detailed account of the researcher's observations, thoughts, feelings, experiences, and perceptions throughout the research process, for later use in the analysis phase. Following each interview, the investigator listened to each recording. The recordings were then labeled with an assigned pseudonym and transcribed using Dragon Naturally Speaking Premium Edition (Version 12) [Computer Software]. Following the initial transcription, the researcher read through the documents with the recordings to ensure that there were no errors. These documents were then printed, catalogued, and analyzed. Transcriptions were read multiple times, both alone and with the corresponding field notes for each interview.

Pre-understandings were identified in the first phase of analysis. Laverty (2003) states that "pre-understanding is the meanings or organization of a culture that are present before we understand and become part of our historicality of background", or background in the world (p. 8). The researcher identified passages, words, and emotions from each interview that connected with her own pre-understandings. This included the emotional overtone of the piece as well as the choice of wording. Themes, the broader concepts that were represented in the account, were then developed from each interview. Finally, a bounding was derived from the themes and put into a single concept so that the personal account was presented accurately in its entirety.

The audio recordings, printed documents, and field notes will be retained for a minimum of three years. This data has been stored in a secured and locked location in the office of the researcher. Any information entered into a computer has been secured through password identification, Norton Anti-Virus and Windows firewall protection. Only the principal investigator, Dr. John Kosciulek, and researcher Erica Wondolowski has access to the data.

Instrumentation

Data for this research has been generated through a single interview for each of the six participants. Each interview used one primary prompt and was conversational in nature (Creswell, 2013; Glesne, 2011). The *Interview Prompt* (Appendix B) was used to maintain consistency across interviews. Sub-questions or probes were used to uncover assumptions and to make explicit what the person speaking may have left implicit, as well as to elicit in-depth narrative descriptions about the participants' experience(s) (Rossman & Rallis, 1998).

Interview guide. The *Interview Prompt* (Appendix B) was developed based on the theoretical framework of the proposed study. Attention was paid to non-verbal cues, including descriptions of facial expressions, posture, gestures, behaviors, and tones of voice, expressions, and behaviors with symbolic meaning, as well as the researcher's own feelings during the interviews. In having family members tell their stories, they were able to state what is meaningful to them, and develop rich descriptions of those events. The content and structure of the *Interview Prompt* (Appendix B) was developed from a variety of sources, including:

1. The empirical and conceptual TBI, family involvement, and Ambiguous Loss Theory literature.
2. Qualitative literature pertaining to the development of phenomenological studies.
3. The investigator's personal experience with an adult family member with a TBI.
4. Review and input by rehabilitation, family and qualitative experts.

Participants were not given a copy of the *Interview Prompt* (Appendix B); however, a copy was placed between the researcher and the participant during in-person interviews in the event that they needed to read the question as it is written. The researcher used the following prompt to establish consistency between the interviews and focus participants on the experience as it was lived: "Can you describe to me what your initial thoughts, experiences and reactions were when you first began to see the impact the Traumatic Brain Injury (TBI) had on your family member?" The prompt was posed to all participants, although individual responses determined the use for further, more pointed, lines of questioning.

Bracketing, validity and reliability. Data was collected and analyzed from conversational interviews that focused on the experience of having a family member who acquired a TBI. For the analysis of this study, both a phenomenological and an open-coding theory were used. Open coding was important for identifying similar themes within the data, and for confirming or challenging ambiguous loss theory as it applies to the acquisition of TBI within the family system (Corbin & Strauss, 1990). Audio recordings were transcribed and validated by the researcher. This process consisted of reading the transcriptions while listening to the audio recordings, to ensure accurate transcription. Any corrections were made at that time.

Analysis of the transcripts implemented a modification of the methods developed by Moustakas (1994). The researcher began by describing her own experience of the phenomenon as a way to bracket her personal experiences and allow focus to then be directed to those of each participant. The researcher then analyzed each account for passages, words, and emotions from each interview that connected with her own pre-understandings both with and without the corresponding field notes. The field log provided an opportunity to survey for applicable nonverbal communication and emotions elicited during the interviews. The researcher continued analyzing the transcripts until such time when a list of non-repetitive, non-overlapping statements had been generated. Key concepts expressed by participants in various different symbolic forms were made into themes. Each theme was compared to other identified themes, within and across interviews, to investigate similarities, differences, and general patterns. The compiled themes were then bounded in order to represent the cumulative experiences of the family members. It was the aim of the researcher to allow for pre-understandings, themes, and boundings of the data to emerge through analysis, rather than creating them prior to data collection.

Giorgi (1988) encouraged hesitancy when trying to apply conventional definitions and evaluations of validity and reliability to studies employing phenomenological methods. Derived from philosophical roots, this methodology operates under the provision of key features, the first of which is that consciousness is viewed as intentional; objects appear within and because of acts, but they also transcend those acts. Secondly, those objects that transcend acts are real objects. There are also ideal objects, which cannot transcend acts, such as essences and ideas.

Lastly, phenomenology is “a philosophy of intuition” (Giorgi, 1988, p. 170). Intuition, being akin to the presence of meanings, consequently becomes evidence. To preserve this evidence, the researcher engages in phenomenological reduction where one brackets what they know and refrains from explicitly conveying that what is given is as it appears.

With the phenomenological method, validity is accepted on the premise that the phenomenon is well substantiated within the study. Giorgi (1988) stated, “If the essential description truly captures the intuited essence, one has validity in a phenomenological sense” (p. 173). Furthermore, it is through the ability to replicate the essential description that an individual achieves reliability in a phenomenological study (Giorgi, 1988). In order to properly and accurately achieve reliability, the researcher needs to be specific about what the essential features of the phenomenon being studied are, including imagined and experienced presences.

Husserl (as cited in Giorgi, 1988) discussed three distinctions between conscious acts: signifying acts, fulfilling acts, and identifying acts. Signifying acts are those acts that orient the consciousness towards the world and allow the individual to name an act based upon the constitution of meaning. Fulfilling acts complement signifying acts by adding symbolic or sensory fulfillment. Lastly, identifying acts are those acts that declare that the fulfillment acts meet the criteria of meaning ascertained in the signifying acts. Through the three different acts, researchers are able to more accurately explore the studied phenomenon.

CHAPTER 4

RESULTS

The purpose of the present study was to explore the experiences of family members of adults who have had recently acquired a traumatic brain injury (TBI). Few studies have examined the experiences of immediate family members of adults with a TBI. A phenomenological study was best suited for this line of inquiry pertaining to the family members' lived experience. The data was analyzed in accordance with those outlined by Moustakas (1994). The audio recording of each interview was transcribed by the researcher using Dragon Naturally Speaking Premium Edition (Version 12) [Computer Software]. Accuracy was ensured by reading each transcript along with the corresponding audio recording.

Transcriptions were read multiple times, both alone and with the corresponding field notes for each interview. Pre-understandings were identified in the first phase of analysis. Illustrated in significant statements, quotations, and phrases, the pre-understandings are important to acknowledge and identify, as they are "not something a person can step outside of or put aside, as it is understood as already being with us in the world" (Laverty, 2003, p. 8). Themes were subsequently developed from this data. After extrapolating the emerging themes from each document via this process, the themes were then examined across all of the documents. Across the six interviews, six major themes emerged as common characteristics of the experience of having an adult family member with a TBI. Those themes are: (1) an abrupt onset requiring necessary and rapid response, (2) the multiform manifestations of fear, (3) the significant role changes within the family system, (4) the diverse practices for emotional expression and protection, (5) the depth to which grief is experienced, and (6) the immutable alterations to established plans for the future.

To maintain the humanistic integrity of the phenomenological method through the presentation of results, all participants were assigned pseudonyms. Following each theme, a brief interpretation and analysis of the experiences will be provided. Two of the four phenomenological lifeworld existentials will be examined: temporality, or lived time, and relationality, the lived human relations (Rich, Graham, Taket, & Shelley, 2013).

An Abrupt Onset Requiring Necessary and Rapid Response

For each family member, the sudden impact of the TBI combined with the need to act immediately in response to the situation roused multiple emotions. Instantaneously, the family members attempted to understand the gravity of the situation at hand, as well as the prognosis. It is important to note that for Participants Michael, Andrea, and Jessica, this shared sense of urgency and need to react occurred despite an asymptomatic period of time between the accident that caused the TBI and TBI symptom expression.

Andrea, a then 51 year-old mother of three adult children whose 55 year-old husband incurred a TBI in 2012 from a fall at work, shared that the beginning of this experience was “devastating” and professed that she was “an emotional wreck”. She continued to state:

> I was panicking. I actually fell to the ground because I thought he was gone. They [hospital staff] got him in a room. His respirations were eight. They tubed him in front of me. They did everything in front of me. And all the while asking me what medications he was on. My mind my spinning…It, it was like...you, you didn't really

> have time to think because everything was going boom, boom, boom, boom, boom, boom, boom.

Despite having a 15-year-career as a licensed practical nurse, seeing her husband undergoing such treatment was jarring. The simultaneous processes of attempting to understand the status of her husband's health and needing to provide accurate information quickly overwhelmed Andrea.

Jessica is one of three children born to Andrea and her husband. 35 years-old at the time of her father's fall at work, she stated:

> It was just really scary, so. Just because we didn't know, and honestly the hospital he was at, they couldn't tell us a whole lot either, so...I...It just wasn't...they didn't know where he was going to progress to. And it wasn't...they can't give a prognosis too far...You know? And it's just like, "Okay well so are you telling me one day he will be back to normal? Are you telling me that one day, you know, he'll just be a vegetable? Are you...what are you telling me?"

In an attempt to make sense of a whirlwind situation of which there was little previous experience or knowledge Jessica, like the five other participants in this study, sought answers that were not readily available due to the capricious nature of a TBI.

Ruth, a then 43 year-old mother of three, shared similar emotions regarding the moment in 2012 when she found out that her 46 year-old husband had been in a car accident that required immediate medical care. She recalled emotional states of confusion as her husband called her and said that she would need to pick up their son from football practice. She shared how she asked him "what's going on? Tell me what is happening" because her husband was supposed to be with their son. Immediately she felt a sense of "panic" thinking that something had happened to her son at football practice. Hearing the ambulance in the background her imagination went wild. It was when her husband stated that he wanted Ruth to "come and find [him]...somewhere downtown" and pick him up, that she told her husband to put the ambulance driver on the phone. Politely, she asked the ambulance driver to bring her husband to the hospital and stated that she would meet him there. The simultaneous combination of needing to coordinate the pick-up of her son, process what had happened to her husband, speculating the level of injury and needing to arrange for her oldest child to watch the baby, had Ruth upset to the point that she had asked a neighbor to drive her to the hospital. Being away from her husband during the accident and hospital admission, she could only guess what his status or depth of injury was.

Michael, the oldest of three children and 26 years-old when his father sustained a TBI in an automobile accident, had previous personal experience with brain injury from the multiple concussions he sustained while playing various sports and a car accident after which he required inpatient care. He felt that his prior experience with brain injury and brain injury rehabilitation had aided in his reaction to his then 46 year-old father's car accident in 2013. Michael revealed the pressure he felt to make the right decisions with his father's care quickly:

> But this was something, like I said, that was very sudden...was a very sudden onset. And was something that was....in my experience, with mine and what I then heard from the friend of mine is that it was something that required care very quickly or the quicker you got care the easier it was to repair the connections and stuff like that. So it was one of those things where I put in a lot of time and effort into making the right choice and trying to find the right situation and the right place and the right care for him very quickly.

In order to potentially prevent any greater permanent damage, Michael felt that he had to consume, assess, and apply an abundance of knowledge and research pertaining to TBI. The encumbrance of this responsibility was one he was able to bear, but also remained a critical process in his experience.

Tiana was 22 at the time of her then 60 year-old father's car accident in 2012. Her uncle who had also been in the car with her father was missing from the scene of the accident. Immediately notified by her grandmother over the phone, she recalled:

> …I just remember getting off the phone, [speaking to cousin] "We don't know where your dad is. My dad is at Middlesex hospital. We have to go. We have to go to the hospital. He is in critical condition. Like, he might die." Like, I just remember freaking out. We're all panicking. We get in the car and we just took off to Middlesex.

Unbeknownst to Tiana or her family at the time, the uncle in question had been transported to a different local hospital after being pronounced dead at the scene.

Participants Michael, Tiana, Andrea, and Ruth shared similar concerns regarding getting and/or attending to their injured family member as soon as possible. Due to other circumstances, Participants Jessica and Allison were not present immediately following each of their fathers' hospitalizations. All participants, however, expressed the need to ascertain as much information as possible regarding the status and prognosis of their family member expeditiously. In doing so, the participants would be able to better brace for what was to come, inform any decisions that had to be made pertaining to a course of treatment for their family member, and to dissolve the ambiguity that they now found themselves sitting in; not knowing whether or not their lives would progress with their injured family member and if so, how. Unfortunately, due to the complex nature of each individual's TBI, this was not achieved until sometime after the initial onset, if at all.

Interpretation and analysis. The account of time as it is experienced within the initial period of TBI onset is one of hastening the anticipated future to the present. Rapid onset leads to a whirlwind of emotions, thoughts, and fears within each individual. As they try to understand, process, and be present in the moment, the family members had to simultaneously provide information and decisions that could greatly affect their loved one. Individuals are presented with a life or death situation that may have not been anticipated to occur for a number of years, if at all. The experience of time had failed them in the sense that suddenly what was anticipated to occur in the future is now their present. Previous knowledge or experience with TBI provided no additional consolation. In fact, it added to the pressure felt to respond and decide both accurately and expeditiously. As it became evident that each individual would live, the question became to what extent? Unfortunately, no doctor could answer these inquiries. The family members sought to make the future known but felt stuck in a period of waiting with which they were not comfortable. This is not unique to TBI, but rather a shared experience for those who have experienced any sudden, life-threatening event.

The desire for answers regarding the prognosis of the individual with the TBI also reflected a need to understand how the established relationship would change. Seeing what was once an autonomous spouse, partner, and provider dependent upon a variety of machines including feeding tubes, ventilators, and medication dispensers is very distressing. Every action, behavior and sound is analyzed as being either potentially promising or of concern. Every opportunity for hope was seized, but each person remained cautiously optimistic. During periods of coma, whether medically induced or otherwise, the family members sit in wait without much indication of who will emerge, if at all. All existing family roles, known framework by which they operate, and general rules of engagement are dependent on the outcome of this experience.

The anticipation and concern is both palpable and intelligible. The relationality of this particular stage of the experience is also shared with those who have experienced any sudden, life-threatening event of a family member.

The Multiform Manifestations of Fear

While acting quickly to get to their family member's bedside and answer all requests and questions asked of them following the TBI onset, the uninjured family members begin to see the depth of the sustained injuries and the role that they play in ensuring that their family member with a TBI recover and return home. The emotion of fear was present for all six of the participants in this study from the moment they were notified of the potential severity in their family member's condition. Although this emotional state lasted for different lengths of time for each participant, a prominent emotion was emphasized multiple times through each interview and central to each experience. Several distinct areas of fear were identified.

Fear of mortality. Tiana expressed how the loss of her uncle helped to inform her initial reaction to her father's condition:

> I just remember being scared and worried. I mean, it made me just worried about my dad. I didn't want to lose him… And everyone was just worried because my uncle passed away and we were just worried my dad was going to go with him. And we didn't want that to happen.

Her uncle's death propagated the reality that her father was mortal. As she watched her family grieve for the loss of this man, the actualization that she too, could lose her father became poignant.

A very palpable fear shared by Andrea pertained to concerns of her own aging, deteriorating health and the possibility of severe injury. With tears running down her face, she shared:

> And you know, the only thing that scares me is if something happens to me. Something happens to me, who's going to take care of me? I think about that. Before I had always thought it would be him….Now I know he physically and mentally cannot.

Knowledgeable of how a TBI can magnify the probability of developing additional medical maladies, Andrea is also fearful that her husband may develop dementia. As a licensed practical nurse, she has worked with "a lot of dementia/Alzheimer's patients" over her 15-year career. She shared, however, that it is much different to take care of an individual you work for and then go home, rather than to live with someone you love whose mental capacity and abilities are deteriorating.

Fear of wrong choice. In addition to being confused at the beginning of this experience, Ruth recalled being scared and unsure as to what she should do to help her husband, her family and herself. She stated that her fear was followed by periods of anger as she tried to understand why her family was disrupted by a TBI. Despite his personal experience with brain injury, Michael shared how he was scared that he would possibly make a poor decision as it pertained to his father's course of care. "I'm not a doctor or an expert in the field or anything like that", he stated, "and I wanted to make sure that my choice were right."

Michael stated that he is predominantly fearful of the possibility that his father will never return to a state of self-sufficiency. He said that his father currently looks to him continually for direction in life.

> Like, he's not...he’s going to look for direction the rest of his life…So that's the biggest...the biggest loss is his direction. So....and it's, it's a lot of pressure back on me because I have to provide him with a direction that's really going to make him happy but he's not going to get hurt or die doing.

This feeling of pressure directly relates to the fear of making a wrong decision when participating in the decision-making process of his father’s care.

Fear of the ultimate outcome. As the time since the onset of their family members’ TBI increased, participants reported wondering how much progress their family member would make in rehabilitation. Jessica shared that she and her husband have a close family friend who has a TBI and is very low functioning, often needing a lot of assistance from his wife. When prompted if she was concerned that her father would need the same level of care she stated, “We were… we were very fearful of that.” As time passed, Jessica and her family found themselves concerned. They would wonder if they, as a family, were going to move beyond a point in time when, as she describes, her father was acting similar to a “toddler”. He has since progressed to an “upper level teenager” in her opinion, citing several behaviors and attitudes similar to that of her 13-year-old son. Andrea also found herself questioning, “Is my life going to be like this forever?”

Fear of giving up. Behaviors that developed as a result of the TBI elicited concern and fear in Allison, who was only 16 years old at the time of her then 46 year-old father’s car accident in 2012:

> …He was smoking so much that, you know, smoking can help…it's a big cause of lung cancer and, um, I just have this fear that he is trying to hurt himself. And, you know, he just wasn't trying to get better.

The eldest child of Ruth, concerns regarding her father's depression and his lack of self-care became very worrisome for Allison. The hope she had regarding whether he would get better were tarnished his behaviors which illustrated to Allison that he had given up on himself.

