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# After the "Silent Epidemic": Marital Satisfaction in Long Term Spousal Caregivers of Individuals with Severe Traumatic Brain Injury

JoAnna Lynn Arguello  
*University of Iowa*

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AFTER THE “SILENT EPIDEMIC”: MARITAL SATISFACTION IN LONG TERM  
SPOUSAL CAREGIVERS OF INDIVIDUALS WITH SEVERE TRAUMATIC BRAIN  
INJURY

by

JoAnna L. Argüello

A thesis submitted in partial fulfillment of the  
requirements for the Doctor of Philosophy degree  
in Psychological and Quantitative Foundations  
(Counseling Psychology) in the Graduate College of  
The University of Iowa

August 2013

Thesis Supervisor: Professor Elizabeth Altmaier

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Graduate College  
The University of Iowa  
Iowa City, Iowa

CERTIFICATE OF APPROVAL

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PH.D. THESIS

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This is to certify that the Ph.D. thesis of

JoAnna L. Argüello

has been approved by the Examining Committee  
for the thesis requirement for the Doctor of Philosophy  
degree in Psychological and Quantitative Foundations (Counseling  
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To my loving family and all those who have been impacted by TBI.

Yes, I am personally the victim of deferred dreams, of blasted hopes, but in spite of that I close today by saying I still have a dream, because, you know, you can't give up in life. If you lose hope, somehow you lose that vitality that keeps life moving, you lose that courage to be, that quality that helps you to go on in spite of all. And so today I still have a dream.

Dr. Martin Luther King, Jr.  
A Christmas Sermon on Peace  
December 24<sup>th</sup>, 1967

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And a big thanks: to my loving family, especially my parents, a long-term couple of severe TBI—you are the greatest role models and supports of my life—it is because of you both that I have not lost the ability to dream. I am proud and honored to be your daughter. My grandma—I miss you, always. My significant other, Eric, who has reminded me daily, some days more than once, of his unconditional love and his belief in me; and my friends Elham, Tina, and Jessi—thank you for your continued encouragement. I have been blessed to encounter many truly wonderful people on this journey who have assisted, carried, and encouraged me throughout the process, so although not named on this page, you all are very much remembered in my heart.

## ABSTRACT

Severe traumatic brain injury (TBI) is a pervasive and devastating condition, often resulting in permanent alterations in cognition, behavior, and personality. As such, survivors of severe TBI usually rely on the assistance of caregivers to navigate situations of daily living throughout their life span. Spouses of individuals with TBI have been shown to experience greater levels of burden than parental caregivers of TBI survivors (Kreutzer et al., 1994; Mauss-Clum & Ryan, 1981) and subsequently rates of divorce and separation have been documented within the research literature to be high (Thomsen, 1984; Wood et al., 2005). Although marital breakdown has been frequently studied, research on marital satisfaction and coping within long-term marriages where one spouse has survived a severe TBI remains insufficient.

The purpose of this study was to provide a descriptive analysis of long-term spousal caregivers of individuals with severe TBI. First, demographic variables of caregiving spouses of individuals with severe TBI, who remained married at least 10 years post injury, were described and comparisons to other spousal caregiver samples were addressed. Second, the relationship between marital adjustment and demographic variables, coping, and quality of life was examined. Finally, an analysis of primary stressors was conducted to better understand the caregiving spouses' continued experience of stressors.

Twenty-one spousal caregivers who remained married for at least 10 years post injury to their spouse who sustained a severe TBI participated in the study. Analyses revealed that spouses had remained married an average of 19 years post-injury and in general were mildly dissatisfied within their marriages. Furthermore, marital adjustment



(Dyadic Adjustment Scale total score) of long-term spousal caregivers of severe TBI was not significantly different than spousal caregivers of individuals with chronic illness. Higher marital satisfaction scores were associated with higher endorsement of emotion-focused coping strategies and greater mental health quality of life. In addition, marital satisfaction was positively associated with the longevity of the marital relationship, the age of the spouse at the time of the injury, and the length of the marriage at the time when the injury was sustained. Findings indicate that higher scores of marital satisfaction were associated with higher levels of mental health quality of life. There were no significant relationships between physical health quality of life and marital satisfaction. An analysis of primary stressors show that long-term caregiving spouses continue to report similar types of stressors as indicated in the research literature from caregiving spouses during the first 5 to 8 years post injury. Findings were discussed in relation to implications for practice and additional research.

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## CHAPTER I

### INTRODUCTION AND LITURATURE REVIEW

Traumatic Brain Injury (hereafter TBI) is a major health concern within the United States, and one that has been receiving more attention during the last decade. Advances in medical technology and acute trauma care, improved first responder services, and better protective devices have increased the survival rates of individuals with acquired brain injury (Gawnade, 2004). The War on Terror has been a catalyst for more recent attention to TBI, as 60% of injuries sustained in the war are the result of high-impact blast injuries leading to TBIs (Defense and Veterans Brain Injury Center [DVBIC], 2005; Okie, 2005; Warden et al., 2005). TBI has been termed the “signature injury” of this current war (Stein & McAllister, 2009, p. 3). In the United States, it is estimated that 1.7 million individuals will sustain a TBI per year (Centers for Disease Control and Prevention [CDC], 2010).