For Michael, his father's lifelong resistance toward acknowledging weakness or deficits, and remain "very contained and strong about things", stirred up feelings of fear. He shared that, "I was afraid that he would put that attitude into this and that's not really what he should have been doing, in my opinion." Michael did not want his father to pass over the evident changes and difficulties that he was now facing, nor did he feel it would be appropriate for his father to remain tightlipped regarding his emotions.

Interpretation and analysis. Fear is a multidimensional experience within the context of a TBI in the family. Due to the unforeseen injury, the family is quickly faced with the possibility that the injured member may not live. This subsequently stirs up thoughts and emotions pertaining to mortality, including their own. For spouses of persons with a TBI, thoughts quickly turn to the future and the anticipation of developing their own health concerns. Their injured partner is no longer capable of providing for them as they may have once expected, resulting in a necessary adjustment to the spouse's plan and aspirations for the future. As time progresses since the onset of the TBI and caregiving becomes a central role for the non-injured spouse, the idea of no longer being able to provide care for their affected partner becomes particularly troublesome. Fear and, to a lesser degree, guilt are infused into future plans. The caregiving companion is scared about dying and leaving the injured spouse without their care, while also feeling pressured to remain alive and present for them until they pass away. For some, it is firmly believed that no one can care for the spouse who has the TBI as well as they have, resulting in additional emotional encumbrance.

Beginning immediately following the TBI onset, family members are required to make decisions which have the potential to greatly impact the prognosis and ultimate outcome of their loved one's disability. For those unaware of the possibility of a TBI, the decisions begin when debating whether to seek medical care after troublesome symptoms emerge. For others, decisions begin at the hospital when members of the medical team turn to them for decisions regarding care and intervention. Regardless of when the decisions begin, the pressure to act quickly and accurately is great. Further convoluted by the intense emotional reaction that the family member is having to the situation as a whole, periods of time seem to pass rapidly. While at the hospital, the family may have few resources to inform important decisions, leaving them to speculate as to the correct direction of care. As the individual with the TBI rehabilitates, the degree to which their cognitive functioning has been affected becomes apparent to the family. Dependent upon the severity of the TBI, family members could potentially be forever responsible for the injured person's daily decisions. Wives, husbands, or children may find themselves the custodial guardian of the individual with the TBI. In a desire to honor the wants and needs of the affected family member as the family knew them prior to TBI acquisition, these family members fear the potential of a wrong decision that could have dire consequences.

Fear and sadness are both present as the family tries to predict the future. In an attempt to see what their situation may look like several weeks or months from the initial onset, concerns pertaining to the permanency of the situation as it is observed in the initial days and weeks since TBI acquisition, begin to arise. The emotional and physical toll of having an immediate family member in the hospital is great and therefore renders any thoughts of situational permanency frightening. This also holds true when the family member with a TBI is discharged from the hospital and return home. Negative personality changes may become more pronounced over time resulting in the considerable desire for the previous personality to return. Fear regarding the permanency of the new personality also emerges. The negative personality changes may also result in an inability to perform or engage in self-care and rehabilitation. Especially for children of individuals with a TBI, this can be especially frightening if the affected parent engages in risky behavior such as alcohol or drug use.

The Significant Role Changes Within the Family System

Beginning while the person with the TBI was still in acute care at a hospital or rehabilitation center, the family began to identify the change in abilities of their family member following onset. With the goal to preserve the family's functioning, adjustments were made in order to accommodate the person with the TBI back into the family once they were discharged. All participants reported experiencing some change in their roles in relation to how they perceive and interact with their family member with the TBI, as well as the family system as a whole.

Tiana, who was only 22 at the time and was one of the four adult children interviewed, was called upon to help her grandmother care for her father following his discharge from the hospital. She stated, "Well my Dad's always been the one to kind of take care of me when I needed him. And I had to step up and kind of take care of my dad. And just be there for him". She no longer has to take care of her father, citing that although he still lives with her grandmother, that he has recovered "probably about 90% of the way". Tiana still maintains a very protective, almost maternal role, with her father. One example she shared pertained to how she tries to protect him from spending too much money. Unable to work and currently receiving

Social Security Disability Insurance (SSDI) benefits, she views this financial monitoring as necessary.

Allison has seen significant changes in her role within the family. The oldest of three children at 16 when her father sustained his TBI, she seeks to help out her mother, Ruth, where her father cannot:

> But yeah, I feel like I do a lot more. And I have been called mini-mommy. It's like "You do so much". You know? "You're driving them around, you're…" And I'll go into the store, I'll buy groceries. Or I'll bring my brother to go buy something he needs for school. I mean, I've been shopping with him for socks. You know, that's something that usually Mom does or Dad will do, but I, but my father can't do that sort of thing. So, yeah…

She stated that she had anticipated having to complete similar tasks when her parents got older and she had moved out of the house, "but I hadn't anticipated doing it like as a full-time job basically, because that's another full-time job that I have at home."

In addition to her contributions at home, Allison is also currently completing a three-year program that will provide her with an Associate's degree and high school diploma, while holding a job that varies between part-time and full-time. She disclosed, "I'm just 18 years old and here I am taking care of my Dad. I'm taking care of my family, to some extent. You know? It's like, I'm just 18. I didn't mean for it to happen now." When interacting with her father, she stated that she treats him "with a little more gentleness," always giving him a "heads up" if she wants to discuss something with him and consistently maintaining the intention of "try[ing] not to hurt him too much" by overwhelming him with too many jokes or questions .

Michael shared that his father’s continuous desire and need for help or assistance has been a new experience in their relationship. He later stated that his newfound role in his family and with his father is similar to that of a parent, explaining, “It'd be the same thing as my two year-old sitting there, you know? And that's unfortunate to say but it's true.” Later he adds:

> I see him as somebody who now I am overseeing and I am taking care of instead of...you know, it seems like there was a role reversal of he was the parent, I was the kid to now I'm the parent and he's the kid. It's....it's different.

He also feels that his family now relies on him for informed opinions and making arrangements for his father’s care. In addition to expressing the pressure that this reliance puts on him, Michael shared:

> It makes me feel finally appreciated and vindicated that I'm doing what's right on my side of it. But then I'm like...and this is...this is horrible to say...but it's like...you waited until there was a problem to ask for my help. You know? You waited until you couldn't do it anymore and now I'm good enough, kind of deal.

Feelings of anger, frustration and disappointment were present as Michael, now 28 years-old, shared this insight regarding how their relationship has changed over the year and a half since his then 46 year-old father sustained his TBI in a car accident.

Jessica affirmed similar sentiments regarding how her mother often seeks her out for support and guidance since her father’s injury. Telephone calls have been as frequent as 12 times a day ranging from topics of general chitchat to resolving a fight between her parents. Feelings of “stress” and being “overwhelmed” are often incurred from these recurrent conversations. Jessica also acknowledged that if something should happen to her mother, that she and her family would need to become the primary caregivers for her father - a thought that is also “overwhelming” to her. She continued to state that since her father’s accident when she was 35, she feels as though she is “parenting them to some extent” and that she had concerns that her role will never revert back to what it was prior to her father sustaining a TBI at the age of 55 from a fall at work.

Ruth, one of two wives who were interviewed, appeared to exhibit defeat when she admits that she has given up asking her husband for any help around the house:

> …I would lose my patience with him because he was taking too long to, uh, you know, do simple things that he could have easily have done. And I never...I stopped asking him to do things because it was frustrating to, you know, that I would give him a list of things to do and he wouldn't do them. So, uh, I started to just stop even asking.

She has taken on much of what her, then 46 year-old, husband used to do around the house and stated that her patterns of living have changed significantly since his car accident.

Admitting to putting pressure on herself in multiple areas of her life, Ruth expressed a sense of numbness that has taken her over emotionally. In order to maintain her family’s happiness, however, she tries to create moments where her three children can let go from any negative emotions and just have fun. She also continues to grow concerned regarding her two sons and how their father will serve as a role model.

Transitioning from mother and wife to mother, wife, and caregiver has left Ruth feeling overwhelmed. The demands on her to attend to her three children, while also taking her husband to doctor appointments and maintaining a full-time job, prove very stressful on a daily basis. She hesitantly shared that “it would be a lot easier to not have small children in the house” but emphasized that she would never want to be without her children. Further emphasizing the level of change in her everyday life and the roles and responsibilities that she has assumed following her husband’s accident, Ruth shared:

> Sometimes it’s hard because it feels like the focus becomes the person with the TBI and we're all held hostage to, uh, his needs and pains and everything else. So it's like, it's like we all have, we all have to live our lives walking about carefully you know, around his needs. And that's not necessarily a bad thing. Sometimes it is and sometimes it's not. So, certainly our whole lives had to change to accommodate who he has become.

Her use of the term “hostage” illustrates the depth of her pain and anguish with the situation, as well as the degree to which her and her family’s life was turned upside down in order to accommodate her husband and his TBI.

Andrea emphatically detests the many changes in her role within the couple and family system. Although she has come to accept the new roles that she has, she shared with unequivocal intensity:

> Like me carrying all the heavier part of the groceries? Heck no, I don't like that. Me having to cook and plan every meal? Heck no, I don't like that. You know? Me having to do dishes? I hate dishes. We had an agreement when we got married: he would do the dishes and I would do the refrigerator, stove, counters, and things like that. Now I'm doing the refrigerator, stove, counters and dishes. You know? No, I don't like it. But if I don't do the dishes, he is not going to get up and do them…So, I've accepted the role but yeah...there's....what I wouldn't give for him to just go up and do dishes one day.

The household chores are just an example of the many areas in which she has had to learn to manage in order to “pick up the stuff that he can't do”. As with Ruth, it is easier for Andrea to do the tasks herself than to try to encourage her now 58 year-old husband to contribute. Prior to his slip and fall at work, their marriage was characteristically shared in terms of chores and tasks, with her husband taking on an estimated 60% of the responsibilities. Her husband’s lack of initiative, which developed following the onset of his TBI, leaves Andrea having to plan out any and all trips they may take, waiting on her husband who will not fix his own meals, fixing various appliances around the house, and managing the upkeep of the vehicle.

As a self-professed “taskmaster” who is “now the full kit and caboodle”, Andrea finds herself encouraging her husband to complete activities such as exercises repeatedly during the day, and also monitors him to make sure that he is doing them correctly. She now feels that she has taken on 75% of the responsibilities around the house, which was “a real hard jump” for her. “I’ve taken on more the roll of being the more dominant one”, she shared while elaborating that she had never been the dominant partner nor ever wanted to be, and that her husband “was always the strong one”.

Interpretation and analysis. To the degree that the TBI alters the family functioning as a whole, the uninjured family members must adjust in order to return the system to a state of balance. Deficits must be identified and re-assigned to other family members. These deficits could include financial responsibilities, caretaking, transportation, and various household chores. Being assigned duties where the family member is not comfortable performing in can often lead to overwhelming feelings of distress, anger, resentment, and helplessness. They may feel as though they have been cornered and are being forced to perform these tasks in order to sustain the family. This holds especially true if there are small children in the house. The feelings the family members have are further exacerbated by a lack of sleep, lack of support and poor self-care. It is important that the family discern what tasks are critical to maintaining the overall function and those that were extraneous. Taking on too many additional responsibilities could heighten feelings that are already present due to the additional stress, function as a method of avoidance, or in extreme cases serve as a means of emotional self-harm.

Throughout this process, roles change as each member attempts to compensate for what the individual with the TBI cannot do. An examination of the relationality in this particular facet of the experience indicated that each individual member begins to reframe his or her relationship to the individual with the TBI. Spouses no longer see themselves as partners, but as caregivers. Children report a reversal of conventional roles and now see the affected parent as a child. For Michael, this change in role ignited disappointment because it wasn't until his father was injured that he was regarded as helpful and a good decision maker. A power differential is established with the non-injured members having more power, regardless of age, over the individual with a TBI. As it pertains to temporality, this may result in young children needing to mature emotionally and cognitively much quicker than their peers.

Tiana's experience was quite different in this particular area and it appears to be, at least in large part, due to her father's near complete recovery. She reported that he is practically back to the person he was before the accident with minimal behavioral, emotional and physical changes. Although she does help him with finances and other small tasks, he is largely independent. She is not uninjured by the injury, however. Tiana shared that she will act to protect her father when others seem to frustrate him, indicating a slight change in role. This supports the ideology that the severity of the injury will dictate the level of disturbance to the family.

The Diverse Practices for Emotional Expression and Protection

As each family member experienced this traumatic event, it became important for him or her to be able to expel emotion and rely on others for support. Beginning immediately at the point of notification of the injury and proceeding from then on, each individual family member began to accrue emotions and beliefs that more than likely were kept to themselves. Each family was confronted on a daily basis with the dynamic experience of having a member with a TBI. Due to the subsequent range of emotions that were aroused in direct relation to that experience, it became important to ensure that family members were processing the emotions and allowing for some type of external release.

For Participants Tiana, Jessica, Allison, and Ruth, religion and faith played a significant role. While her father was still in a coma at the hospital, Tiana and those holding vigil had a pastor come in and pray with them. “That’s all we did,” she shared, “was pray, pray, pray.” When asked to clarify on what was being prayed for, Tiana said:

> We were praying for God to heal him. To help him, help us. Um, we just kept praying for the best. Just kept praying that He would heal his brain. That he would be back to normal as possible and…anything like that. We wanted him to stay. We didn’t want to lose another one.

Very firm in her faith and the role that God played in her father’s recovery, Tiana who was 22 at the time of her father’s car accident stated unwaveringly, “…God helped us and he lived”. Jessica stated that in addition to leaning on her husband for support that she went and spoke with her priest “quite often”. In similar sentiment, Allison cited going to church, participating in prayer meetings and spending “a lot of time at church with my church friends” as outlets. Ruth stated:

> I said this to someone the other day that I don't know how people can go through this without faith. We happen to be Roman Catholic Christians and so, I feel like my faith and our parish community, uh...the priest...that we have surrounded ourselves with are a great help for us.

Ruth also later added that her other friends, mother and aunt were influential supports in her life. The only participant to do so, she also shared that she and her children routinely attend individual counseling, including her three year-old son who has begun to exhibit some troubling behavior.

Humor is something that Andrea and her husband reported using quite often. She shared stories of how she may jokingly make fun of him and vice versa, smiling at the thoughts. If her husband does not appreciate what she is saying, he has been known to respond, “Do I know you?”, while she has utilized his short-term memory deficit to appear as though she has predictive powers. Andrea also stated that she uses a “biofeedback” method to help her since she has adverse reactions to psychotropic medications. She compares herself to others and seeks individuals who have “got it a lot worse” than she does in order to maintain positivity. Jessica shared that she and her family tend to routinely try “to roll with whatever comes up for a minute”, taking each experience in stride and trying to not get overly emotional in their reaction.

Michael seeks competition as a healthy outlet for his emotions. He shared that he is “emotional on my own time” but routinely tends to “put on that front for everybody else” until a given task is completed and he can be alone. When he is alone, however, he likes the use of physical challenge to process his emotions:

> Sometimes I'll go golf. Golf is probably one of my biggest outlets so I'll go hit the golf course or I'll go shooting. I have several firearms and I like to shoot, trap and stuff like that. So I'll go shooting, or, you know something...just...something that challenges me so that I can get out the emotion through, you know? Competition is my best outlet.

These activities allow Michael to utilize a physical component where he can also be alone with his emotions and away from the pressures he feels from his family.

Having realized "how precious it is to be with people during their good times and their bad times", Allison finds herself cherishing everyone around her. This was not always the case, however. Prior, she recalls being in a depression and sitting either in her room, doing nothing or on her phone "just trying to see that other people were happy". Now she surrounds herself with people and friends, doing "anything for anyone" in order for "everyone to be happy". When Tiana's grandmother told her that she was not to get emotional or cry around her father, she turned to an inner strength. "So I just….had to…be strong" she stated, seemingly distracted.

While describing multiple mechanisms that appear to be positively applied daily in an attempt to cope with the insertion of a TBI to the family system, participants also reported that these coping techniques do not always work. Ruth evaluated her family in saying, "I would say we're about 25% living, 75% coping." The dwindling hope for improvement of her father's condition seemed to trouble, then 16 year-old, Allison, who stated, "I'm not going to expect him to get better". When asked if her expectations were low in order to protect her from getting hurt, she responded:

> Um, yeah. I think it's, yeah, maybe it's just from more from my mindset so I can try to just move on and try to, try to grow as a person so I can move on. You know, go to

> college. I got to get ready to go to college and move on with my life after college and have a career, you know. It's just things I'm trying to tell myself though.

She recalls coaxing herself into ignoring the situation entirely and "let it be". She cited being busy, lack of knowledge regarding the injury and rehabilitation process, and that she "didn't really like the way things were going, you know, my dad changing and all", as motivators for this particular approach.

Interpretation and analysis. For those who had a strong connection to a particular religion, continuous prayer and ongoing support from their religious community was a resource that was utilized beginning at the hospital. Prayer may allow the person to connect with their higher power and request help, subsequently easing the feelings of helplessness that are commonly felt. Outside support systems including religious communities are also very important to the family as the person with the TBI is treated in the hospital, begins to recover and returns home. These friends and family members may provide a listening ear, non-judgmental attitude, or alleviate responsibilities by helping with tasks. As caregiving becomes more central to the uninjured members' role within the family, they may not have the opportunity, time, money or drive, to seek out counseling or other types of emotional support. Friends and family may not be clinically trained, but nevertheless provide the opportunity for the family members without a TBI to express themselves. Engaging in sports and competitive events may provide the family member with a medium where they can let out pent up aggression, frustration, or fear. The exertion allows for both a physical and emotional exhaustion that seems to provide a sense of cleansing.

Other examples that were provided seemed to indicate a necessary distraction was necessary in order to be happy or, at the very least, content. The seemingly over-investment into the happiness of others may serve as an opportunity for the family member without a TBI to regain feelings of power over a given situation as well the satisfaction from pleasing others. The lowering of expectations for the person with the TBI, staying busy in other areas of their lives, or purposefully ignoring the situation within their home in full indicates a protective need. Shifting the focus away from the injury and the person with the injury appears to be directly related to the aforementioned levels of fear experienced throughout the process of rehabilitation for the person with the TBI. In order to not be let down or anguished further, the uninjured family member may make these changes to how they participate in the experience. Doing so has the potential to strain the relationships within the family, especially if it results in tasks not being completed or if another family member resents the other for creating a physical and/or emotional distance. It seems that, at times, the family member acts as if to "pause" one area of their life by focusing on others.