Traumatic Brain Injury can result in a variety of symptoms that present differently depending on the location and severity of the injury. Changes in an individual’s overall functioning may manifest in an array of negative physical symptoms, cognitive changes, personality changes, and difficulties interacting in social and occupational settings. Consequently, primary caregivers—particularly spouses—often experience a wide range of emotions including anxiety, depression, anger, shock, disbelief, denial, guilt, and frustration (Cavallo & Kay, 2005; Lezak, 1978; 1986; 1988; 1996), especially as they provide the majority of direct care and support. Considering the growing population of individuals living with a TBI, counseling psychologists need to be prepared to assist a range of potential clients who have been impacted by TBI, both directly and indirectly.

Spouses of individuals who have sustained a TBI are perhaps the most affected of the family system, as they tend to provide the majority of support and encouragement for the individual. Additionally, they are usually closely involved with the decision making of their spouse's medical care and rehabilitation plan, assist in the transition back to the home, and are the primary support for their loved one with a TBI through the multiple changes the injury creates. Although spouses experience high levels of stress and grief, they may under-utilize the health care and mental health system with regard to their own needs, as the majority of services focus on assisting the patient who has sustained the TBI. This chapter will provide an overview of the prevalence, etiology, and sequelae of TBI. The chapter will then discuss the experiences of caregivers as they adjust to caring for their loved one with a TBI, with a specific focus on spouses' perceptions of change within the relationship and home. This chapter will also provide an overview of the coping mechanisms and support systems that caregivers and/or spouses can utilize, and will conclude by discussing the limitations of the current literature as well as the aims and hypotheses of the current study.

### Traumatic Brain Injury

Traumatic Brain Injury has been traditionally coined by researchers as the "silent epidemic" because the injuries to the brain are physically hidden from view once all external injuries have healed. Traumatic Brain Injury is defined by the CDC (2013) as "a bump, blow, or jolt to the head or a penetrating head injury that disrupts the function of the brain." (Injury Prevention & Control: Traumatic Brain Injury, para. 2). When an extreme force is exerted on the brain, neural structures may suffer shearing, twisting, straining, or tearing of brain tissue due to the movement of the brain. Injury to these

structures can occur through penetration of the skull, or from sudden changes in velocity, which exert unequal force on the brain, causing the brain to collide with the internal structures of the skull (Kolb & Whishaw, 2003). TBI can occur from falls, motor vehicle accidents, gunshot wounds, assaults, anoxia (e.g. occurring from drug overdose or near drowning), or internal injuries (e.g. bleeding in the brain).

### Types of Brain Injury

There are two types of acquired traumatic brain injury: open and closed head injury. Open head injuries or penetrating injuries occur when an object (e.g. a bullet) creates an opening in the skull and causes damage to structures and tissues of the brain. Closed head injuries occur when there is no external damage to the skull itself. Damage instead occurs from significant acceleration or deceleration of the brain, causing the brain to move quickly from one state of being to another (e.g. in a vehicle accident). Prognosis and recovery of the individual is highly dependent on the area or areas of the brain affected and also the extent of damage. Severity of injury ranges from mild (e.g. brief changes in mental status or level of consciousness) to severe (e.g. prolonged state of coma and/or amnesia post-injury). Open head injuries are associated with focal damage to the brain, whereas closed head injuries are associated with diffuse damage to several structures of the brain, resulting in a greater likelihood of coma (Kolb & Whishaw, 2003; Zillmer et al., 2007). Closed-head injuries may result in multiple types of damage to the brain, such as impact (the result of the brain colliding with the skull) and countercoup injuries (the brain tearing away from the skull). The most severely affected areas of the brain in this type of injury are the frontal and temporal lobes (Zillmer et al., 2007). Furthermore, these injuries may cause marked shearing and tearing of axons within the

brain, damage to blood vessels, and may cause the covering of the brain to rupture. When closed head injuries are severe, such as when the brain is forced against the skull many times, the brain may become extremely swollen, which often leads to other complications including neuronal disruption, ischemia, hemorrhaging, and edema (Teasdale & Mendelow, 1989).

### Prevalence

Every human is at risk of sustaining a TBI due to the multitude of experiences and interactions individuals encounter on a daily basis. The CDC indicates that non-fatal TBI impact approximately 1.6 million individuals per year on a national level (CDC, 2010). Of this population, the CDC (2010) estimates that 52,000 individuals will die from their injuries, 275,000 will be hospitalized, and 1.4 million will be treated in an emergency room. There are a significant number of individuals who experience a mild head injury or a mild concussion and may not be formally evaluated or treated for their injuries; thus the total number of individuals who experience this type of injury are unknown. Fatalities as a result of sustaining a TBI have been estimated at 618 individuals per 100,000 in a national survey (Sosin, Sacks, & Webb, 1996).