The Depth to Which Grief is Experienced

Regardless of what activities they turn to for emotional release or protection, or the groups that they look to for support, grief is experienced by most that have a family member with a TBI. The devastating changes that occur to the individual who has sustained the injury carries throughout the family system, incurring multitude of grievous emotional reactions within those family members who do not have a TBI. Each of the participants discussed having experienced a process of grieving related to the TBI causing event.

Prior to beginning the audio-recorded interview, Tiana stated that she "had done her grieving". When encouraged to elaborate, it was revealed that her grief was specific to her uncle passing away in the car accident in which her father was injured. She seemed hesitant, saying "and then…" as though she wanted to continue to list areas where she grieved, but quickly stated "that's about it".

Jessica spent a period within the interview depicting how others, such as her mother Andrea, her husband, and children, were affected rather than defining her personal experience. It took some time to get her to focus solely on her own experience. Revealing the depth of the emotional anguish she experienced around the TBI in her family, she shared, "…if I try to look back too much, I...I just might fall apart and I, I can't afford to fall apart."

Generalized anger took place within Ruth's grieving process:

> Anger at him [her husband]. Anger at my kids. Anger at myself. Because you know, I, I just...In the moment I feel angry. Why doesn't somebody help me? And then I say to myself, 'Why don't you just get over it and just do it?' So I get angry at myself for being upset with my family.

Ruth illustrated a sense of loneliness compounded by the demands made upon her by her children, and now her husband. A sense of isolation and helplessness is tangible as she spoke. She then discussed how the anger she felt was turned inwards when she realized how it might affect her family. It seemed as though keeping her family happy and without conflict was one of the previously discussed areas where she places pressure on herself.

The significant level of change in cognitive functioning and physical appearance introduced a large amount of the grief for Participants Michael, Andrea, Jessica, Allison, and Ruth. For each of these participants, an idea of their injured family member being "different" was discussed. When asked to compare her father from before he incurred the TBI to after, Jessica shared, "…they look similar but yeah, it's two different personalities. Completely different personalities." She continued to share that at times she felt as though she was grieving the loss of who her father was and that she would "spend a lot of time crying".

A hardworking man, then 35 year-old Jessica rarely saw her father growing up. It was not until she donated a kidney to him six years prior to his accident that she felt a "bond that wasn't there before" and was beginning to forge a relationship with her father. With regard to her relationship with her father following his TBI, she shared:

> We were developing the relationship and so...I kind of feel like we lost some of that because we've gotten to the point where he calls me to settle arguments but he doesn't call just...we don't call and chat anymore, you know? It's...so we've lost some of that.

When discussing the changes to her father's personality, Jessica viewed the evolution of his new personality comparable to a developing child. She cited examples of how he first acted like a toddler who needed to be reprimanded and constantly supervised. Later he progressed to an "elementary aged child", making up stories, needing to have things explained, and showing impulsive behavior. Today, Jessica believes her father has plateaued in his development at the stage of an "upper level teenager". "It feels like we've had to learn a whole new stage in life", she laments, "how to deal with your teenage parent… I'm not sure I feel equipped to deal with teenagers, let alone my teenage parent." She also finds it very jarring to think about the man her father was before the accident. Awkwardly she chuckled and reiterated, "Like I said, we try to roll with whatever he's doing right now. Hah. Because I can't...I just mentally and emotionally cannot dwell on who he was."

Michael, having confirmed that he was purposefully not allowing himself to get emotional during the interview, shared matter of factly, "I think the script has completely flipped". When asked if he sees his father when he looks at him, Michael responded, "…I'd have to say no. I don't see...I don't see him personality-wise, I don't see him in the ability-wise, I don't see him as a kind of looming figure. I don't see him as an oversight figure." He indicated these are all areas that were critical to his father's character and presence before the accident.

With great emotion, Allison discussed the impact her now 50 year-old father's car accident had on him and, subsequently, the relationship she had with him. Her initial thoughts following his TBI included "What happened to my dad?", "Why is he not the person that he used to be?", as she began to notice that her father was no longer the "happy, cheerful person" she once knew.

> And so I wondered, you know, like what happened to…what…how could that happen so badly that it changed him completely? 'Cause people have experiences that change them but I never would have thought that my dad could have changed that much.

She discussed fond memories of going fishing with her Dad throughout her childhood. Sorrowfully, Allison shared that her father "kind of just dropped away" and that she "didn't know him anymore".

She continued, "I just can't believe he's even here anymore. Like, his body's here but he isn't. It's sort of like he died but his body is still here." In discussing how her relationship with her father has been impacted, she stated:

> …Dads are supposed to be the little girl's hero. They look up to them. They're your knight in shining armor and I sort of felt like I lost that, you know, because I was doing more things for him that he should be doing for me. And I just feel like that came so suddenly. And I didn't really get a chance to be with him the way a teenage girl should

> spend time with her Dad. So, I guess it just….It's different. 'Cause it was meeting someone new.

Allison no longer sees her father as a man who can come to the rescue or support her in the way that she feels a teenage girl needs. She sorrowfully shared that although she can physically see her father, that the personality of the man that is with her today is not the father that she knew growing up before his accident.

The sentiments regarding how the family member with the TBI had "completely changed", was "gone", and "different", identified in three of the four adult children interviews were also shared by the two wives that were interviewed. Ruth discussed several of the reasons she was initially attracted to her husband such as mutual interests, enjoying the same music, and going on adventures. "There was a lot of fun things that we liked doing together", she remarked. When questioned as to whether any of the qualities that attracted her to him were present after his TBI, she said "no" and referenced his diagnoses of anhedonia and disinhibition as possible reasons why. Ruth admitted to feeling "flatlined" or numb, and discussed how her marriage has been negatively affected:

> You know, that good marriage…it's like you would lay down your life for your spouse and lay down your life for your friends, and I…I…I don't think that he, he can. I don't know that he wouldn't do it but I don't think he has the ability to, to be that knight in shining armor.

Her overall view of her husband has been altered as well. She admitted that when she looks at him she sees "a poor sick person" that she feels "terribly sorry for and helpless to, to give assistance to". She goes on to state that at times she consciously tries "to look through that and see the person that I married".

Ruth later elaborated that her dedication to her marriage is a mixture of adherence to wedding vows and being a kind individual who wants to help. She discussed how if his TBI had been a different ailment such as cancer or liver disease, that she would not abandon him:

> You know, he might behave differently with a different disease but I have to still look at him, you know as this other person. The person that he...I have to endear him as the person that I got married to. I think it's critical for my children.

Ruth also shared that although her husband believes that the family would have been better off if he had died in the car accident, she does not. "In general, it might be easier", she expressed, "but I think that there are things that would definitely be way harder".

According to Andrea, her spouse was significantly impacted by his TBI to the extent that "…he's not the guy I married. He definitely is not the same". She actively searches the Internet for information and had recently looked up what it is to grieve. Utilizing the information that she had gathered, she appraised her experience and concluded that she had grieved for her husband already "…because I went through a period where I said, 'I want the old you back'. ' I want the old you back'. 'I want the old you back'". She explained, however, that her grieving differed from the grieving she would experience with a death:

> It's...it's not the same as if you bury a person and you know this person's alive and right next to you, so you can't really put in your mind, "Okay, the old one's buried". You know? What you have to do is just put it back in the memory and bring your new life forward.

She stated that rather than burying her husband, that she had to “forget about the way he used” to be and put memories of him before the accident “in the back of my mind”.

Although past memories have a tendency of resurfacing, she works to tuck each one into the back of her memory and brings her “new life” forward. This change in approach and regard for her husband began following a support group meeting where it was said that, “…if you tell your spouse that you want him to be like the old person he was, that puts a lot of guilt onto that person”. Andrea said that she cannot “pursue that way anymore” and has come to accept who her husband is today. As with her role changes, she accepted the change without necessarily liking it.

Jessica was the only person involved in the current study who shared that she had seen some positive change emerge from her father’s injury. Interestingly, one of Jessica’s two daughters, who is diagnosed with high functioning autism and a seizure disorder, had experienced an improved relationship with her grandfather:

> So, um, whereas he didn't really “get” her before, they...they're on the same wavelength now. They, they know about seizures and their, their personalities...they're a lot alike now so it's very...it, it's very, um, uh...very interesting to watch them progress like that.

All other individuals engaged in the present study, however, felt negatively impacted by the TBI onset.

Interpretation and analysis. Family members of those who have significant personality changes attributed to their TBI experience heightened states of grief that rock the foundation of their relationship with them. For the family members, the physical representation of who the person with the TBI was prior to onset is quite distressing, as the personality has now become drastically different. They struggle with allowing the past personality to become a memory while looking at the same person. Family members are caught in a temporality where they desire to return to the past, but are faced on a daily basis with the present. Their new reality can challenge their beliefs about life, death, and their understanding of what it means to be person. The uninjured family members are caught in a purgatory where they are unable to grieve the loss of their family member because they are still present physically and may have moments where a glimpse of the personality from before TBI onset can be seen, but are significantly changed for a majority of their days. Dependent upon the changes that occur to the personality following the onset of a TBI, relationships between the individual with the TBI and their family could become strained or lost completely. For some, it is likened to meeting someone new while other family members may change their frame of reference to incorporate the feelings of pity or regarding the family member with the TBI as a child. At times, the family members may have to exert themselves cognitively and emotionally in order to force themselves to see the person that they knew prior to TBI onset.

Family members also experience a deep loneliness throughout this ordeal as they desire not only the personality to return, but are faced with the reality that their partner, spouse, or parent, as they once knew them, are likely to be gone forever. Anger may arise as family members experience feelings of persecution from a higher power, hopelessness, loneliness, or abandonment. The abundance of emotion that is evoked throughout this experience is further complicated by the need to ensure the functioning of the family system. This often disallows for the family member to process or be present with all that they are thinking and feeling. As a result, some family members may be terrified of falling apart. They have roles to play and tasks to complete. Should they allow themselves to experience the profoundness of all they have encountered, they may run the risk of breaking down with the inability to put themselves back together and function again. Instead, they may encourage an emotional numbing within them and push forward to overcome another day.

As is common with many experiences of grief, those grieving show a propensity to recall the good qualities of the person being grieved and possibly elevate them to a position of reverence. Interestingly, both Ruth and her daughter, Allison, used the term “knight in shining armor” to describe a role that their injured family member would never embody, eluding to the idea that prior to his TBI he could have done so. Allison had much adoration for her father that is common to children while Ruth admitted to a strained relationship before her husband’s TBI. It is possible that Ruth, in elevating her husband to a position of honor, exacerbated her own grief. She was now not only grieving who her husband was, but also the man he could have been as well as her idealized version of him. Both women were disabused by their idealistic rendering of this man in their life and confronted with the truth of mortality much sooner than they had anticipated.

Tiana’s experience was different in this particular area as well. Again, it appears to be in large part due to her father’s near complete recovery. She reported that her father is “fine” and that the minimal changes to her father’s personality had little impact on who he is following his TBI. Although Tiana had grieved the loss of her uncle, who had died in the same accident where her father was injured, little to no grief was directed toward or pertaining to her father. This supports the ideology that the severity of the injury will dictate the level of emotional distress and grief experienced by family members.

The Immutable Alterations to Established Plans for the Future

Each family member and the family as a whole experience the changes incurred by the person with the TBI, at different levels. During the time following the initial onset of the TBI, none of the participants knew what the end result or prognosis for their family member would be although many feared the worst as they held vigil at their bedside. Questions were asked regarding whether their family member would live or die, to what extent they would be impacted physically, cognitively and emotionally, and to what degree the family system would need to change in order to support this disability. As time passed and answers to such questions began to emerge, each family member made the necessary changes in behaviors, hopes, goals, and plans for the future to accommodate the person who returned home from the hospital.

Tiana shared memories of her wedding, discussing how “it was a little awkward because like, before his accident he probably wouldn’t have had trouble walking down the aisle” which consisted of grass for her outdoor wedding, and how they “were kind of balancing each other down the aisle”. An experience she reported was “amazing” and “totally fine”. While recovering, Tiana did not know whether he would be able to walk down the aisle. Today, she is very happy and stated that “he’s still there for everything I need him for, so everything seems fine”.

For those participants who voiced a distinct change in their loved one’s personality, the idea of the future and/or completion of plans that had been made prior to the TBI onset seemed bleak. Allison, in contrast to Tiana, had to significantly alter her expectations of what her wedding day may be like:

> I started feeling sad about things because, um…You have to know that I love weddings. I am obsessed with weddings…But I just, all I could think of is my wedding day and him not being able to walk me down that aisle. You know? That's every girl's dream that she…you know, that loves her dad. And my dad and I had a really good relationship when I was really little.

Having already had her wedding, Jessica was looking forward to building on the relationship she had fostered when she donated a kidney to her father several years before his accident at work. Unable to do so she ruefully reflected, "I feel like we lost some of that. We don't call and chat anymore." Her father's grandchildren, some of which are her children, have had to alter their expectations for the future, according to Jessica. She stated, "They've had a really hard time coping with dealing with him" and that they often do not want to be around him.

Michael previously enjoyed attending professional football games, concerts, and various sporting events with his father. He shared that his father is "very scared in crowds" and is "very uncomfortable in crowds", so they have not attended any of those types of events since his accident. Although they can still complete projects following his TBI, Michael said that there is a marked change in how he experiences time with his father:

> If we do anything together I have to...it can't be like we're going to build a shelf and it's relaxing and I can just sit back and enjoy building a shelf. It's I have to be a parent of a....and it seems like a small child...that's using power tools that I have to watch and be vigilant and be protective of everything while I'm trying to help build a shelf, in that sense.

Michael shared that although “before it was a situation where I kind of relaxed, kind of enjoyed the making of what we were doing or enjoy making whatever it we were making” that to take on such a task now is “kind of a burden at this point”. He has had to adjust his expectations for his father in these areas, but doesn’t find that there is anything else that he would not get to do or enjoy with his father due to his TBI.

Ruth explained that prior to her husband’s TBI, that she had thought about “aging and getting older” and anticipated when she would “get married and grow old together with someone”, often contemplating the “stuff you had hoped to do as your got older”. And then their “lives changed”. Now, Ruth envisions a lonely and isolated future if no further progress is made in her husband’s recovery. Dispiritedly she shared, “Now, I, I, I can't imagine...I feel he's looking to me. Looking forward for me, it looks like it's going to be kind of lonely as my children grow up and move on if things are status quo”.

Andrea shared that “this isn’t what we planned”, chuckling at the thought:

> I figured that I would work until I ...he and I would work until retirement age and then we'd travel. And, um, now retirement has come a lot sooner and we didn't have time to prepare for it financially. Or, you know, do it as we planned. You know, we had plans set out for years on what we were going to do. And now, even if like, we do travel, we're going to have to stop for frequent rest breaks...

Differences in her husband’s stamina due to TBI-related challenges such as neural fatigue results in a maximum driving time of two hours and leaves Andrea confident that they would no longer be able to travel at “a normal pace”. Even if she were to drive more and make the frequent rest stops, another concern is her husband’s ability to perform once they arrived at the destination(s):

> When we get there, like if we went to the Grand Canyon....if I wanted to go up and see the sights, it would take him quite a while to get up there because of...he'd tire out and have to sit.

Although Andrea still intends on travelling with her husband, she does not display any indication of being excited or eager for the trip(s). “So you see how traveling is going to be?” she asked rhetorically, exasperated with the idea.

Interpretation and analysis. As with experiences of grief, the family members of those who had incurred significant personality changes as a result of their TBI felt that their future had been considerably changed, dwindled, or taken away from them completely. The varying degrees to which the future has been altered for the uninjured family member is directly connected to the extent of the personality change in the person with the TBI. For Tiana, who believes that there was little residual impact from her father’s TBI, there were hardly any change to her foreseeable future. Although some accommodations were made to help her father walk her down the aisle at her wedding, she still believes that he has a plethora of options available to him as he progresses through life. Allison, however, realizes that her father may never walk her down the aisle for her wedding. An experience, she feels, is critical for every young girl who loves her father. As the TBI experiences progresses over time, the relationships that were once had prior to the TBI between the injured and uninjured family members may be lost. This includes immediate family members and grandchildren. Those who once had close relationships with the family member before their TBI onset may feel a distancing or disconnect from the person following their TBI. As was referenced in the prior section on grief, some family members may not be able to or want to get to know someone “new”.

Projections of the future become bleak as the family members without a TBI reconcile that what had been planned with their family member with a TBI may never come to fruition or, at the very least, as it had once been envisioned. Quality time that requires tools or situations that could be potentially harmful can no longer be casually enjoyed, as the family member with a TBI may need to supervise the person with the TBI much more closely. The shared enjoyment of events prior to TBI onset may not be able to be pursued following the TBI due to limits in stimulation or physical function. As the spouses discuss the future with their partner who has a TBI, statements may be shared regarding how the future they see now is not what they had planned as a couple, prior to the TBI onset. Due to the significant personality and physical changes in their partner, in conjunction with the role changes that the uninjured spouse may experience, there may be feelings of loneliness and not having a partner to proceed through life with. Exasperation is a common feeling to this area of the TBI experience as well. With all of the time and effort, mentally and physically, expelled in putting together trips, the family members without a TBI may feel as though the significant adjustments to plans are too cumbersome to warrant actually carrying through with preexisting plans.

For the family members of those persons with a TBI, their sense of the world is much more defined now. Prior to the TBI onset, the uninjured family members held a sense of their future and the world characterized as having a multitude of options from which to choose from and explore. As the beginning of this TBI journey was characterized by a quickening experience of time, for those with family members who have severe personality and physical changes from their TBI, the concept of the future seems to feel stifling. It is as if they are stuck in time, unable to progress any further. This is especially true if rehabilitation efforts have finished and little to no progress is being seen in the person with the TBI.

Information Not Included in Analysis

Six unique experiences of being a family member to someone with a TBI were shared in the current study. Through the data analysis process, there were consistencies identified within a sub-group of these six people, as well as with one person’s experience particularly, that was not reflective of all individuals involved in the study. Therefore, these particular pieces of data were not considered when identifying themes. The unique data to the sub-group and the individual, respectively, is shared in this section of the manuscript.