In developed countries, head injuries have been deemed a serious health issue. Half of all deaths within the United States have been associated with TBIs (Rimel, Giordani, Barth, Boll, & Jane, 1981). The primary causes of TBIs within the United States are due to falls and vehicular accidents, which include cars, boats, motorcycles, bicycles, and other modes of transportation (Annegers et al., 1980; CDC, 2010; Jager, Weiss, Coben, & Pepe, 2000; Kalsbeek, McLaurin, Harris, Miller, 1980; Kraus et al., 1984; Sosin et al., 1996). The CDC (2010) indicates that the majority of TBIs inflicted



on children 0 to 14 years and adults 65 years or older were the result of falls, whereas the vehicle accidents account for the second leading cause of TBI across all age groups.

Other causes of head injuries may be attributed to sports injuries, violence, struck by/against events, and industrial accidents (CDC, 2010; Zillmer et al., 2007).

Traumatic Brain Injury, especially those moderate to severe in classification, may result in chronic disability. Approximately 70,000 to 90,000 individuals with a TBI will experience chronic functional impairments (National Institute of Health, [NIH], 2010). For instance, in 2005 it was estimated that within the United States 1.1% of Americans—3.17 million people—cope with a chronic disability due to sustaining a TBI (Zaloshnja, Miller, Langlois, & Selassie, 2008). The costs associated with loss of productivity, inability to engage in the workforce, and psychosocial and physiological limitations are estimated to be highest for individuals between the ages of 15 to 44 who have sustained a mild, moderate, or severe brain injury. In the early 1990s the direct and indirect cost of TBI was estimated to be more than 48 billion dollars per year: 32 billion dollars for survivors and 16 billion for fatalities (Lewin/ICF & James Bell Associates, 1990). More current estimates place the direct and indirect cost closer to 60 billion dollars per year (Finkelstein, Corson, & Miller, 2006). These estimates may be low, however, given the deleterious effect of the War on Terror and the increased number of TBIs sustained in combat related traumas.

The risk of sustaining a TBI pervades every group within the human race; although, there are groups who have been found to be at a higher risk for sustaining a TBI. In the research literature it has been established that the group at the highest risk for suffering a TBI within the United States are individuals between the ages ranges of: 0 to

4, 15 to 19, and adults 75 years or older (CDC, 2010). The literature consistently reports that men are at a higher risk for sustaining a TBI than women, and studies within the United States tend to report a ratio of risk between 1.6 to 2.8 to 1 between men and women; however, other studies estimate that this ratio may be as high as 4 to 1 (Zillmer et al., 2007). Socio-economic status has been associated with the incidence of TBI, and several studies have suggested that the highest risk of sustaining a TBI is correlated with the lowest levels of socio-economic standing despite differences in geographical regions (Kraus et al., 1984; Sosin et al., 1996). There are several theories regarding why social class standing may be related to higher incidence of TBI, including greater exposure to violence, increased chances of substance abuse, higher numbers of cognitive and mental disorders, and greater prevalence of homelessness (Calantonio, Stamenova, Abramowitz, Clarke, & Christensen, 2007; Silver & Felix, 1999). The chances of acquiring a subsequent brain injury is also higher in individuals who have a previously sustained a TBI (Annegers, Grabow, Kurland, & Laws, 1980; Dams-O'Connor et al., 2013) and individuals who survive TBI with loss of consciousness in their later years are especially at risk for subsequent head injury (Dams-O'Connor et al., 2013). Although prevalence rates for suffering a TBI are vital to our understanding of this disorder, perhaps one of the most important areas of research is focused on the lasting consequences of TBI.

### Consequences of Traumatic Brain Injury

Individuals may have a wide range of symptoms resulting from head trauma, all of which are dependent on the type, location, and level of severity of the injury. As such, each case of TBI may affect an individual differently. The extent of injury has been widely covered within the research literature. An individual who survives a TBI may

experience cognitive changes, executive dysfunction, amnesia, delirium, amotivation, fatigue and sleep problems, frequent headaches, balance problems and chronic dizziness, visual deficits, chronic pain, sexual dysfunction, changes in personality, mood disorders, difficulty controlling aggression and impulsivity, seizures, anxiety, and posttraumatic stress disorder. This list is not exhaustive and individuals may experience a range of symptoms depending on the type and level of severity of the injury. Some of these conditions may be reversible while others are permanent changes.

Individuals may also present with unique symptoms and alterations from their base level of functioning. Research on the consequences of TBIs frequently report on the cognitive changes survivors experience. The severity of a TBI may not be indicative of the types of changes in cognition that an individual may experience; however, in cases of severe TBI, patients and caregivers continued to report difficulty over the long term coping with changes in cognition, behavior, and emotions, more so than changes in physical ability (Brooks, 1984; Oddy, Coughlan, Tyerman, & Jenkins, 1985). Cortical regions of the brain that are responsible for attention are typically impaired as a result of focal and diffuse injury to the brain. As such, individuals who survive a TBI may have difficulty with various aspects of attention, including arousal and alertness, vigilance, their ability to shift focus and divide their attention, concentration, processing speed, and short term memory (McCullagh & Feinstein, 2005). Impairments in memory are a hallmark symptom of TBI and individuals with a TBI report that these impairments, more than any other cognitive change, continue throughout their life span (King, Crawford, Wenden, Moss, & Wade, 1995; Van Zomeren & Van den Berg, 1995). Areas of memory that may be affected include declarative and implicit memory as well as memory used in

executive functions. In addition, survivors of a TBI may not be able to remember past events and have difficulty learning and remembering new information, such as recalling activities or conversations. Moreover, and perhaps more troubling to both the individual suffering from a TBI and their family members, individuals with TBI may not be able to recall the names of those closest to them. They may be unable to recollect specific memories, or when reading a book may not be able to remember the plot of the story midway through the reading.

Frontal areas of the brain are particularly susceptible to contusional damage. Harm to the frontal lobe has been associated with impairments in executive functions. Executive functions control an individual's ability to resist impulses, engage in goal setting, organization, planning, judgment, social awareness, and self-regulation. Language functions and the ability to communicate with others may also be affected. It is well cited in neuropsychological research that individuals coping with a TBI may have difficulty with word finding, verbal fluency, and object naming. Snow and Douglas (2000), in their clinical work with patients of TBI, have suggested that language difficulties underpin the problems these individuals experience with social interactions because the frontal areas of the brain also underlie purposeful conversation. For example, Snow and Douglas (2000) indicated that individuals may experience difficulty retelling an event or may be unable to explain a process to someone else. They may have difficulty perceiving subtle intentions within another person's utterances, such as sarcasm, and may have problems attending to the needs of the listener (e.g. initiating conversation; possessing the ability to continue the flow of the conversation).

Research on the symptoms and severity of TBIs suggest that the most disturbing changes that both individuals with acquired TBI and their caregivers report are changes to personality. The severity of the injury, however, may not be indicative of how an individual's personality changes as he or she heals (Brooks & Mckinlay, 1983; Lishman, 1973; Malia, Powell, & Torode, 1995; Prigatano, 1992; Tyerman & Humphrey, 1984). An individual with a TBI may or may not be aware of his or her own changes in personality, depending on one's level of insight. Changes to personality often become more noticeable as the time from the injury increases. Individuals who survive a TBI and their loved ones report that these personality changes are more difficult to cope with than cognitive or physical symptoms (Brooks, Campsie, Symington, Beattie, & Mckinley, 1986; Lezak, 1978; Mckinlay, Brooks, & Bond, 1981; Oddy, Humphrey, & Uttley, 1978; Thomsen, 1984). Personality changes can range from social awkwardness and mild inappropriateness to extreme social inappropriateness, apathy, and lack of conventional social norms.

The most famous account of the devastating effects of personality changes in individuals with a TBI is the story of Phineas Gage. Harlow (1993), in 1868 was the first to describe this phenomenon. Prior to the accident, Gage was described as reliable, polite, and even-tempered. After his injury, however, Gage became socially inappropriate, as evidenced by his frequent swearing, gambling, and excessive sexual activity. He made inappropriate comments and had extreme difficulty controlling his temper, and was largely unaware of the effect his behavior had on others. So dramatic were these changes that those who knew him described him as "no longer Gage"

(Harlow, 1993, pp. 277.). This study was the first to increase awareness of the effects of TBI on the individual and those in his or her life.

More recent studies focusing on the changes individuals experience after acquiring a severe TBI describe a common cluster of symptoms. Experts within the field have posited that changes to personality may arise from reduced blood flow in the cerebral cortex, disruption to the reticular system, and specific damage to the prefrontal, orbitofrontal, and anterior temporal regions and their related structures within the cortical and limbic system (Silver, Hales, & Yudofsky, 1994). Personality changes are also highly associated with damage to the frontal lobe. Lesions in this area are closely correlated with irritability, paranoia, impulsivity, rapid cycling of emotions, poor judgment, rigidity, lack of insight, apathy, difficulty concentrating, and troubles carrying out tasks (Silver et al., 1992). Lezak (1982) examined the relationship between brain lesions of the frontal lobe and personality and behavioral changes after an individual has sustained a TBI. The common symptoms she noted in individuals with frontal lobe TBI include difficulty initiating, rigidity in thinking, problems changing current behavior, lack of insight, and closed or unreasonably inflexible thinking.