Adult children. Of the six individuals who shared their experiences of being a family member to someone with a TBI, four were adult children. Having a parent who experiences a traumatic life event or illness can be hard for those children, whether adult or otherwise, who have become accustomed to regarding their affected parent as a caregiver, defender or support, since the moment they were born. Dependent upon where the child is developmentally, and their ability to acknowledge the finite nature of life, they may have believed their parents to be indestructible. Allison, who was only 16 years old at the time of her then 46 year-old father’s car accident in 2012, shared that she “hadn’t anticipated” being relied on by her family to fulfill some of the roles and responsibilities her father once had. When asked if she had thought she may have had to do so later in her parents’ lives she confessed, “I wasn’t really prepared to do that either.” This may be attributed to her young age, where she is developmentally, or her willingness to identify her parents’ mortality. Of the four adult children, Allison was the only who lived at home and did not have a family of her own.

Michael, on the other hand, who was 26 years-old when his father sustained a TBI in an automobile accident has a family of his own and anticipated caring for his parents when they got older. The abrupt nature of the TBI caught him off-guard, however:

> ...I think that since it was such a sudden onset and it wasn't a gradual thing...that it was very difficult to kind of jump into that role because yeah, to be honest I was expecting some kind of care along this line, you know, in 15 years, 20 years. You know...but I wasn't expecting it when we just got done visiting Santa Claus and having some hot cocoa.

A tensioned vacillation began to emerge as Michael, Allison, and Jessica discussed how they were in a position where they had to assume greater roles and responsibilities for their parents, invest a greater amount of time to complete those roles and responsibilities, and subsequently, potentially struggle to embody a raised position within the family system than that of child. It is possible that when interacting with each other, that the parent who did not have the TBI and the adult child had begun to blur the relational boundaries between friend, child, and counselor.

Birth order also appeared to be a unique factor to this adult children sub-group with regard to how much the mother relied on them for support and help. Jessica shared that all that she did is attributed to the role she has always played in the family, “That’s my role in the family. I’m the helpful child.” This reliance was sometimes perceived to occur at an overwhelming frequency, particularly for Michael and Jessica who had families of their own to care for and no longer resided with their parents. Jessica’s parents had moved closer to her following her father’s TBI onset and still her mother called her “several times a day” while she also “went over there [her parent’s house] two to three times a week.” Jessica illustrated the tension she felt between meeting the needs of her parents and those of her own family stating,

> And it’s stressful because it just feels like we can’t...They want us to meet their needs and we’re trying but we’re, we’re trying to keep up with our own needs too...And sometimes it feels like our [Jessica’s family] stuff falls in the cracks.

Michael, Allison and Jessica all shared bits of their experiences that indicate a sense of loyalty, if not to the parent who sustained the TBI, to siblings and the uninjured parent. This loyalty appeared to have repercussions on mental health and wellbeing, particularly for Jessica.

Tiana. As discussed throughout this chapter Tiana, who was 22 at the time of her then 60 year-old father’s car accident in 2012, shared an experience that was markedly different in a variety of areas from those of the other family members involved in the present study. A self-confessed “daddy’s girl”, Tiana shared that she had always been “really close” with her father and had “never really thought anything would happen to him.” Four words that Tiana used to describe her father before his car accident were “Hardworking, generous, kind, [and] awesome.” When prompted for four words describing her father following the onset of his TBI Tiana replied with a smile, “He’s still the same...Same four words.” To Tiana, her father looked “exactly the same” with minute differences that only someone close to him would notice. Although she acknowledged the awkwardness when her father asked her to wipe him after using the bathroom, the way in which she regarded her father never changed. “Even if my dad was a vegetable,” she shared, “he would still be my father.”

It is possible that Tiana’s unique experience can be credited to her ethnic and racial heritage. She was the only family member in the current study to share her cultural background.

Being of partial Korean descent, communalism may have influenced the way she handled her father's TBI. It can also be posited that the differences in her experience are due to her perception of her father's near-complete recovery from the injury. Her ability to view her father in this way may have allowed Tiana to reframe the experience and the way in which she shared it in her interview. There are endless possibilities and conjectures that can be made, as to why Tiana's experience stands out from the five others involved in this study.

Conclusion

The purpose of the present study was to explore the experiences of family members of adults who have acquired a TBI within the last three years. Although each experience was unique with regard to how it was felt and encountered, six areas were experienced across all six accounts. Those areas were: (1) an abrupt onset requiring necessary and rapid response, (2) the multiform manifestations of fear, (3) the significant role changes within the family system, (4) the diverse practices for emotional expression and protection, (5) the depth to which grief is experienced, and (6) the immutable alterations to established plans for the future. Chapter 5 will discuss the implications of these findings as it pertains to researchers, family members of a person with a TBI, practitioners, and evaluate whether the application of ambiguous loss theory is appropriate for the familial experience of TBI.

CHAPTER 5

DISCUSSION

The purpose of the present study is to explore the experiences of family members of adults who have acquired a Traumatic Brain Injury (TBI). The research question that was sought to be examined was: How do immediate family members describe, and what is the meaning of, the experience of having an adult family member with an acquired TBI within the first three years. Research posits that the family members will be impacted equally to that of the member with the brain injury, if not more so (Brooks, 1991). The literature further states that due to the likelihood that family members will have a direct impact on the person with the TBI and the rehabilitation process, it is important to gain a deeper understanding of their experiences, with particular attention paid to how they cope emotionally and practically (Dausch & Saliman, 2009; Oddy & Herbert, 2003).

Factors which may impact the experience of the family members of a person with a TBI include social perceptiveness; impaired control and self-regulation of the person with a TBI; the family's perception of the impact; premorbid family stability and coping behaviors; the trajectory of the illness and rehabilitation process; behavioral, personality, and emotional changes; as well as issues pertaining to memory, concentration, problem-solving difficulties, and executive functioning, are all argued to have an inverse relation to caregiver life satisfaction (Brooks, 1991; Brooks et al., 1987; Duff, 2002; Flanagan, 1998; Knight et al., 1998; Kosciulek, 1995; Kreutzer, 1992; Lezak, 1978; Livingston et al., 1985; McKinlay et al., 1981; Oddy, 1995; Oddy et al., 1978; Thomsen, 1974; Thomsen, 1984; Ergh et al., 2003; Kneafsey & Gawthorpe, 2004; Ponsford et al., 2003; Semlyen et al., 1998). The repercussions of a TBI on the family system have been reported to remain impactful up to 15 years post-acquisition (Frosch et al., 1997).

Comparison to Previous Research Findings

The present study has confirmed much of what the TBI literature has reported within the past 30 years while also bringing lesser acknowledged or focused on areas to the forefront of the experience that family members have when there is a person with a TBI within the family system. The sections that follow will discuss each of the identified themes of the present study in relation to previous brain injury research. The appropriateness of the application of ambiguous loss theory to family members of persons with a TBI will be evaluated. In addition, limitations, implications, and suggestions for further research will be reported.

An abrupt onset requiring necessary and rapid response. As presented in the current study, the initial period of TBI onset is experienced as a hastening of the anticipated future to the present. Rapid onset leads to a whirlwind of emotions, thoughts, and fears for each individual. As they tried to understand, process, and be present in the moment, the family members had to simultaneously provide information and decisions that could greatly impact their loved one. Previous knowledge or experience with TBI added to the pressure felt to respond and decide both accurately and expeditiously. Caregiver emotional distress began upon injury onset and was exacerbated when the individual with the TBI is discharged from acute care. It has been postulated that due to the focus of practitioners and care team members being primarily on the person with the injury and not toward helping the family to process and understand, that family members tend to perceive a lower overall quality of their life and greater psychiatric morbidity both during and following hospital treatment (Sinnakaruppan & Williams, 2001).

The family members sought to make the future known during this period, but instead were stuck in an uncomfortable period of waiting. Literature supports this aspect of the experience as being common, positing that the family has needs while their family member is engaged in in-patient care. These needs include the need to know information concerning treatment, drugs administered, and pain management both while the member with the TBI is in the hospital and once they are discharged; the need for consistent information; the need for involvement in care; help finding and evaluating providers; hospital discharge support; employer support for the family caregiver; life planning assistance; networking needs; and the need to make sense of the experience (Bond et al., 2003; McLennan et al., 1996;   Lefebvre & Levert, 2012; Leith et al., 2004; Murray et al., 2006; Rotondi et al., 2007; Sinnakaruppan & Williams, 2001).

Directly following the TBI onset and the execution of medical care, every action, behavior and sound was analyzed by the individuals in this study as being either potentially promising or of concern. Optimism was present, but not without caution. During periods of coma, whether medically induced or otherwise, the family members sat without much indication of the overall outcome. All existing family roles, known frameworks by which they operate, and general rules of engagement were dependent on the outcome of this experience. The men and women who participated in the present study all communicated a deep desire for answers regarding the prognosis of the individual with the TBI, and a need to understand how the established relationship would change, consistent with the literature. The experience of uncertainty regarding the future, anticipated necessary caregiving, precarious condition prognosis, and the self-perceived coping ability of the caregiver is reported to result in an exacerbation of distress (Lefebvre & Levert, 2006; O'Callaghan, et al., 2011; Turner et al., 2007).

Dependent upon the severity of the injury, there may be several life sustaining technologies utilized, as well as physicians and other care team members who are instructing the family that their loved one may not survive the injury (Oddy, 1995). For the people in the present study, seeing what was once an autonomous spouse, partner, or provider dependent upon a variety of machines, including feeding tubes, ventilators, and medication dispensers, proved to be very distressing. They were presented with a life or death situation that had not been anticipated to occur for a number of years, if at all. Should life be the outcome, it was automatically believed that the individual with the TBI would return to functioning as he or she was prior to the TBI. Most often not the case, this belief is a leading factor associated with extended grieving processes (Oddy, 1995). The interactions that occur between and within family members during this time is not unique to TBI, but is also shared with any person who has experienced a sudden, life-threatening event of a family member.

The multiform manifestations of fear. Within the present study, fear was experienced in a multidimensional way as it pertained to having a person with a TBI in the family. The unanticipated nature of the injury and resulting disability brought the concept of mortality to the forefront of the person's mind. Concerning family resiliency, the literature supports this experience in positing that "family members may be tormented, hoping for the best while fearing the worst," and developing problematic clinical symptomology (Walsh, 2006, p. 201). Other phenomenological research has reported that, "close relatives' struggles with feeling of fear and despair – mixed with the willingness to fight - are seen from the beginning when they 'got into the unknown'" (Jumisko, Lexell, & Soderberg, 2007, p. 362).

Fear and sadness were both present for the family members in this study as they tried to predict the future. Concerns, pertaining to the permanency of the situation as it was observed in the initial days and weeks since TBI acquisition arose. Both while in the hospital and after being discharged, the emotional and physical toll of having a family member sustain a TBI was great, and produced frightening thoughts of situational permanency.

At least two of the family members who participated in the current study were required to make decisions which had the potential to greatly impact the prognosis and ultimate outcome of their loved one's disability beginning immediately following TBI onset, as is also documented within the TBI literature,. During acute treatment, the present study found that family members felt great pressure to act quickly and accurately while also experiencing an intense emotional reaction to the situation, causing periods of time to seem as if they were passing rapidly. While at the hospital, the family had few resources to inform important decisions, which left them to speculate as to the correct direction of care. In a desire to honor the wants and needs of the affected family member as the family knew them prior to TBI acquisition, these family members feared the potential of a wrong decision that may have dire consequences. This fear continued following discharge if the person with the TBI was unable to make sound decisions for themselves and a family caregiver was awarded permanent guardianship. With regard to the ambiguity of the situation, the literature finds similar emotional reactions where "the family may feel tremendous guilt and may be unable to make decisions, fearing that the wrong choice will be made" (Betz and Thorngren, 2006, p. 361).

Fear, as well as the specific areas in which a person becomes fearful while experiencing a family member with a TBI, is an area that is not well documented within the TBI literature. It is possible that this is because people assume that fear is an innate part of this experience. The present study would then confirm this assumption. However, fear, as exhibited in the present study, is not just a one-dimensional emotion, but rather, pertains to several different areas of the experience for each person. Specific areas of fear that the present study contributes to the literature includes: the permanency of the new personality, the possibility that the individual with the TBI may engage in risky behavior, not knowing who would take care of the uninjured spouse in the event of their decreased health status, and of the family member dying and leaving the injured spouse without their care.

The significant role changes within the family system. To the degree that the TBI alters family functioning as a whole, the uninjured family members in this study had to adjust in order to return the family system to a state of homeostasis. Areas within the family where the person with the TBI primarily took responsibility included financial responsibilities, caretaking, transportation, and various household chores. As illustrated within the present study and the literature, the loss of this person's ability to fulfill his or her roles in the family may result in other family members having to compensate for this absence, by taking it on themselves (Von Suhr, 2003). Being assigned and having to balance multiple additional duties, some of which the family member may not be comfortable performing in, was shared in the experiences of those involved in the current study. This resulted in overwhelming feelings of distress, anger, resentment, and helplessness. There is a strong position within the research that supports this finding stating that caregivers may feel "overwhelmed due to the lack of assistance by other significant others, feeling restricted socially and dealing with the reality that their pre-morbid loved one may be permanently different" (Elbaum, 2007, p. 275; Dell Orto & Power, 2000; Jumisko et al., 2007; Von Suhr, 2003).

Both Ruth and Andrea shared that they felt as though they had been cornered and were being forced to perform these tasks in order to sustain their family. This held true especially if there were small children in the house, as was the case for Ruth. Several research studies report what has been shared by those engaged in the present study; that the daily lives of the uninjured family members have been permanently changed (Ponsford, et al., 2003; Rappaport, et al., 1989; Thomsen, 1984). The current study illustrated how each individual member began to reframe his or her relationship to the individual with the TBI over time. Spouses shared that they no longer saw themselves as partners, but as caregivers or a parent, as is documented within the literature (Gosling & Oddy, 1999; Muir, et al., 1990). Children report now seeing the parent with a TBI as a child, possibly resulting in young children needing to mature emotionally and cognitively much quicker than their peers (Muir et al., 1990).

Tiana’s experience was quite different in this particular area and it appears to be, at least in large part, due to her father’s near complete recovery. Having reported that he is practically back to the person he was before the accident, with minimal behavioral, emotional and physical changes, he was largely independent. This supports the position reported in the literature that states that the severity and level of impact on functioning in the individual with the TBI determines whether the person with the disability can continue to fulfill the roles s/he operated within, such as husband, wife, child, and employee (Frosh et al., 1997). Tiana did share that she acted in a manner that was protective of her father at times. Having had to be a support and caregiver for a length of time, her experience appears to support the presupposition that “the increased responsibility for the ill person changed [sic] when the person got better, but it never ended” (Jumisko et al., 2007, p. 363).

The diverse practices for emotional expression and protection. Much of the research pertaining to family members of people with a TBI inquires into the degree to which coping methods are used or seek to confirm whether a hypothesized intervention could address established areas of coping, such as social support (Ergh et al., 2003). Of the studies that research the varying forms of coping mechanisms for the family members of people with a TBI, many are quantitative in methodology resulting in participants having to select from pre-existent categories (Wells et al., 2005).

The limited number of qualitative studies that provided open-ended questions regarding coping strategies reported that family members may engage in religious rituals or seek support within the religious community (Duff, 2002), and seek support from family and friends (Duff, 2002; Smith & Smith, 2000). Knight et al. (1998) report that while conducting their research, the spouse of a person with a TBI had emphasized that the idea of coping did not exist, but rather referred to doing what she had to do without a choice. Other qualitative literature did not include individual responses, but provided the categories that were developed from analyzing them. Man (2002) included categories of acceptance, rationalization, planning activities, actively looking for solution, seeking support and encouragement, directing attention to other activities, and use of social resources. Kosciulek's (1994; 1997b) supposition that coping strategies vary depending on the region in which they are learned and executed encourages the use of more qualitative, open response methodology in this area in order to attain specific practices.

In agreement with existing literature, those family members involved in the present study also shared that they made use of their religion and religious community, utilized family and friends as support systems, and stayed busy in other areas of their lives as a means to redirect their focus. The present study added to the body of TBI literature by identifying ways of emotional expression or protection that had not been previously reported, such as engaging in sports and competitive events, over-investment into the happiness of others, the lowering of expectations for the person with the TBI, or intently ignoring the situation within their home as a whole. Engaging in sports and competitive events may have provided the family member with a medium where they can let out pent up aggression, frustration, or fear. The exertion allowed for both a physical and emotional exhaustion that seemed to provide a sense of cleansing. Over-investment into the happiness of others may have served as an opportunity for the family member without a TBI to regain feelings of power over a given situation as well the satisfaction from pleasing others. Finally, shifting the focus away from the impact of the injury on the family and the person with the injury appears to be directly related to the aforementioned levels of fear experienced throughout the process of rehabilitation for the person with the TBI. The latter two experiences appear to have provided an opportunity for the family member to "pause" one area of their life by focusing on others.

The depth to which grief is experienced. Brooks (1991) stated, "For the family members, severe brain injury is forever, although few, if any, family members realise [sic] this in the early stages" (p. 181). To varying degrees, each of the people involved in the current study shared this same experience. Even Tiana, who felt her father has recovered 90% of the way from his injury, cited some long lasting changes to her life including how she now treats her father. For the other people involved, the cycle of hope and disappointment seemed to consistently prolong the experience of grief.

It has been posited within the literature that post-injury deficits and changes, the kin relationship between the caregiver and the person with the TBI, the ability of the family system to cope with crisis-imposed stress, and established family schemas all influence the extent to which the family perceives that they have been affected and are able to adapt (Flanagan, 1998; Kosciulek, 1997b). Furthermore, the trajectory of the illness and rehabilitation of the individual with the TBI is reported to influence the level of hope experienced and overall functioning enacted by the family system and its individual members (Brooks, 1991; Duff, 2002; Knight, et al., 1998). Kosciulek (1997b) postulated that if a family does not value ideologies such as connectedness and the value of a human being with a disability, they are less likely to adapt positively to the presenting situation.

The present study does not support this, but rather illustrates how, through the great love and value that family members have for the person with a TBI, grief is heightened, the cycle of hope and disappointment is extended, the feelings of ambiguity are deepened, and the likelihood that the family member or family system as a whole will not adapt or cope in a positive or effective way is enhanced. This is supported through the research of Walsh (2006) who posited that the cyclical nature of hope and disappointment might hinder the family members' ability to adapt and cope with the sudden onset of the TBI in a loved one. Consequently, "family members may be tormented, hoping for the best while fearing the worst", and developing problematic clinical symptomology (Walsh, 2006, p. 201; Boss, 1999).

TBI sequelae and the effect on the family. To the extent that TBI sequelae impact the psychosocial adjustment of uninjured family members, it is important to acknowledge the lasting negative effects. Variables identified within the literature include: severity of injury; psychosocial maladjustment of the person with a TBI; restrictiveness in the day to day physical functioning of the person with a TBI; the person with the TBI being a father of young children; less marital cohesion and increased marital conflict (Perlesz et al., 1999); impaired social perceptiveness; emotional alterations (Lezak, 1978); memory and concentration problems; problem-solving difficulties; executive functioning deficits (Ergh et al., 2003; Kneafsey & Gawthorpe, 2004; Ponsford et al., 2003; Semlyen et al., 1998); a loss of inhibition; inflexible concrete thinking; irritability (Oddy, 1995); childishness; and aggression being the most disturbing (Brooks et al., 1987; Kosciulek, 1995; Kreutzer, 1992; Livingston et al., 1985; McKinlay et al., 1981; Oddy et al., 1978; Thomsen, 1974; Thomsen, 1984).

For the individuals involved in the present study, those who perceived significant personality changes in their family member that were attributed to the TBI experienced heightened states of grief that altered the foundation of their relationship with the injured family member. Jessica had shared how although her father may look similar to the person she knew prior to his slip and fall accident, that the personality differences were remarkably different. She went on to discuss how she felt she was parenting her parent, who exhibited tendencies that she compared to those of her teenage son. Michael also no longer saw his father as he was before his TBI onset, in multiple areas of his personality. For the people in the present study, the long lasting effects of the TBI on their family member's personality greatly disrupted the relationship between them and prolonged their experience of grief.

Psychosocial health and wellbeing. The present study illustrated how anger may arise as family members experience feelings of persecution from a higher power, hopelessness, loneliness, or abandonment, as a result of the onset of TBI within their family member. The abundance of emotion that was evoked throughout this experience is further complicated by the need to ensure the functioning of the family system, often disallowing for individual family members without a TBI to process or be present with all that they are thinking and feeling. Due to the need to complete and fulfill their tasks and roles, in addition to those they assumed following the family member's TBI, family members were frightful of allowing themselves to experience the emotions attributed to all they have experienced and did not want to risk the possibility of breaking down. This could have potentially resulted in being unable to regain composure and resume everyday functioning. Instead, they may have encouraged an emotional numbing, similar to depression, within themselves in order to push forward to overcome another day.

The experiences shared in this study are in congruence with the existing TBI literature. A number of studies have reported that being the caregiver for a person with a TBI may result in a variety of difficulties including, but not limited to: stress; affective disturbance; depression; anxiety; psychosomatic disorders; substance abuse; financial difficulties; and poor social performance (Albert et al. 2002; Flanagan, 1998; Lefebvre & Levert, 2012; Leith et al., 2004; Murray et al., 2006). The number of unmet needs and of complications brought on by the TBI perceived, are posited to be related to psychiatric morbidity in the caregiver (Kreutzer, et al., 1994a; Moules & Chandler, 1999; Nabors et al., 2002).

Family members are often the ones to provide care for a family member with a TBI (Degeneffe, 2001). It is postulated that this is due to a sense of obligation and necessity that the uninjured family member feels rather than voluntary choice. Kreutzer et al. (1994a) further report that this sense of duty that exists may serve as a predictor for increased depressive symptomology. Ruth's experience of feeling as though she was held captive to her husband's needs and wants, was in agreement with these inferences. Andrea, also a primary caregiver, shared that she has had "situational depression" all of her life and goes through depressive states. She did not elaborate as to whether her depression had been exacerbated by her husband's TBI but did share that she had to work through her depression on her own because, due to adverse reactions, she cannot take any antidepressant medications.

Of relative caregivers to individuals with a TBI, approximately 31%-45% experience clinically significant anxiety, while 21%-32% report clinically significant depression (Flanagan, 1998; Kreutzer et al., 1994b; Perlesz et al., 2000; Ponsford et al., 2003). The present study extends on these postulations, and suggests that close family members who are not the primary caregiver may also experience similar affects, including those close family members who may not live in the same household as the person with the TBI, such as adult children,. Boss (1999) and Duff (2002) hypothesize those family members who experience an extensive loss of control over a crisis situation that includes ambiguity, may feel a barrier to the coping and grieving process, subsequently resulting in greater rates of depression, anxiety, and family conflict symptomology.

The loss of the person they once knew. The people involved with the current study shared that they, at some point throughout this experience, felt a deep loneliness as they longed not only for the personality of their family member with the TBI to return, but were faced with the reality that their partner, spouse, or parent as they once knew them, are likely to be gone forever. For many families in the initial stages of TBI onset, there are two possible outcomes: death or living. For many individuals, these extremes are the only sensible options available, regardless of whether the experience is in reaction to the acquisition of a TBI by a family member or other life-threatening situation. Living is instinctually interpreted as a full recovery from the injury, resulting in a full return to the personality and functioning of that before TBI acquisition. This however, is not the most common outcome for persons with a TBI (Oddy, 1995). Rather, most individuals find that the person with the injury returns to a state physically, cognitively, and emotionally within the continuum between life and death.

For five of the six people involved in the current study, as described above, the family member with the TBI’s physical body remained present while the personality had been drastically changed. Romano (1972) reported that this drastic change, coined personality death, is far greater of a loss than physical death. With personality death, the uncertainty of whether the person will recover and reassume their prior personality and role often leaves family members in a state of constant or extended grief (Duff, 2002; Lezak, 1978; Oddy, 1995; Oddy & Herbert, 2008). This grief is further compounded by forced isolation brought about by the perception that society finds the grief of the family member unwarranted (Del Orto & Power, 2000; Harvey, 2000; Harvey, 2002; Kozloff, 1987; Oddy & Herbert, 2008; Sacks, 1970; Walsh, 2006).

Oddy (1995) posited that how the family caregiver perceives the impact of the TBI on their family member informs the degree to which the family caregiver perceives their loved one to have changed. Feelings of anxiety and confusion within the family arise from the ambiguous nature of a TBI diagnosis, making the uninjured family member cautious about sharing concerns about death and loss to others outside of the experience. As with the aforementioned relationship of family caregivers to clinical levels of depression and anxiety, the present study provides support to extend this postulation to non-caregiving family members through the shared experiences of Michael, Allison and Jessica. Furthermore, the experience of Tiana, a non-caregiving family member who shared that there was minimal lasting impact of the TBI on her father, confirms the inverse when she stated, “he’s still the same.”

Muir et al. (1990) postulated that, “In some cases, the survivor’s family members report that fundamental aspects of the survivor’s personality have changes [sic]…In other words, that the person they knew and loved is ‘dead’” (p. 436). Allison’s experience with her father, who incurred a TBI when she was just 16 years-old, supports this statement. Allison had shared that she had seen the enjoyable and entertaining part of her father disappear and that without those qualities, her father no longer felt like the same person to her. The ambiguity of her situation, supported within the literature, was captured when she conveyed that speaking with her father following his accident was as if she were meeting someone for the very first time that had miscellaneous memories of her and their prior life together. The cycle of hope and disappointment was addressed by Michael when he commented that he viewed his father's TBI as a loss "in some sense" but that he would not classify his reaction as grief due to his anticipation of milestones that he believed would be achieved in the future.

Ruth seemed to have an inflated perception of who her husband was prior to his TBI onset. Despite stating that her relationship had been moderately strained prior to onset, Ruth conveyed concerns regarding her husband's ability to return to a state where he would act as her "knight in shining armor." This may have extended and deepened the grief that she has experienced, as the misinterpretation of external events has been reported to mediate emotional distress (Koopermans et al., 1994; as cited in Stebbins & Pakenham, 2001). Ruth's conviction toward recalling her husband's good qualities and possibly elevating him to a position of honor, according to the definition found within the literature, supports the postulation of the existence of unrealistic misinterpretation within the experience of having a family member with a TBI. This may prove troublesome as the literature further posits that "unrealistic misinterpretations are related to caregiver psychological distress after controlling for the effects of characteristics of the caregiving situation and the individual with TBI" (Stebbins & Pakenham, 2001, p. 187). How Ruth perceives her husband as he was now and prior to his accident may be one step in a transformative process that she engaged in, possibly mitigating the emotional pain or thoughts that may have been deemed socially unacceptable. The perceived meaningfulness of the brain injury affects family adjustment outcomes, at times more significantly, than clinical assessment scores (Kosciulek, 1997; Muir & Haffey, 1984; Stebbins & Pakenham, 2001). On this premise, it is critical for the family members to be able to honestly and accurately evaluate the condition of the family member with a TBI. Only then will the family system, as a whole, be able to begin to cope and adapt to the disability successfully (Beck, 1995; Lazarus & Folkman, 1984; Stebbins & Pakenham, 2001).

The literature has posited that the reactions of the family, as well as the pursuance of coping and adaptation, typifies that seen in family members who have experienced a death or significant trauma of a loved one (Man, 2002). Kean (2010) reported that when speaking to family members of individuals who have a severe TBI, most utilize the past tense when discussing their loved ones. In order to attain a strong level of coping and adaptation, Smith and Smith (2000) suggest that the family members of individuals with a TBI "…needed to mourn the loss of the person they knew" (p.30).

The immutable alterations to established plans for the future. As with opportunities for emotional expression and protection, the TBI literature provides little insight in the area of changes to plans for the future. Superficially, research pertaining to the future identifies that the family members have difficulty with the significant, life-long changes that have occurred and will continue to as a result of the TBI. The literature postulates that by 12 months post-injury, families begin to establish a clear idea of what the future will look like (Ponsford et al., 2003; Rappaport et al., 1989; Thomsen, 1984). The experience of having a family member with a TBI has been posited to be replete with loss, and a concentration of those feelings manifest as the family member tries to envision the future of, and with, the person with the TBI (Godwin, 2014; Kean, 2010). Kean (2010) extrapolated several broad categories in which loss is experienced in his research, one of which was future dreams. The literature does not, however, discuss how specific, established plans have been changed and the resulting emotions that arise from this aspect of the experience of having a family member with a TBI. The present study added to the existing body of TBI literature by identifying a number of specific, established future plans and gaining insight as to the emotional effect the necessary changes had on the uninjured family member.

The family members of those who had incurred significant personality changes as a result of their TBI in the present study felt that their future had been considerably changed, dwindled, or taken away from them completely. For Tiana, who believed that there was little residual impact from her father’s TBI, there were very minute changes to her foreseeable future. Allison, however, realized that she might never have the anticipated experience of her father walking her down the aisle for her wedding; a dream that she had maintained since she was a young girl.

Relationships that were established prior to the TBI between the injured and uninjured family members may feel more distanced or disconnected from the person following their TBI, or could be lost altogether. Some family members may not be able, or want, to get to know someone they perceive as “new.” Jessica experienced a sudden loss in some areas of the relationship she had built with her father in the few years preceding the onset of his TBI. Their relationship following her father’s accident no longer included casual conversations. She also discussed how the TBI had impacted her children in that they are unsure of their relationship with their maternal grandfather and often avoid being around him.

Projections of the future become bleak as the family members without a TBI reconcile that what had been planned with their family member with a TBI may never come to fruition or, at the very least, as it had once been envisioned. Michael shared that quality time with his father, which might require power tools or situations that could be potentially harmful, could not be casually enjoyed as they were prior to his father’s accident. Rather, he felt as though he needed to watch over his father, just as he would with his young child, and ensure that he remained safe from harm. Michael later shared that there are other activities that he hopes he can resume with his father such as sporting events.

The shared enjoyment of events prior to TBI onset may not be able to be pursued following the TBI due to acquired limits in stimulation or physical function. Andrea had articulated how the future she envisions no longer aligns with what is possible following her husband's TBI including traveling and the possibility of her husband caring for her during times of illness or poor physical health. Due to the significant personality and physical changes in their partner, in conjunction with the role changes that the uninjured spouse may experience, there may be feelings of loneliness due to the perception that the uninjured spouse no longer has a partner to proceed through life with, as was the case for Ruth.

For the family members of those persons with a TBI, their sense of the world is much more defined. Prior to the TBI onset, the uninjured family members held a sense of their future and the world that was characterized as having a multitude of options from which to choose from and explore. Jumisko et al. (2007) postulates that the family members of people with a TBI are "…forced to relinquish the life they had planned and instead find a new way of living with the changed person" (p. 363). This may result in a concept of the future that seems to feel stifling, ensnaring them into a given point in time where they feel they are unable to progress any further.

Relationship of Findings to Ambiguous Loss Theory

Boss (1999) defined ambiguous loss as "an incomplete and uncertain loss" (p. 3). Although this ambiguity may be exhibited as a result of two distinct situations, that which applies to the experience of having a family member with a TBI involves having a family member be physically present but psychologically absent. Ambiguous loss is composed of several factors that serve to hinder the grief experience of the family as a direct result of the unattainable resolution to the loss, subsequently suspending family dynamics until comprehensibility is provided (Betz & Thorngren, 2006; Boss, 1999; Boss, 2002; Boss, 2004; Von Suhr, 2003).

It is posited that ambiguous loss is the "most stressful kind of loss because it defies resolutions and creates long-term confusion about who is in or out of a particular couple or family" (Boss, 2006, p. xvii) and can result in "behavioral and psychological helplessness" within each of the members included in the family system (Boss, 2004, p. 211). Betz and Thorngren (2006) acknowledged that this phenomenon might result in family members going through unending cycles of hope and disappointment.

Physical symptoms of ambiguous loss include fatigue, headaches and sleep disruption, while cognitive issues manifest as an ongoing preoccupation with the loss and its surrounding circumstance, forgetfulness, and worry. Behavioral impacts include persistently remaining quiet, hypervigilance, dependence, avoidance, and overall withdrawal from daily activities. Lastly, emotional complications from ambiguous loss include loneliness, anger, irritability, anxiety, depression, or apathy (Betz & Thorngren, 2006; Blieszner, et al., 2007; Boss, 1999; Boss, 2002; Weiner, 1999).

The current study illustrated how each of the emotional complications was embodied for five of the six people who shared their experience. Michael, Andrea, Jessica, Allison and Ruth experienced negative emotions ranging from "scared", "reminiscent", "overwhelmed", "depressed", "anger", "stressed" and "isolated." Furthermore, these five individuals also shared how they independently experienced moments of hope as the person with the TBI made progress in rehabilitation or if they acted in a manner characteristic of their personality prior to onset. In accordance with the vacillating nature between longing and disappointment of ambiguous loss, these family members did not maintain much hope for their injured family member's recovery. With each positive experience, however, they could not help but hope for just an instant that they may have been wrong. This natural fluctuation is documented within the ambiguous loss literature. Boss et al. (2003) posit "…it is human to hang on to any sliver of hope for some miraculous return" (p. 456).

Tiana shared a different long-term experience regarding having a family member with a TBI. For her, there was boundary ambiguity at the beginning of her journey. Boundary ambiguity, being independent of ambiguous loss, is broadly defined as "a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system" (Boss & Greenberg, 1984, p. 536; Carroll, Olson, & Buckmiller, 2007). For those who have a TBI, it has been reported that boundary ambiguity develops as a result of disruption to interpersonal relationships, among other areas (Landau & Hissett, 2008).

Tiana's ambiguity was also coupled with fear, mild role changes, and a period of time where she was unable to attain concrete information pertaining to her father's prognosis. As Tiana's father improved both physically and cognitively, returning to a state near that of himself prior to TBI onset, Tiana no longer found herself in this ambiguous state. She was able to return, for the most part, to her role as daughter and her father progressed to a position of general independence. Boss (2007) postulated, "When loss combines with ambiguity, there is no closure and the rupture continues until a perceptual shift restores relations, meaning, and hope" (p. 108). For Tiana, the perceived potential for loss during the time when she was unsure of her father's prognosis was reduced as he regained functioning. Michael, Andrea, Jessica, Allison, and Ruth remained in a state of rupture, as there had yet to be a full restoration of relationships, meaning, and hope.

The seven assumptions. Boss (2007) posited seven assumptions of ambiguous loss theory that "represent key elements underlying the theory" (p. 107). The following section will assess the fit of the experiences shared by those family members involved with the current study to each of the seven assumptions.

A psychological family exists, and that this perceived construction of one's family may differ from the physical or legal family structure. The first of Boss's (2007) assumptions was not explicitly assessed in the current study. None of the individuals who shared their experiences explicitly identified who was included in their perceived construction of family. Each participant did, however, include individuals such as children, grandchildren, siblings and parents when discussing familial considerations as it pertained to having a family member with a TBI. No non-genetic family members were mentioned, although this does not rule out the possibility of their inclusion. The current study supports the first assumption through informal references to individuals within the family who were a part of their experience of having a family member with a TBI.

Ambiguous loss as an external situation is assumed to be neutral. The experiences shared in the current study support the second assumption. The phenomenological methodology utilized served to ascertain the perceived impact of ambiguous loss and boundary ambiguity of each family member's experience. Aside from the initial diagnostic and evaluative assessments that were conducted at the beginning of treatment for the individual with a TBI, no family member reported the results of standardized tests. Rather, they conveyed how the experience was influenced and informed by their interpretation or perception of the impact that the TBI had on their family member, and the family system as a whole.

Cultural beliefs and values influence a family's tolerance for ambiguity and how it is perceived. The current study sought to establish an environment that was comfortable for the family members who participated. Phenomenological inquiry is based heavily in the ability to establish relaxed and safe conversation. Rather than focus on specific demographic criteria, the researcher developed a rapport with the family members involved. It is believed that by doing so, the researcher was able to gain much richer data regarding the family member's experience of having a family member with a TBI. Unfortunately, this precludes the current study from wholly assessing the application of Boss's (2007) third assumption regarding the influence of cultural beliefs and values on a family's tolerance for, and perception of, ambiguity. The only person to volunteer information regarding their cultural background was Tiana, who is of partial Korean descent. It can be hypothesized that this may have influenced her reaction toward her father's TBI, as she was the only participant who felt as if there were minimal residual changes to her father but this would remain conjecture at most. The study as a whole cannot provide support for this assumption due to a lack of data.