Given that personality changes may be associated with lesions in specific areas of the brain, early experts within the field posited that there may be a common pattern of personality changes in individuals who sustain a TBI; however, research in this area has not been conclusive. For example, Hibbard et al. (2000) examined the frequency and relationship of post-TBI personality disorders by conducting a structured clinical interview for DSM-IV Personality Disorders, Clinician Version (SCID-II) of 100 individuals with a TBI. Results of the study indicated that 24% of the sample met criteria

for a personality disorder prior to acquiring a TBI. After acquiring a TBI, 66% of the sample met criteria for at least one personality disorder when TBI severity, age at injury, and time since onset of TBI were held constant. The researchers of the study indicated that the most common disorders after an individual sustains a TBI are borderline disorder, avoidant personality disorder, paranoid personality disorder, obsessive-compulsive personality disorder, and narcissistic personality disorder. Men within the sample were more likely to be diagnosed with antisocial and/or narcissistic personality disorder. Those individuals in the study who met criteria for a personality disorder prior to the onset of their TBI had a higher probability of meeting criteria for a personality disorder than those who did not. The researchers of the study suggested that personality changes differ by individual characteristics. Results of the study did not support the theory that there is a common personality change in individuals after he or she sustained a TBI. Instead, the results indicated that an individual's personality change may be related to his or her individual pre-TBI personality characteristics, post-TBI coping strategies, and changes in functioning since acquiring a TBI.

Research literature focusing on the symptoms associated with TBIs may vary by sample size and severity of the participants polled. For example, rates of depression reported in the literature on individuals with a TBI ranged from 6% to 77% (Levin & Grossman, 1978; Rutherford, Merrett, & McDonald, 1977; Varney, Martzke, & Roberts, 1987). Hibbard, Uysal, Kepler, Boddany and Silver (1998) studied the incidence, comorbidity, and prevalence of Axis I disorders in 100 adults between the ages of 18 to 65 who had acquired a TBI eight years prior to the study. The researchers assessed participants at pre-TBI, post-TBI, and current-level functioning through a structured

clinical interview using the DSM-IV diagnosis criteria. Results suggested that, after controlling for gender, occupational status, age at the time of injury, length of time since the onset of the injury, and severity of the TBI, 40% of the sample met criteria for substance abuse disorders prior to acquiring the TBI. In addition, the results further indicate that 80% of participants at post-injury met criteria for an Axis I disorder, and 44% met criteria for two or more Axis I disorders. Major Depressive Disorder presented with the highest frequency within this sample, with 61% of participants post-injury meeting the disorder criteria. In addition, 23% of the participants who met criteria for Major Depressive Disorder also presented with psychotic symptoms. Similar results have been found in additional studies and add that individuals who have sustained a TBI may also be at higher risk for suicidal ideation (Silver, Kramer, Greenwald, & Weissman, 2001; Simpson & Tate, 2007). Guitierrez, Brenner, and Huggins (2008) investigated a sample of 28 veterans who survived a TBI from 1968-2005, 22 of the participants were hospitalized a total of 114 times during the course of the study and 72.7% of the participants endorsed suicidal ideation during at least one of their hospitalizations. Additionally, six participants attempted suicide 14 or more times (Guitierrez et al., 2008). This is the first study to date that seeks to explore the level of suicidal ideation in veterans who sustained TBI.

One of the few longitudinal studies conducted on TBIs followed patients of severe TBI from 4-5 months to 15 years post-injury. Thomsen (1984) followed 40 patients of severe TBI and reassessed personality symptoms at 4-5 months, 2-5 years, and 10-15 years after the event that led to their injury. The first follow-up was conducted at the primary care hospital by interviewing the individual, his or her care team, and the patient's



family. The additional follow-ups took place at the patient's home, and both the patient and any caregivers were interviewed. In the initial follow-up of the 40 patients, two-thirds indicated that there was a significant loss of social contact, and, moreover, a majority of the patient's caregivers reported significant negative changes in their loved ones' personality and behavior. For example, 7 married patients' spouses filed for divorce post-injury, stating the reason for the separation was that his or her spouse had become a "complete stranger" (p.264). Spouses reported that their loved ones had difficulty controlling his or her emotions, and that their mood altered quickly between apathetic, aggressive, childish, and irritable. At the second follow-up, 2-5 years post injury, two-thirds of spouses indicated that the changes to their partner's personality appeared permanent, with few improvements. The most painful consequence for patients at this follow-up was social isolation. Two-thirds reported no contact outside the immediate family. In addition, due to the patients' cognitive and personality changes, 93% were on disability by this time. At the final interview both the patients and their families reported social isolation and little contact outside the immediate family and personality complaints persisted. Thomsen's (1984) longitudinal study suggested that the symptoms and consequences of TBI result in multiple changes to an individual's life, and frequently these changes are permanent. However, the changes are not isolated to the injured person, but pervade the entire family unit (Kay & Cavallo, 1991).