With situations of ambiguous loss, truth is unattainable and thus relative. Particularly towards the beginning of the experience, family members who participated in the current study shared that although they were able to gather general information regarding brain injuries, from a variety of sources, the prognosis for their family member with the TBI remained a mystery. Doctors were unable to answer questions regarding the injured family member due to the convoluted nature of the injury and the numerous factors that, over time, could influence recovery and rehabilitation.

Family members who did not have a TBI, instead, developed their own meanings and interpretations of the traumatic event on the impacted family member and the family system as a whole based upon their perceptions. Due to the evidenced cycle of hope and distress illustrated in the experiences of the individuals involved in the current study, these meanings and interpretations were constantly in a state of evaluation and change. The current study also provided insight, through the inclusion of two mother/daughter dyads, as to how perspectives within the same family may vary by individual family member and how that individual perceived the impact of the TBI on their family member, independent of how another family member feels. The dyads of mother and daughter shared their unique experiences to having a husband or father with a TBI, all of which displayed the relativity of the experience and independent meaning making. The experiences shared in the current study provide support for the fourth assumption of ambiguous loss theory.

Ambiguous loss is inherently a relational phenomenon and thus cannot be an individual condition. Ambiguous loss theory aids in understanding the relational processes within family systems that are altered through the intrusion of ambiguous loss. The fifth assumption of this theory is that ambiguous loss is not a problem within the family system or the ability to relate to the members within it, but rather the consequences of an outside influence. When a family member has a disabling condition, the outside influence is the disability. As in the current study, the outside influence is the TBI. Each family member experienced relational and individual sequelae that may have included emotional or behavioral symptoms until such a time that the outside influence, or TBI, was reframed in a way where the family was able to regain meaning and coherence.

Five of the six people who participated in the current study all meet Boss's (2007) fifth assumption. Michael, Andrea, Jessica, Allison and Ruth, all reported experiencing long-term, perpetual emotional and cognitive distress as a direct result of their family member's TBI. Considerable personality change in the person with the TBI, convoluted by the vacillation between hope and disappointment regarding prognosis, rendered these five family members unable to reframe their experiences and regain family cohesion just yet. Until such a time, they may remain in a position where their distress will continue. Tiana, however, was able to reassess her situation following her father's perceived improvement and return to near total independence, and has allowed her to reframe this experience into one of growth and love.

There is a natural resiliency in families. This assumption was not explicitly addressed in the current study. The experiences shared by all six family members, however, illustrated various facets of resiliency including a renewed commitment to the family as a whole, the redistribution of roles and responsibilities, and the ability to step beyond wrongs that may have occurred in the past between them and the person with the TBI in order to attain better overall care. In addition, many of the family members involved in the study engaged in a variety of emotional expressions that did not put the individual with the TBI in any position of risk or retribution for resentment. The experiences shared in the current study presents support for the assumption of a natural resiliency in families, despite having not deliberately addressed it in the line of interview questioning.

A phenomenon can exist even if it cannot be measured. The TBI literature has posited that it is not the clinical measurements that inform family adjustment to the injury, but rather the extent to which family members of individuals with a TBI perceive the TBI to have affected the family member and the family system as a whole (Kosciulek, 1997; Muir & Haffey, 1984;

Stebbins & Pakenham, 2001). Data regarding ambiguous loss has predominantly been gathered through qualitative means such as interviews. Boss (2007) advocates for a quantitative method of data collection, however. Experiences of the family members involved with the current study often include specific situations and emotions that may not be socially accepted, and may result in a socially motivated need to hold them in secret. This can serve as a hindrance to those trying to measure or determine their existence. The seventh assumption is supported in the current study. Despite whether or not ambiguous loss is quantifiable, it still exists within the qualitative realm of experience.

Considerations for the theory. The experiences shared within the current study supported six of the seven assumptions of ambiguous loss theory: 1. A psychological family exists, and that this perceived construction of one's family may differ from the physical or legal family structure; 2. Ambiguous loss as an external situation is assumed to be neutral; 4. With situations of ambiguous loss, truth is unattainable and thus relative; 5. Ambiguous loss is inherently a relational phenomenon and thus cannot be an individual condition; 6. There is a natural resiliency in families; and 7. A phenomenon can exist even if it cannot be measured (Boss, 2007). The support for the application of ambiguous loss theory to the familial experience of TBI is established through the alignment of the experiences of those involved in the current study to the posited assumptions (Boss, 2007) and attributions of stress when engaged in ambiguous loss (Boss, 1999; as cited in Price, Price, & McKenry, 2010).

When deliberating on the application of ambiguous loss theory to the familial experience of TBI, inclusion criteria should be considered. That is, this theory may not be appropriate for family members of those people with a moderate to mild TBI, or those who have made substantial rehabilitation gains. As with the experience of Tiana, family members of such individuals may experience boundary ambiguity, but the current study does not support the possibility that they would experience ambiguous loss as defined in the literature.

Summary. Ambiguous loss theory is particularly well suited for application to the familial response to a TBI within the family unit due to the unique and irreconcilable nature of the condition. As has been illustrated within the current study, the ambiguity surrounding the experience interferes with adaptation, often producing depression and conflict (Betz & Thorngren, 2006; Blieszner, et al., & Winston, 2007; Boss, 1999; Boss, 2002; Weiner, 1999). Patrick-Ott and Ladd (2010) posited that in studying parents of children who had been born with a disability "feelings of loss and disappointment are revisited throughout the child's life span as the child grows, matures, and yet is unable to master age-appropriate developmental milestones or experiences" (p. 76). The current study supports the extension of this observation to adult persons with a TBI and their family members.

As with ambiguous loss, the insertion of a TBI into the family system not only disrupts family functioning, it also results in a lack of clarity regarding who is "in" and who is "outside" of the family and regarding the designation of appropriate roles for each family member (Price, et al., 2010, p. 9). Boss (1999) posited that ambiguous loss is highly stressful and attributed such levels of "stress to the following factors: (a) People are unable to problem solve because they do not know whether the problem is final or temporary; (b) the ambiguity prevents people from adjusting by reorganizing their relationship with the loved one; (c) families are denied social rituals (e.g., funeral, death certificate) that usually support a clear loss; (d) friends/neighbors tend to withdraw rather than give support; and (e) ambiguous loss may continue for a long time; therefore, those who experience it become physically and emotionally exhausted" (as cited in

Price, Price, & McKenry, 2010, p. 9). The current study supports all of the listed characteristics pertaining to ambiguous loss and the stress it creates within the system.

Limitations

The current study had several limitations that should be considered prior to the interpretation and application of results. As a qualitative study of phenomenological methodology, the results contained within this manuscript are not generalizable to all family members of persons with a TBI, but rather are the unique experiences of six family members that have several aspects of their experiences in common. Moustakas (1994) ascertains that it is the inconsistencies across shared experiences that add authenticity and credibility to the study.

The interpretation of the results were developed by the researcher following a period of bracketing, in an effort to allow for focus to then be directed to the experiences of the family members involved in the study. The interpretations were discussed with a faculty member in an effort to consider alternatives. It cannot be guaranteed, however, that the researcher was devoid of all pre-understandings as they pertained to a personal experience with familial TBI. Although pre-understandings are understood within the phenomenological literature as being inherently part of individuals in the world, it should be noted nonetheless.

The demographic diversity of the individuals involved in the current study was limited in a number of areas. Despite having a large variation in the age of the family members involved, all but one of the six participants was female. In addition, for all of the family members involved, the person with the TBI was either a husband or father. The current study provided no insight on how the sex of the family member with or without the TBI altered or affected the individual experiences and perceptions. Stereotypically, women provide more of a caring and relationship focused approach to the family. It is possible that if the mother or wife had been the person to incur the TBI, that recollection of the experience by family members who were not injured could have been dramatically different from those that were shared in the current study. Additionally, if the family members within the present study were more balanced with regard to gender, greater insight may have been provided into the impact on the father/son dichotomy and relationship. Furthermore, the intention to establish a comfortable, safe environment that was conducive to a discussion of sensitive content precluded the collection of information pertaining to race/ethnicity or socioeconomic status. These influences may play a role in the interpretation and adaptation to having an individual with a TBI in the family system, however the current study was unable to assess for this.

Although each experience of the six shared experiences were unique and provided valuable insight, two mother/daughter dyads representing two distinct families were of those interviewed. Of the six individual experiences, four pertained to two people with a TBI. This may have limited the breadth of the experiences shared. Conversely, however, including the dyads may have provided greater insight into the variability of the experience when seen from different relational standpoints. As with all experiences, time may have influenced the way in which the events are remembered or interpreted. Interviewing two people from the same family regarding the same event seemed to provide experiences mitigated, in part, by developmental stages, difference in relational expectations, and overall maturation

Each individual that participated in the current study was recruited from a mid-Michigan brain injury rehabilitation facility. The current study limited participation to those individuals who had a family member incur a TBI within three years of the date they were interviewed. This criteria was applied because it was believed this small time window would allow for a more fresh and raw recollection of pertinent emotions and experiences. The three-year time-frame since onset also functioned as a method to reduce the influence of any care the family members may have received at this facility or other outside sources (e.g., therapy). As each person reacts, perceives, and interprets their own timetable in their own way, this was not necessarily guaranteed in the current study. The potential remains that a family member of someone with a TBI that was incurred longer than three years ago may share experiences that are similar to those family members who are within three years of onset. It is also possible that those family members who are involved in available support groups are characteristically different socioeconomically or in their personality from those that do not, or cannot, attend. A greater variation in recruitment locations and time since onset would have allowed for a more representative representation.

Despite limitations, this study and the experiences shared by those involved provoked what has been coined as a ‘phenomenological nod’, by the researcher. Van Manen (1997) stated that “a good phenomenological description is collected by lived experience and recollects lived experience-is validated by lived experience and it validates lived experience” (p. 27). The description developed in the current study validated the personal experience of the researcher, who also has a family member with a TBI. This process is also referred to as the “validating circle of inquiry” (van Manen, 1997, p. 27). Phenomenological validity was achieved in the current study as the essential description of the experience was identified within and across all six individual recollections. In accordance with Giorgi (1988), “If the essential description truly captures the intuited essence, one has validity in a phenomenological sense” (p. 173).

Implication for Practitioners

The current study has provided insight regarding the familial experience of TBI that may benefit practitioners in effectively addressing family coping and adjustment needs. Support for ambiguous loss theory was identified through the alignment of the experiences of the six family members involved in the present study to Boss's (2007) seven assumptions and stress level attributions (1999; as cited in Price et al., 2010). Although there remains a need to evaluate this application more extensively, in addition to quantitatively, it is important to acknowledge the potential for the development of an appropriate grief model based on ambiguous loss theory. In doing so, clinical practitioners can begin to better serve family members during acute care, and to provide greater long term support following discharge, resulting in potentially greater coping and adaptation outcomes.

Oddy and Herbert (2008) identified the importance of medical staff having an "understanding of why family members react as they do and of the possibility and causes of friction between staff and families" so that practitioner behaviors and actions are informed and do not create a rift in the partnership (p. 443). There is strong support within the TBI literature and in the present study for the postulation that it is not clinical assessment results that predict family needs, but the family members' perception of the person with the TBI's functioning (Serio et al., 1995). Seeking to understand the experience of the family has also been posited to increase "the possibility of alleviating their suffering" (Jumisko et al., 2007, p. 365).

It remains possible that the experience of grief and the feelings of "holding on" may be an appropriate reaction to the experience of having a family member with a TBI, in addition to other disabilities or experiences. For some, it may be that to muster up the strength to face the coming day is the best that they can do with the emotional resources that they have available to them. Practitioners, rather than focusing on moving beyond the emotions associated with the experience as it pertains to the family members of a person with a TBI, may benefit from rather establishing a sense of manageability while the family member is actively experiencing the emotions. Due to the significant role that the family plays in transitioning the person with the TBI from the hospital to the home, and then to the general community, it is critical that the needs of the family be addressed effectively and expeditiously (Turner et al., 2007).

The existing TBI literature, in addition to the current study, have underscored the importance of ensuring that clinicians and practitioners have a strong understanding of what the familial experience is when another family member has incurred a TBI as an adult. There is a distinct need for family members to receive greater and longer continuing support at the beginning of, during, and following, acute care for the person with the TBI. Education and training should be provided to practitioners, counselors, social workers, and all other members of the care team in a variety of areas pertaining to this experience. One of the most important of the aforementioned areas is the impact of how society perceives and judges a person who feels that their family member with a TBI is “gone,” on psychosocial health, wellbeing, and coping. With professional communities permitting the opportunity for family members to feel as though they are not alone in their experience or their subsequent interpretations of it, while also being validated by medical staff, steps toward coping and adjustment to the TBI of their family member may be perceived as more readily and easily feasible. Other supports such as day care programming for the person with the TBI where the family member is able to continue to work or take time for themselves, or weekly assistance with household tasks so the family member does not become overwhelmed with the additional roles and responsibilities, may also be a valuable method by which to support the family. Psychoeducational support groups would provide family members with peer support, accountability, and a safe environment to discuss personal experiences free from societal judgement as to whether their grief is acceptable or not. Insight into family members' thoughts and feelings can provide. The current study provides a glimpse into the experiences of six family members, in addition to interpretations and analyses of those experiences, to inform practitioner interactions and treatment of family members to those persons with a TBI.

Recommendations for Future Research

The current study identified several gaps in the TBI literature as it pertains to the familial experience. While this study provided a number of areas where family members may experience fear, there is little documented within the literature. Short of acknowledging that fear is a critical component to the familial experience of TBI, there remains a need for greater understanding regarding what specifically within the experience creates fear. In addition, the same need exists regarding the specific areas where family members feel they need to discard or significantly alter established plans for the projected future. In doing so, future research could inform more targeted interventions for familial adjustment to a TBI.

Ergh et al. (2002) posit that those caregivers who do not receive adequate social support feel increasing distress as time since disability onset accrues. There remains a gap in the literature regarding the specific methods of emotional expression and protection. The current study provided a small number of practices. However, if the intention is to decrease the distress experienced a better understanding of the range of specific coping practices needs to exist. In doing so, the areas and methods by which family members of persons with a TBI seek support and protection can be identified, informing the development of and subsequent interventions. Research that results in the development of interventions for family members of individuals with TBI specific to the renegotiated role changes and re-integration of the injured family member may also further aid in the mitigation of psychosocial distress.

Although there is strong support for the application of ambiguous loss theory to the familial experience of TBI, there remains one assumption that the current study did not evaluate: 3. Cultural beliefs and values influence a family's tolerance for ambiguity and how it is perceived. Although a strong argument can be established for the application of ambiguous loss theory from the six assumptions that were supported, additional research that addresses the impact of cultural beliefs and values on the familial experience of TBI may provide a greater acceptance and adoption within the clinical environment.

Conclusion

Approximately 1.365 million of individuals who acquire a Traumatic Brain Injury (TBI) are treated and released from an emergency department (U.S. Department of Health and Human Services, Centers for Disease Control, National Center for Injury Prevention and Control, 2010). Those family members of a survivor of a TBI are posited to be equally impacted, if not more so, then the person with the TBI. The high likelihood of the psychosocial adjustment and coping of the family as a system, and individually, affecting the person with the TBI makes this area of research pertinent (Dausch & Saliman, 2009; Oddy & Herbert, 2003).

The purpose of the present study was to explore how immediate family members describe, and what is the meaning of, the experience of having an adult family member with an acquired TBI within the first three years. Six participants, all of whom had an immediate family member who had a TBI within the last three years, had regular contact with the injured family member, and were 18 years of age as of their interview, were recruited from a mid-Michigan brain injury rehabilitation facility. Although each experience was unique with regard to how it was felt and encountered, six areas were experienced across all six accounts. Those areas were: (1) an abrupt onset requiring necessary and rapid response, (2) the multiform manifestations of fear, (3) the significant role changes within the family system, (4) the diverse practices for emotional expression and protection, (5) the depth to which grief is experienced, and (6) the immutable alterations to established plans for the future. The sudden onset of the TBI in their family member caused an immediate need and pressure to react accurately with both answers to questions, and informed decisions regarding care. Fear of the ultimate outcome, including death, of their injured loved one became a prominent focal point of worry in the early days of the TBI experience. As the family member with the TBI returned home, changes in roles and assigned tasks within the family were experienced often resulting in the disruption of the family system or resentment from needing to take on more than they could handle.

Family members without the TBI engaged in practices where they could express themselves emotionally by utilizing physical exertion, competition, support systems and religion. Some had also chosen to engage in behaviors that allowed them to briefly distance themselves from the reality of living with, and being related to, a person with a TBI. Grief was experienced as the uninjured family members recalled who the person was prior to TBI onset but is no longer. Loss of expectations, loss of hope, perceiving who the person was in an idealized fashion, and seeing the family member with a TBI as being someone “new”, were all common experiences. As thoughts turned to the future and any future plans that the family had made together prior to TBI onset, attitudes of hope and anticipation quickly turned to those of exasperation, disappointment, or loneliness. Those family members of persons with a TBI may have felt that they have lost their partner or protector, cannot manage to accommodate the TBI in what was previously planned, or that the future is bleak, definite and limited for both the person with the TBI and their family. Feelings across this experience ranged from “scared”, “reminiscent”, “overwhelmed”, “depressed”, and “isolated”, to “pride”, “amazement”, “hopeful” and “accepting.” It is important to note that the level to which roles change, grief is felt, and future plans are altered, appears to be related to the extent of behavior, personality, physical ability and appearance, and/or emotional changes of the individual with the TBI from before onset to after. With regard to the present study, the postulation that neither injury severity nor functional outcome is significantly related to caregiver distress nor overall family functioning was not supported (Kreutzer et al., 1994a).

Several areas of the experience of having an adult within the family who incurs a TBI are not unique to the disability of TBI, however. There remains universality to the experiences shared. With any life threatening accident or illness, most of those in the immediate family will seek to react swiftly and accurately, pressuring themselves to act in the best interest of their injured family member. During acute treatment and throughout the rehabilitation period following, fear regarding the prognosis of their injured loved one may be present and various avenues for emotional expression and protection may be engaged in. Considerable changes to the roles that each family member embodies must be made when any significant disability is introduced into the family system. As significant disabilities may affect the personality, physical ability and appearance, emotionality and behaviors of those persons who have them, future plans may need to be drastically altered to accommodate new needs or discarded altogether. The temporality, or lived time, and relationality, or lived human relations, of family members to an adult with a TBI may parallel those experienced by family members of an adult with a different significant disability.

It is within the area of grief pertaining to TBI where the uniqueness of the experience is captured. For family members of persons with a TBI who have had radical changes in various areas of their life, the experience is of great distress. These family members are looking at a person who may look very much like the person they once knew, but most interactions with this person following TBI onset nullifies their presence. Allison highlighted this finding when she commented, “It’s sort of like he died but his body is still here.” This emotional purgatory created a struggle within the uninjured family members as they attempted to reconcile who this person in their family was prior to, and now is following, their TBI. Society would look down upon those who say that the person with the TBI was “dead” or “gone” with regard to their personhood, and subsequently move on with their lives. For some family members, however, it may be incomprehensible to engage in day-to-day life with an individual who was once your partner, parent or spouse. Spouses may find themselves recalling their wedding vows where they committed to the marriage with phrases such as “till death do us part” and “in sickness and in health.” No one plans, however, for a TBI to enter into consideration when planning for a future with your spouse and family. Traumatic brain injury (TBI) remains, one of the most jarring of the significant neurological disabilities with regard to the impact it has on the person who sustained it and how that impact proliferates throughout the family system.

The experiences shared within the current study supported six of the seven assumptions of ambiguous loss theory: 1. A psychological family exists, and that this perceived construction of one’s family may differ from the physical or legal family structure; 2. Ambiguous loss as an external situation is assumed to be neutral; 4. With situations of ambiguous loss, truth is unattainable and thus relative; 5. Ambiguous loss is inherently a relational phenomenon and thus cannot be an individual condition; 6. There is a natural resiliency in families; and 7. A phenomenon can exist even if it cannot be measured (Boss, 2007). The support for the application of ambiguous loss theory to the familial experience of TBI is established through the alignment of the experiences of those involved in the current study to the posited assumptions (Boss, 2007) and attributions of stress when engaged in ambiguous loss (Boss, 1999; as cited in Price, Price, & McKenry, 2010).

Inclusion criteria should be considered when applying ambiguous loss theory to the family members of persons with a TBI. Specifically, family members of those people with a moderate to mild TBI, or those who have made substantial rehabilitation gains, may not benefit from interventions or models based upon this theory. Areas for further research have been identified including specific areas in which family members of a person with a TBI may experience fear and changes to future plans, a better understanding of the range of specific coping practices, and the impact of cultural diversity on the fit of ambiguous loss theory to the familial experience of a TBI in an adult family member. Most importantly, the current study provides a glimpse into the experiences of six family members, in addition to interpretations and analyses of those experiences, to inform practitioner interactions and treatment of family members to those persons with a TBI.

APPENDICES

APPENDIX A

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Research Participant Information and Consent Form

Study Title:	Family Members' Initial Experience of Having an Adult Family Member with a Traumatic Brain Injury
Researcher and Title:	Erica L. Wondolowski, Doctoral Candidate
Department and Institution:	Department of Counselor Education, Psychology and Special Education, Michigan State University
Address and Contact Information:	[redacted] East Lansing, MI 48824 [redacted]

You are being asked to participate in a research project. Researchers are required to provide a consent form to inform you about the study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researcher any questions you may have.

Purpose of the Research. I am interested in studying the ways that family members respond when learning that someone in their life has acquired a traumatic brain injury. I'd like you to be a part of my study because you have someone in your life who has been diagnosed with a traumatic brain injury and are located within the mid-Michigan area. The main criteria for invitation is interest on your part in talking about this event in your life and the experiences that surround it. This study will only require no more than a one time, hour and a half commitment.

I plan to collect data by audio-recording our conversation together, so I can really understand your experience better and ensure that I do not miss any of the important details. Data-collection, for me, involves conversations. So most of my data will be in an interview format.

What You Will Do. In this study, we will meet once. During this meeting we will talk about the moment when the impact of the traumatic brain injury of your family member first became apparent to you. I may take field notes in addition to audio-recording our conversation, and make transcriptions of those recordings.

Potential Benefits. It's very important to me that you find our conversation helpful, interesting, and beneficial – particularly as it relates to your processing this poignant event. Before I was a researcher and doctoral student, my mother acquired a traumatic brain injury at the age of 47. It is my hope that through our interaction that you will find peer support.

Since I view research as best emerging out on ongoing and mutually beneficial relationships, I will strive to negotiate with you the way in which the study is conducted. That is to say, I will want to hear and discuss experiences that you find important. Of course, there are particular ideas and themes I want to study. Therefore, I view our potential relationship as maturing, and subject to renegotiation, so as to ensure that the study benefits you as well as me.

Finally, you should note that there is no financial compensation for participating in this study.

Potential Risks. In every human relationship, there are risks: these include hurt feelings, being let down by the other person, and misunderstandings. Additionally, within a research context, there are additional risks. There may be times where I inadvertently ask you a question you find too personal, or uncomfortable. You never need to answer a question or talk about a topic that you do not want to talk about.

Privacy and Confidentiality. The data for this project will be kept confidential. In any written texts I keep, I will use pseudonyms for all persons – including you – so that your actual name will never be used. When we meet to talk, we will be in an environment in which you feel comfortable and private.

Any information you share with me will be kept confidential to the maximum extent allowable by law.

All data for the project will be stored in a digital format – either written files on my laptop, or digital audio files, which I will immediately transfer over to my laptop, and delete from my audio voice recorder. My laptop is password protected, and I never leave it lying about in public places.

The only persons who will have access to this data are you, me, my Dissertation Committee, and members of the Institutional Review Board (an agency that monitors the protection of research participants).

The results of this study may be published or presented at professional meetings, but the identities of all research participants – yourself included – will remain anonymous.

For our meeting I will want to audio-record you. I will double check with you that this is okay when we meet.

Your Rights to Participate, Say "No," or Withdraw. Participation in this research project is completely voluntary. You have the right to say "no" at the time of invitation, or any time thereafter. You may change your mind at any time and withdraw from the study. You may choose not to answer specific questions or to stop participating at any time. Choosing not to participate or withdrawing from this study will not make any difference in your relationship with me or any support group or rehabilitation facility.

Costs and Compensation for Being in the Study. There may be minimal costs associated with the study, such as those associated with driving to the chosen location to meet.

Contact Information for Questions and Concerns. If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact me (Erica Wondolowski, Michigan State University, Department of Counselor Education, Psychology and Special Education, [redacted], East Lansing, MI 48824, [redacted], [redacted]).

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48824.

APPENDIX B

INTERVIEW PROMPT

Interview Prompt

- Can you describe to me what your original thoughts, experiences and reactions were when you first began to see the impact the Traumatic Brain Injury (TBI) had on your family member?

Potential Follow-Up Questions Include:

- How old were you when your parent acquired their traumatic brain injury?
- How old was your affected parent?
- Were there any differences in behavior, emotions, and/or conversation from before the accident to after?
    - If so, do you feel that one area was more impactful to you than the others?
- Can you discuss the emotions you experienced and what motivated them, when you first began to see the impact of the traumatic brain injury on your parent?
- Was this your first experience with traumatic brain injuries?
- How long ago did the injury occur?
- How did the injury occur?
- What was your relationship like prior to onset?
- Can you recall your last contact with your family member prior to the onset of their traumatic brain injury?

REFERENCES

REFERENCES

Adams, N. (1996). Positive outcomes in families following traumatic brain injury (TBI). *Australian and New Zealand Journal of Family Therapy*, *17(2*), 75-84.

Albert, S. M., Im, A., Brenner, L., Smith, M., & Waxman, R. (2002). Effect of social work liaison program on family caregivers to people with brain injury. *Journal of Head Trauma Rehabilitation, 17(2),* 175-189.

Allen, K., Linn, R. T., Gutierrez, H., & Willer, B. S. (1994). Family burden following traumatic brain injury. *Rehabilitation Psychology, 39(1)*, 29-48.

Beck, J. (1995). *Cognitive therapy: Basics and beyond*. New York: Guilford Press.

Betz, G., & Thorngren, J. M. (2006). Ambiguous loss and the family grieving process. *The Family Journal*, *14*, 359-365. doi: 10.1177/1066480706290052

Blieszner, R., Roberto, K. A., Wilcox, K. L., Barham, E. J., & Winston, B. L. (2007). Dimensions of ambiguous loss in couples coping with mild cognitive impairment. *Family Relations, 56(2),* 196-209.

Bond, A. E., Draeger, C. R. L., Mandleco, B., & Donnelly, M. (2003). Needs of family members of patients with severe traumatic brain injury: Implications for evidence-based practice. *Critical Care Nurse, 23*, 63-72.

Boss, P. (1987). Family stress: Perception and context. In: M. Sussman & S. Steinmetz (Eds.), *Handbook on Marriage and Family* (pp. 695–723). New York: Plenum.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.

Boss, P. (2002). *Family stress management* (2nd ed.). Newbury Park, CA: Sage.

Boss, P. (Ed.) (2003). *Family stress: Classic and contemporary readings*. Newbury Park, CA: Sage.

Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss.* New York, NY: W. W. Norton & Co.

Boss, P. (2007). Ambiguous loss theory: Challenges for scholars and practitioners. *Family Relations, 56(2),* 105-111.

Boss, P., Beaulieu, L., Weiling, E., & Turner, W. (2003). Healing loss, ambiguity, and trauma: A community-based intervention with families of union workers missing after the 9/11 attack in New York City. *Journal of Marital and Family Therapy, 29(4),* 455-467.

Boss, P., & Couden, B. A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples, and families. *Psychotherapy in Practice, 58(11),* 1351-1360. doi: 10.1002/jclp.10083

Boss, P., & Kaplan, L. (2003). Ambiguous loss and ambivalence when a parent has dementia. In K. Pillemer & K. Luscher (Eds.), *Intergenerational ambivalences: New perspectives on parent-child relations in later life (Contemporary perspectives in family research, Volume 4*; 207-224). Bingley, United Kingdom: Emerald Group Publishing Limited.

Brooks, D. N. (1991). The head-injured family. *Journal of Clinical and Experimental Neuropsychology,* 13, 155-188.

Brooks, N., Campsie, L., Symington, C., Beattie, A., & McKinlay, W. (1987). The effects of severe head injury on patient and relative within seven years of injury. *Journal of Head Trauma Rehabilitation, 2(2),* 1-13.

Campbell, C. H. (1988). Needs of relatives and helpfulness of support groups in severe head injury. *Rehabilitation Nursing, 12(6),* 320-325.

Carnes, S. L., & Quinn, W. H. (2005). Family adaptation to brain injury: Coping and psychological distress. *Families, Systems, & Health, 23(2),* 186-203. doi: 10.1037/1091-7527.23.2.186

Carroll, J. S., Olson, C. D., & Buckmiller, N. (2007). Family boundary ambiguity: A 30-year review of theory, research, and measurement. *Family Relations, 56(2),* 210-230.

Chronister, J., Chan, F., Sasson-Gelman, E. J., & Chiu, C. (2010). The association of stress-coping variables to quality of life among caregivers of individuals with traumatic brain injury. *Neurorehabilitation, 27,* 49-62.

Cope, D. N., & Wolfson, B. (1994). Crisis intervention with the family in the trauma setting. *Journal of Head Trauma Rehabilitation, 9(1),* 67-81.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13,* 3-21.

Corrigan, J. D., & Deming, R. (1995). Psychometric characteristics of the Community Integration Questionnaire: Replication and extension. *Journal of Head Trauma Rehabilitation, 10(4),* 41-53.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Los Angeles, CA: SAGE Publications, Inc.

Dauch, B. M., & Salimann, S. (2009). Use of family focused therapy in rehabilitation for veterans with traumatic brain injury. *Rehabilitation Psychology, 54(3),* 279-287. doi: 10.1037/a0016809

Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health and Social Work, 26(4)*, 257-268.

Degeneffe, C. E., & Burcham, C. M. (2008). Adult sibling caregiving for persons with traumatic brain injury: Predictors of affective and instrumental support. *Journal of Rehabilitation, 74(3),* 10-20.

Degeneffe, C. E., & Lee, G. K. (2015). Brain injury and the family: A guide for rehabilitation counselors. In M. J. Millington & I. Marini (Eds.), *Families in rehabilitation counseling: A community-based rehabilitation approach* (pp. 153-170). New York: Springer Publishing Company, LLC.

Degeneffe, C. E., & Olney, M. F. (2008). Future concerns of adult siblings of persons with traumatic brain injury. *Rehabilitation Counseling Bulletin, 51(4*), 240-250. doi: 10.1177/0034355207311319

De Jong, G., Batavia, A. I., & Williams, J. M. (1990). Who is responsible for the lifelong well-being of a person with a head injury? *Journal of Head Trauma Rehabilitation, 5*, 9-22.

Del Orto, A. E., & Power, P. W. (2000). *Brain injury and the family*. New York: CRC Press.

DePompei, R., & Williams, J. (1994). Working with families after TBI: A family-centered approach. *Topics in Language Disorders, 15(1),* 68-81.

Devany Serio, C., Kreutzer, J. S., & Gervasio, A. H. (1995). Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation, 10(2*), 32-45.

Douglas, J. M., & Spellacy, F. J. (2000). Correlates of depression in adults with severe traumatic brain injury and their carers. *Brain Injury, 14(1)*, 71-88.

Dragon Naturally Speaking Premium Edition (Version 12) [Computer software]. Burlington, MA: Nuance Communications, Inc.

Duff, D. (2002). Family concerns and responses following a severe traumatic brain injury: A grounded theory study. *Axon, 24(2)*, 14-22.

Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion and Health*, *23(3),* 197-203.

Elbaum, J. (2007). Acquired brain injury and the family: Challenges and interventions. In J. Elbaum & D. M. Benson (Eds.), *Acquired Brain Injury* (pp. 275-285). New York: Springer. doi: 10.1007/978-0-387-37575-5_15

Ergh, T. C., Hanks, R. A., Rapport, L. J., & Coleman, R. D. (2003). Social support moderates caregiver life satisfaction following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology, 25(8),* 1090-1101.

Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation, 17(2),* 155-174.

Fahy, T. J., Irving, M. H., & Millac, P. (1967). Severe head injuries: A six year follow-up. *Lancet, ii*, 475-479.

Falvo, D. R. (Ed.). (2009). *Medical and psychosocial aspects of chronic illness and disability*. Sudbury, MA: Jones and Bartlett Publishers

Faul, M., Xu, L., Wald, M. M., & Coronado, V. G. (2010). *Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control.

Finkelstein, E. A., Corso, P. S., & Miller, T. R. (2006). *The Incidence and Economic Burden of Injuries in the United States*. New York: Oxford University Press.

Flanagan, D. A. J. (1998). A retrospective analysis of expressed emotion (EE) and affective distress in a sample of relatives caring for traumatically brain-injured (TBI) family members. *The British Journal of Clinical Psychology, 37(4),* 431-439.

Florian, V. & Katz, S. (1991). The other victims of traumatic brain injury: Consequences for family members. *Neuropsychology, 5(4),* 267-279.

Foster, M., Tilse, C., & Fleming, J. (2004). Referral to rehabilitation following traumatic brain injury: Practitioners and the process of decision-making. *Social Science and Medicine, 59,* 1867-1878. doi: 10.1016/j. socscimed.2004.02.017

Frosch, S., Gruber, A., Jones, C., Myers, S., Noel, E., Westerlund, A., & Zavisin, T. (1997). The long term effects of traumatic brain injury. *Brain Injury, 11(12),* 891-906.

Gan, C., Campbell, K. A., Gemeinhardt, M., & McFadden, G. T. (2006). Predictors of family system functioning after brain injury. *Brain Injury, 20(6*), 587-600. doi: 10.1080/02699050600743725

Gervasio, A. H., & Kreutzer, J. S. (1997). Kinship and family members' psychological distress after traumatic brain injury: A large sample study. *Journal of Head Trauma Rehabilitation, 12(3),* 14-26

Giorgi, A. (1988). Validity and reliability from a phenomenological perspective. In W.J. Baker, L.P. Mos, H.V. Rappard & H.J. Stam (Eds.), *Recent Trends in Theoretical Psychology* (pp. 167-176). Verlag, Berlin: Springer.

Glesne, C. (2011). Beco*ming qualitative researchers: An introduction* (4th ed.). Boston, MA: Pearson Education, Inc.

Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain Injury, 28(4),* 398-413. doi: 10.3109/02699052.214.880514

Gosling, J., & Oddy, M. (1999). Rearranged marriages: Marital relationships after head injury. *Brain Injury, 13(10),* 785-796.

Grant, J. S., & Bean, C. A. (1992). Self—identified needs of informal caregivers of head-injured adults. *Family Community Health, 15(2),* 49-58.

Gray, D. S. (2000). Slow-to-recover severe traumatic brain injury: A review of outcomes and rehabilitation effectiveness. *Brain Injury, 14(11),* 1003-1014.

Groswasser, Z. (1995). Coma to community. In M. A. Chamberlain, V. Neumann & A. Tennant (Eds.), *Traumatic Brain Injury Rehabilitation: Services, Treatment and Outcomes*, pp. 25-36. London; Chapman & Hall.

Harris, D. L. (2011). *Counting our losses: Reflecting on change, loss, and transition in everyday life.* New York, NY: Routledge.

Harvey, J. H. (2000). *Give sorrow words: Perspectives of loss and trauma.* Philadelphia, PA: Brunner/Mazel.

Harvey, J. H. (2002).*Perspectives on loss and trauma: Assaults on the self*. Thousand Oaks, CA: Sage Publications.

Hoge, C. W., Auchterlonie, J. L., & Milliken, C. S. (2006). Mental health problems, use of mental health services, and attrition from military service after returning from deployment to Iraq or Afghanistan. *Journal of the American Medical Association, 295,* 1023-1032.

Horwitz, R. C., Horwitz, S. H., Orsini, J., Antoine, R. L., & Hill, D. M. (1998). Including families in collaborative care: Impact on recovery. *Families, Systems and Health, 16(1/2),* 71-83.