### Experiences of Caregivers

Caregivers experience with TBI typically begins when they are informed that an unforeseeable event has occurred, resulting in a loved one acquiring a TBI (and, often, other serious injuries). From this point forward, the lives of all those connected to the

patient are changed: brain injury affects and alters the experience of all the family members (Cavallo & Kay, 2005; Kay & Cavallo, 1991). The transformation within the family system is related as much to the severity and type of injuries sustained as it is the pre-existing family dynamics, values, senses of responsibility, types of social support, and financial standing (Lezak, 1987). The family system is composed of the patient as an individual family member, the family as a system (e.g., immediate family members such as children), and the community as related to the family. Family units maintain equilibrium to balance the roles and responsibilities encountered on a daily basis (Cavallo & Kay, 2005). When one individual in the family system acquires a brain injury, the entire family system is presented with a significant challenge. The individual with the TBI must face the arduous process of recovery and rehabilitation: similarly, the family will undergo a lengthy journey seeking familiarity inside the family structure. However, just as the injured individual cannot always return to previous functioning, the family system can often no longer return to its previous standing (Cavallo & Kay, 2005). Changes within the family structure tend to occur quickly once the individual is back within the home environment. Personality changes are the most devastating to family structures, and the chronic alterations to relationships can cause considerable strain, not only during the adjustment phase but also in the long term (Brooks et al., 1986; Brooks, Campsie, Symington, Beattie, & Mckinlay, 1987; Brooks & McKinlay, 1983; Cavallo, Kay, & Ezrachi, 1992; Livingston, 1987; McKinlay et al., 1981).

Lezak (1978), in her work with families of individuals with TBI, described the common issues families encounter when the individual returns home. The presentation of symptoms may be conceptualized in five broad domains that often co-occur, overlap,

and interact with one another. These domains are: (1) self-centered behavior, with a lack of empathy or understanding of others' perceptions; (2) difficulty with self-control, which is evident in impulsive behavior, impatience, and feeling restless; (3) marked difficulty planning, organizing, and executive functioning, all of which present in being overly dependent on primary caregivers; (4) personality changes that may present as apathy, rapid cycling through moods, irritation, acting immature, and either lack of or increased sex drive; and (5) perseverating on topics, inflexibility, and rigidity of thinking.

Individuals with a TBI may also be aware of their deficits and may remember who they were before their injury, which creates more emotional pain for the individual and his or her family (Lezak, 1986). Awareness of personal impairments has been linked with chronic rates of depression for individuals with acquired brain injury. This can be especially problematic for individuals who remember their previous life but are unable to glean insight from or lack the ability to change their perceptions of the situation. Lezak, in her clinical work (1978) and research on the effects of TBIs on individuals and their families (1988), presented observations of the common issues that family members experience as the recovery stages continue to evolve. For example, she described "chameleon-like characteristics" in individuals with TBI as the patients may be able to engage in conversation and appear happy in public, but when he or she is in the comfort of his or her own home, the individual may become "[an] irascible tyrant" (Lezak, 1988, p. 113). This behavior is bewildering for family members, especially when they are trying to understand the changes in their loved one and the changes appear to be at least somewhat controllable.

In addition, those people who are not privy to the immediate family home environment may see the individual with a brain injury as the same person they remember, and may not understand the complaints and distress of the caregivers. Lezak (1988) further suggested this dual behavior is particularly problematic for family members seeking support, since outside the immediate family unit other family and friends who do not live within the household see the individual on his or her best behavior. As a result, caretakers may receive little support or empathy. In addition, others may suggest that the caregiver does not understand the individual with a TBI, are not adequate caregivers, or have some personality trait that is negatively altering their perceptions and attitudes. Outsiders may not truly understand the internal struggle within the home or appreciate that caregivers are experiencing and coping with a multitude of negative and distressing behaviors from their loved one. Based on her clinical work, Lezak (1978; 1986; 1987; 1988) indicated that caregivers of individuals with a TBI frequently find themselves the unprepared recipients of irrational jealousy, fear, anger, verbal rejection, and anxiety from the individual with a TBI. Care providers are confronted with a range of emotions, and due to the lack of visible support services frequently feel that they are expected to manage these symptoms without outside assistance. The varying degrees of change an individual who sustains a TBI encounters can be painful, and also impacts the immediate family. The recovery process is lengthy, and continues throughout the individual's lifespan.

#### Phases of TBI on Family System

Researchers studying the impact of TBI on the family system theorize that it tends to occur in three distinct stages (Cavallo & Kay, 2005). These stages are the acute phase,

the rehabilitation phase, and the reintegration phase. The acute phase focuses is on the stabilization of the injured family member and the prevention of secondary trauma. This is a stage in crisis mode, as the family is devoting all of its time and resources to the injured family member and to being available should new information present itself. The rehabilitation phase is focused on readjustment and reorganization of previously held family roles, as well as the recovery and healing of the injured loved one. Within this stage the patient is typically in the process of transitioning from the hospital to the home. The third stage, the reintegration phase, focuses on re-establishing long-term family roles and expectations. In this stage the individual with a TBI attempts to re-establish him or herself within the community and the workforce. The phases will be described in greater detail in the following sections.

#### Acute Phase

The acute stage is one of great stress for caregivers and the family. To understand what has occurred, caregivers seek information about the status and prognosis of their loved one. This process can be a relief for family members, but can also lead to additional stress. Health care professionals, especially in the initial stages of injury, are often unable to give detailed information about the prognosis or progression of the injuries because of the complexity of the brain, the potential for secondary trauma, and the contribution of other injuries that may impact overall healing (Gregory, 2001). Medical professionals primarily seek to stabilize the individual, treat symptoms, and limit secondary and critical health conditions. Due to the nature of the injuries and the uncertainty of the situation, the relationship between the primary caregiver and the health care provider is of central importance to the family members of the patient. At this point, caregivers try to find

meaning in the abrupt changes to their lives, and attempt to gain control of the chaos that is inherent in the initial stages of a severe brain injury. Acute concerns that caregivers and family may ask health care providers range from short to long term concerns, such as “How long will my loved one need hospital care?” “How long will it take my spouse to wake up?” “Will my spouse remember me?” “What will he or she be like when he or she wakes up?” and “Will my loved one be able to talk or walk?” Health care providers are focused on the immediate health needs of the patient and due to the complexity of brain injuries may need to deliver information about prognosis in vague terms (Kendell, Buys, & Larner, 2000; Lowler & Mattingly, 1998). The patient may also be seen by multiple health care providers, each with a specialty area, and none of them may be able to provide concrete answers to specific questions.

Misconceptions of Experiences of TBI during the Acute Phase. The medical treatments team and close family friends represent the first points of contact for caregivers as they attempt make sense of their loved one’s injury and reach out for support. Often, however, individuals with a TBI and their caregivers report feeling alone in their circumstances. Initial research within this area suggests that caregivers have difficulty understanding information provided to them by hospital staff during the time their loved ones are in acute care (Thomsen, 1974). Additionally, a classic study by Rosenbaum and Najensen (1976) that interviewed female spouses described the vulnerability of caregivers to depression and disappointment due to having unrealistic expectations for their spouse’s recovery. Misconceptions of the effects of brain injury are unfortunately common (Gouveir, Presholdt, & Warner, 1988; Willer, Johnson, & Rempel, & Linn, 1993) and may lead to miscommunication between caregivers and

professionals, especially regarding what caregivers can expect. Gouvier et al. (1988) investigated the common misconceptions of brain injury via a structured interview of the general populace. Participants of the study (n=221) were approached randomly in a large shopping center in an urban area. Approximately 70% of the sample believed that recovery from brain damage was dependent on the individual's effort to recover. Additionally, approximately half the sample believed that an individual was considered recovered when they "felt normal," and that it was entirely possible for the individual to return to pre-injury functioning. Of note, nearly half (42%) of the participants in the study, relied on information about TBIs from talk shows and from discussions with health care professionals to answer the questions. A replication study with a sample of 331 individuals supported the finding that the majority of people in the general public are misinformed about the long term consequences of TBIs (Willer et al., 1993).

Regarding family members who have a loved one with a TBI, Springer, Farmer, and Bouman (1997) interviewed 51 family members using a modified version of the questions used in Gouvier et al.'s (1988) study. Although family members' responses in this study were more accurate in regards to the acute impact of TBI, they also had more misconceptions about the long term effects of TBI. This may, however, be partly a result of the study taking place during the first week that individuals were transitioned from acute care to a rehabilitation setting. Swift and Wilson (2001) examined misconceptions of brain injury in the general public and among health care professionals (who are not TBI specialists) by individuals who have direct experience with TBI (e.g. caregivers, professionals who work with individuals with TBIs, and individuals who have sustained a TBI). Major themes gleaned from semi-structured interviews with participants (n=22)

suggest that “experts” feel the majority of the general population and other professionals do not understand the recovery process or the length of time of recovery for individuals who have sustained a TBI. More specifically, participants identified a general lack of understanding of the consequences of TBI, including the behavioral, cognitive, and emotional sequelae. These misunderstandings lead to inaccurate labels of TBI as the result of mental illness or learning disabilities rather than legitimate symptoms of TBI. For example, participants in the study described instances in which the individual with the TBI displayed inappropriate behavior in front of hospital staff, family, friends, and the general public, all of whom were made aware that the individual had a TBI. Despite knowing about the TBI, those who viewed the behavior did not attribute it to the TBI or indicate that they even thought it was related to symptoms of TBI. Despite growing awareness of the prevalence, etiology, sequelae of TBI, and to the long term effects of TBI, research continues to suggest that inaccuracies regarding what TBI is, how it affects the individual, its long term effects, and its impact on the family continue to remain prevalent among the general public and among professionals who may provide services to individuals who have sustained a TBI and his or her family and caregivers. These misconceptions, in particular those of professionals, is concerning, as treatment, recovery, and support by those who are affected by TBI could result in more harm than benefit.