Jacobson, I. G., Ryan, M. A. K., Hooper, T. J., Smith, T. C., Amoroso, P. J., Boyko, E. J…Bell, N. S. (2008). Alcohol use and alcohol-related problems before and after military combat deployment. *Journal of the American Medical Association, 300*, 663-675.

Jumisko, E., Lexell, J., & Soderberg, S. (2007). Living with moderate or severe traumatic brain injury: The meaning of family members' experiences. *Journal of Family Nursing, 13(3),* 353-369. doi: 10.1177/1074840707303842

Kean, S. (2010). The experience of ambiguous loss in families of brain injured ICU patients. *Nursing in Critical Care, 15(2),* 66-75.

Kneafsey, R., & Gawthorpe, D. (2004). Head injury: Long-term consequences for patients and families and implications for nurses. *Journal of Clinical Nursing, 13,* 601-608.

Knight, R. G., Devereux, R. T., & Godfrey, H. P. D. (1998). Caring for a family member with traumatic brain injury. *Brain Injury, 12(6),* 467-481.

Kolakowsky-Hayner, S. A., Miner, K. D., & Kreutzer, J. S. (2001). Long-term life quality and family needs after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 16(4),* 374-385.

Koopermans, P., Sanderman, R., Timmerman, I., & Emmelkamp, P. (1994). The Irrational Beliefs Inventory (IBI): Development and psychometric evaluation. *European Journal of Psychological Assessment, 10*, 15-27.

Kosciulek, J. F. (1994). Dimensions of family coping with head injury. *Rehabilitation Counseling Bulletin, 37(3)*, 244-258.

Kosciulek, J. F. (1994). Relationship of family coping with head injury to family adaptation. *Rehabilitation Psychology, 39(4),* 215-230.

Kosciulek, J. F. (1995). On identifying head injury family types. *Journal of Applied Rehabilitation Counseling, 26(3)*, 13-18.

Kosciulek, J. F. (1996), The circumplex model and head injury family types: A test of the balanced versus extreme hypothesis. *Journal of Rehabilitation, 62(2)*, 49-54.

Kosciulek, J. F. (1997a). Dimensions of family coping with head injury: A replication and extension. *Rehabilitation Counseling Bulletin, 41(1),* 43-53.

Kosciulek, J. F. (1997b). Relationship of family schema to family adaptation to brain injury. *Brain Injury, 11(11),* 821-830.

Kosciulek, J. F., & Lustig, D. C. (1998). Predicting family adaptation from brain injury-related family stress. *Journal of Applied Rehabilitation Counseling, 29(1),* 8-12.

Kosciulek, J. F., & Lustig, D. C. (1999). Differentiation of three brain injury family. *Brain Injury, 13(4)*, 245-254.

Kosciulek, J. F., McCubbin, M. A., & McCubbin, H. I. (1993). A theoretical framework for family adaptation to head injury. *Journal of Rehabilitation, 59(3),* 40-45.

Kosciulek, J. F., & Pichette, E. F. (1996). Adaptation concerns of families of people with head injuries. *Journal of Applied Rehabilitation Counseling, 27(2)*, 8-13.

Koskinen, S. (1998). Quality of life 10 years after a very severe traumatic brain injury (TBI): The perspective of the injured and the closest relative. *Brain Injury, 12(8)*, 631-648.

Kozloff, R. (1987). Network of social support and the outcome from severe head injury. *Journal of Head Trauma Rehabilitation, 2,* 14-23.

Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994a). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury, 8(3)*, 211-230.

Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994b). Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury, 8(3),* 197-210.

Kreutzer, J. S., Marwitz, J. H., & Kepler, K. (1992). Traumatic brain injury: Family response and outcome. *Archives of Physical Medicine and Rehabilitation, 73*, 771-778.

Kűbler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.

Landau, J., & Hissett, J. (2008). Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health, 26(1),* 69-85. doi: 10.1037/1091-7527.26.1.69

Lauer-Listhaus, B. (1991). Group psychotherapy for families of head injured adults: A psychoeducational approach. *Counseling Psychology Quarterly, 4(4),* 351-354.

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2(3)*, 1-29.

Lawlor, M. C., & Mattingly, C. F. (1998). The complexities embedded in family-centered care. *The American Journal of Occupational Therapy, 52(4),* 259-267.

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Lefebvre, H., & Levert, M. J. (2012). The close relatives of people who have had a traumatic brain injury and their special needs. *Brain Injury, 26(9*), 1084-1097. doi: 10.3109/02699052.2012.666364

Lefebvre, H., & Levert, M. J. (2006). Breaking the news of traumatic brain injury and incapacities. *Brain Injury, 20(7),* 711-718. doi: 10.1080/02699050600744244

Lefebvre, H., Pelchat, D., Swaine, B., Gelinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury, 19(8),* 585-597. doi: 10.1080/02699050400025026

Leith, K. H., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience. *Brain Injury, 18(12),* 1191-1208. doi: 10.1080/02699050410001719943

Lezak, M. D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology, 10*, 111-123.

Lezak, M. D. (1978). Living with the characterologically altered brain injured patient. *Journal of Clinical Psychology, 39(7)*, 592-598.

Livingston, M. G., Brooks, D. N., & Bond, M. R. (1985). Patient outcome in the year following severe head injury and relative's psychiatric and social functioning. *Journal of Neurology, Neurosurgery, and Psychiatry, 48*, 876-881.

Man, D. W. K. (2002). Family caregivers' reactions and coping for persons with brain injury. *Brain Injury, 16(12*), 1025-1037. doi: 10.1080/0269905021000010087

Max, J. E., Robertson, B. A. M., & Lansing, A. E. (2001). The phenomenology of personality change due to traumatic brain injury in children and adolescents. *Journal of Neuropsychiatry and Clinical Neurosciences, 13(2)*, 161-170.

McCubbin, M. A., & McCubbin, H. I. (1989). Theoretical orientations to family stress and coping. In C. R. Figley (Ed.), *Treating stress in families* (pp. 3-43). New York, NY: Brunner/Mazel.

McKinlay, W. W., Brooks, D. N., Bond, M. R., Martinage, D. P., & Marshall, M. M. (1981). The short-term outcome of severe blunt head injury as reported by relatives of injured persons. *Journal of Neurology, Neurosurgery, and Psychiatry, 44*, 527-533.

McLennan, M., Starko Anderson, G., & Pain, K. (1996). Rehabilitation learning needs: Patient and family perceptions. *Patient Education and Counselling, 27*, 191-199.

McNulty, P. A. (2005). Reported stressors and health care needs of active duty Navy personnel during three phases of deployment in support of the war in Iraq. *Military Medicine, 170,* 530-535.

Mitchley, N., Gray, J. M., Pentland, B. (1996). Burden and coping among the relatives and carers of brain-injured survivors. *Clinical Rehabilitation, 10*, 3-8.

Moore, A. D., Stambrook, M., Peters, L. C., & Lubusko, A. (1991). Family coping and marital adjustment after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 6(1)*, 83-89.

Moules, S., & Chandler, B. J. (1999). A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Injury, 13,* 983-993.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: SAGE Publications, Inc.

Muir, C., & Haffey, W. (1984). Psychological and neuropsychological inventions in the mobile mourning process. In B. A. Edelstein & E. T. Couture (Eds.), *Behavioral assessment and rehabilitation of the traumatically brain damaged* (pp. 89-112). New York: Plenum Press.

Muir, C., Rosenthal, M., & Diehl, L. N. (1990). Methods of family intervention. In M. Rosenthal, E. R. Griffith, M.R. Bond, & J. D. Miller (Eds.), *Rehabilitation of the adult and child with traumatic brain injury* (2nd ed., pp. 433-448). Philadelphia: Davis.

Murray, H. M., Maslany, G. W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20(6),* 575-585. doi: 10.1080/02699050600664590

Nabors, N., Seacat, J., & Rosenthal, M. (2002). Predictors of caregiver burden following traumatic brain injury. *Brain Injury, 16(12),* 1039-1050.

O'Callaghan, A. M., McAllister, L., & Wilson, L. (2011). Experiences of care: Perspectives of carers of adults with traumatic brain injury. *International Journal of Speech-Language Pathology, 13(3),* 218-226. doi: 10.3109/17549507.2011.549240

O'Callaghan, A. M., McAllister, L., & Wilson, L. (2010). Experiences of care reported by adults with traumatic brain injury. *International Journal of Speech-Language Pathology, 12(2),* 107-123. doi: 10.3109/17549500903431774

O'Connell, B., & Baker, L. (2004). Managing as carers of stroke survivors: Strategies from the field. *International Journal of Nursing Practice, 10,* 121-126.

Oddy, M. (1995). He's no longer the same person: How families adjust to personality change after head injury. In M. A. Chamberlain, V. Neumann, & A. Tennant (Eds.), *Traumatic brain injury rehabilitation: Services, treatments and outcomes* (pp. 167-180). New York, NY: Chapman and Hall.

Oddy, M., & Herbert, C. (2008). Brain injury and the family: A review. In A. Tyerman & N. S. King (Eds.), *Psychological Approaches to Rehabilitation after Traumatic Brain Injury* (pp.431-448). Malden, MA: Blackwell Publishing.

Oddy, M., & Herbert, C. (2003). Intervention with families following brain injury: Evidence-based practice. *Neuropsychological Rehabilitation, 13(1/2),* 259-273. doi: 10.1080/09602010244000345

Oddy, M., Humphrey, M., & Uttley, D. (1978). Stresses upon the relatives of head-injured patients. *British Journal of Psychiatry, 133*, 507-513.

Orsillo, S. M., McCaffrey, R. J., & Fisher, J. M. (1993). Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation, 8(1),* 102-115.

Papastrat, L. A. (1992). Outcome and value following brain injury: A financial providers perspective. *Journal of Head Trauma Rehabilitation, 7,* 11-23.

Patrick-Ott, A., & Ladd, L. D. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health, 5,* 74-86.

Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary, and tertiary carers. *Journal of Head Trauma Rehabilitation, 15(3),* 909-929.

Perlesz, A., Kinsella, G., & Crowe, S. (1999). Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology, 44(1),* 6-35.

Pessar, L. F., Coad, M. L., Linn, R. T., & Willer, B. S. (1993). The effects of parental traumatic brain injury on the behavior of parents and children. *Brain Injury, 7(3),* 231-240.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), *Existential-phenomenological perspectives in psychology* (pp. 41-60). New York: Plenum Press.

Ponsford, J., Olver, J., Ponsford, M., & Nelms, R. (2003). Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury, 17(6),* 453-468. doi: 10.1080/0269905031000070143

Price, S. J., Price, C. A., & McKenry, P. C. (2010). Families coping with change: A conceptual overview. In S. J. Price, C. A. Price, & P. C. McKenry (Eds.), *Families and change: Coping with stressful events and transitions* (pp. 1-23). Thousand Oaks, CA: SAGE Publications Inc.

Rappaport, M., Herrero-Backe, C., & Rappaport, M. L., & Winterfield, K. M. (1989). Head injury outcome up to ten years later. *Archives of Physical Medicine and Rehabilitation, 70*, 885-892.

Raphael, B., & Dobson, M. (2000). Bereavement. In J. H. Harvey & E. C. Miller (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 45-61). Philadelphia: Taylor & Francis.

Redpath, S. J., Williams, W. H., Hanna, D., Linden, M. A., Yates, P., & Harris, A. (2010). Healthcare professionals' attitudes towards traumatic brain injury (TBI): The influence of profession, experience, aetiology and blame on prejudice towards survivors of brain injury. *Brain Injury, 24(6),* 802-811. doi: 10.3109/02699051003709623

Resnick, C. (1993). The effect of head injury on family and marital stability. *Social Work in Health Care, 18(2),* 49-62.

Rich, S., Graham, M., Taket, A., & Shelley, J. (2013). Navigating the terrain of lived experience: The value of lifeworld existentials for reflective analysis. *International Journal of Qualitative Methods, 12,* 498-510.

Ridley, B. (1989). Family response in head injury: Denial…or hope for the future? *Journal of Social Science Medicine, 29(4),* 555-561.

Romano, M. D. (1989). Ethical issues and families of brain-injured persons. *Journal of Head Trauma Rehabilitation, 4*, 33-41.

Romano, M. D. (1972), Family response to traumatic brain injury. *Scandinavian Journal of Rehabilitation Medicine, 6,* 1-4.

Roscigno, C. I., & Swanson, K. M. (2011). Parents' experiences following children moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research, 21(10),* 1413-1426. doi:10.1177/1049732311410988

Rossman, G. B., & Rallis, S. F. (1998). *Learning in the field: An introduction to qualitative research.* Thousand Oaks, CA: Sage.

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of person who have experienced traumatic brain injury and their primary caregivers. *Journal of Head Trauma Rehabilitation, 22(1),* 14-25.

Roy, C. W., Thornhill, S., & Teasdale, G. M. (2002). Identification of rehabilitation problems after head injury. *Brain Injury, 16(12),* 1057-1063. doi: 10.1080/02699050210154231

Sachs, P. R. (1985) Beyond support: Traumatic head injury as a growth experience for families. *Rehabilitation Nursing, 10(1),* 21-23.

Sacks, O. (1970). *The man who mistook his wife for a hat.* New York, NY: Harper Perennial.

Sander, A. M., Davis, L. C., Struchen, M. A., Atchison, T., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2007). Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *Neurorehabilitation, 22,* 9-17.

Seaton, J. D., & David, C. O. (1990). Family role in substance abuse and traumatic brain injury rehabilitation. *Journal of Head Trauma Rehabilitation, 5(3)*, 41-46.

Semlyen, J. K., Summers, S. J., & Barnes, M. P. (1998). Aspects of caregiver distress after severe head injury. *Neurorehabilitation and Neural Repair, 12*, 53-59. doi: 10.1177/154596839801200202

Singer, G. H. S., Glang, A., Nixon, C., Cooley, E., Kerns, K. A., Williams, D., & Powers, L. E. (1994). A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. *Journal of Head Trauma Rehabilitation, 9(4)*, 38-49.

Sinnakaruppan, I. & Williams, D. M. (2001). Family carers and the adult head-injured: A critical review of carers' needs. *Brain Injury, 15(8),* 653-672. doi: 10.1080/02699050010025759

Smith, J. E., & Smith, D. L. (2000). No map, no guide: Family caregivers' perspectives on their journeys through the system. *Care Management Journals, 2(1)*, 27-33.

Sohlberg, M. M., Glang, A., & Todis, B. (1998). Improvement during baseline: Three case studies encouraging collaborative research when evaluating caregiver training. *Brain Injury, 12(4),* 333-346.

Sohlberg, M. M., McLaughlin, K. A., Todis, B., Larsen, J., & Glang, A. (2001). What does it take to collaborate with families affected by brain injury? A preliminary model. *Journal of Head Trauma Rehabilitation, 16(5),* 498-511.

Stebbins, P., & Leung, P. (1998). Changing family needs after brain injury. *Journal of Rehabilitation, 64(4),* 15-22.

Stebbins, P., & Pakenham, K. I. (2001). Irrational schematic beliefs and psychological distress in caregivers of people with traumatic brain injury. *Rehabilitation Psychology, 46(2),* 178-194. doi: 10.1037/0090-5550.46.2.178

Stein, M. B., & McAllister, T. W. (2009). Exploring the convergence of posttraumatic stress disorder and mild traumatic brain injury. *American Journal of Psychiatry, 166(7)*, 768-776.

Stilwell, J., Hawley, C., & Stilwell, P. (1997). *National Traumatic Brain Injury Study*. Warwick: University of Warwick.

Terrio, H., Brenner, L., Ivins, B., Cho, J., Helmick, K., Schwab, K., & Warden, D. (2009). Traumatic brain injury screening: Preliminary findings in a US Army brigade combat team. *Journal of Head Trauma Rehabilitation, 24*, 14-23.

Thompson, S. C., & Kyle, D. J. (2000). The role of perceived control in coping with the losses associated with chronic illness. In J. H. Harvey & E. C. Miller (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 131-145). Philadelphia: Taylor & Francis.

Thomsen, I. V. (1974). The patient with severe head injury and his family. *Scandinavian Journal of Rehabilitation Medicine*, 6, 180-183.

Thomsen, I. V. (1984). Late outcome of severe blunt head trauma: A 10-15 year follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry, 47,* 260-268.

Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., Kendall, M., & Chenoweth, L. (2007). A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury, 21(11),* 1119-1130. doi: 10.1080/02699050701651678

Ulvik, A., & Kvåle, R. (2012). Outcome after severe traumatic brain injury (TBI). In T. Sundstrøm, P. Grände, N. Juul, C. Kock-Jensen, B. Romner, & K. Wester (Eds.), *Management of severe traumatic brain injury: Evidence, tricks, and pitfalls* (pp. 383-388). Verlag, Berlin: Springer Science & Business Media.

Urbach, J. R., & Culbert, J. P. (1991). Head-injured parents and their children: Psychosocial consequences of a traumatic syndrome. *Psychosomatics, 32,* 24-33.

U.S. Department of Health and Human Services, Centers for Disease Control, National Center for Injury Prevention and Control. (2010). Traumatic brain injury in the United States: Emergency department visits, hospitalizations and deaths 2002-2006. Retrieved from http://www.cdc.gov/traumaticbraininjury/pdf/blue_book.pdf

Van Baalen, B., Ribbers, G. M., Medema-Meulepas, D., Pas, M. S., Odding, E., & Stam, H. J. (2007). Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. *Brain Injury, 21(9),* 925-931. doi: 10.1080/02699050701553197

van Maanen, M. (1990). *Researching lived experience.* New York: State University of New York Press.

Von Suhr, J. (2003). *The sibling experience of ambiguous loss in families with a missing child: Grief, coping, and support-seeking behaviors.* (Doctoral dissertation). Retrieved from ProQuest, LLC. (UMI 3083510)

Walsh, F. (2006). *Strengthening family resilience* (2nd ed.). New York, NY: Guilford Press.

Weiner, I. (1999). *Coping with loss*. Mahwah, NJ: Lawrence Erlbaum.

Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury, 19(13),* 1105-1115. doi: 10.1080/02699050500150062

Williams, J. (1993). Supporting families after head injury: Implications for the speech-language pathologist. *Seminars in Speech-Language, 14(1),* 44-60.

Wood, R. L., & Yurdakul, L. K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury, 11(7),* 491-502.