Although misconceptions and miscommunication does occur throughout the recovery process of an individual with TBI, professionals within the area have taken steps towards further understanding the immediate needs of family members. Caregivers have reported feeling frustrated by the uncertainty of information, and may feel that their loved



one is being viewed in pieces, and may experience a lack of appreciation for his or her knowledge of the patient. Lefebvre, Pelchant, Swaine, Gelinias, and Levert (2005) examined the experiences of caregivers (n=8), patients of TBI (n=8), treatment team/service providers (n=22), and attending physicians (n=9) throughout the process of acute care to rehabilitation for the healing individual. Participants of the study took part in a 90 minute semi-structured interview by the primary investigator. The patient and caregivers responded to questions focusing on experiences from the initial onset of the injury through each stage of healing (i.e. hospitalization, transition to the home, and rehabilitation services) and, finally, provided the opportunity for reflection on the interaction and quality of health care providers, the value of resources shared with the caregivers, and quality of rehabilitation support. Health care providers were asked questions about their experience within their current field, experience with the stages of TBI recovery, personal interactions with family members, caregivers, and the interdisciplinary team, and finally their opinion on the state of current services. Results suggest caregivers felt a positive connection with health care professionals when they are able to share their experiences and memories of their loved one, when they feel supported by the treatment team, when they are included in the treatment and planning of care for their loved one, and when they feel that the physician was willing to try to answer the questions posed by the family. All participants in the study acknowledged that uncertainty was the most difficult aspect of TBI.

The initial phase of healing occurs within the hospital setting, in which family members are often focused on the question of whether or not their loved one will ever be the same again, or even be able to come home. This phase, however, represents the

beginning of many unknowns and questions that, unfortunately, will take a long time to answer. A positive step in the healing process for both the family and the individual with the acquired TBI is the transition home.

### The Rehabilitation Phase

The transition from the hospital to the home can be a relief to the family. Their loved one is making tangible progress, and the hope of re-establishing the family structure is fresh not yet challenged. This transition occurs within the rehabilitation phase. The focus of this phase is readjustment and reorganization of previously held family roles, and the recovery and healing of the injured loved one (Cavallo & Kay, 2005). Despite the many positive emotions that the family may experience when their loved one returns home, there is also a significant level of stress which is likely to most dramatically impact the uninjured spouse or primary caregiver. Many families are satisfied with the resources and level of care they experience during the acute stage and inpatient rehabilitation; however, once the loved one transitions to the home, resources become scarce (Lefebvre et al., 2005). As such, the majority of caregivers feel overwhelmed by the multiple changes for which they were completely unprepared (Turner, Fleming, Ownsworth, & Cornwell, 2008).

Spouses or primary caregivers may lack the resources, support, and skills that they need to manage the array of circumstances an acquired brain injury produces. When the family member returns home, he or she and the rest of the family unit are adjusting to several conditions at once, such as level of disability, awareness of impairments, changes in social support, differences in personality, changes in occupational or educational status, and pace of recovery of the individual with a TBI. These factors together create a

multitude of experiences which must be processed by the entire family system. Rotonidi, Sinkule, and Balzer (2007) interviewed 80 individuals with a TBI and their primary caregivers (n=85) six years post injury to examine the continued needs of individuals with a TBI and their caregivers. Results of the semi-structured interviews indicated that caregivers expressed a significant lack of appropriate education and preparation for the changes and needs of their loved one. For example, caregivers reported that information given about the TBI was focused on rehabilitation needs and provided limited information regarding the transition from the hospital to the home, and that no information was provided on the evolving changes and issues which occur throughout the individual's lifespan—nor how these changes may impact caregivers. The researchers suggested that services need to be directed towards the long term needs of both the patient and the caregivers, and that information needs to be individualized to the family.

In many cases of TBI, even though a loved one is reintegrating back into the home, the recovery process is still within the initial stages. It is not uncommon for all parties involved in the transition to the home to feel that they are moving from one difficult situation to another, without time to fully process through each new and stressful experience. Similar to the Acute Phase, caregivers have a high level of need for information when their loved one returns home. Caregivers in this stage seek out sources of support and additional information. For example, they may look for resources to assist them in adjusting to the symptoms of their loved one's injury, resources to assist in the care of the injured individual, or resources to help alleviate financial concerns (Lezak, 1986). Turner et al. (2008) examined the needs of caregivers as their loved one with a TBI transitioned from the hospital to the home. Using phenomenological methods, the

researchers engaged caregivers (n=13) in semi-structured interviews focusing on their experiences of the transition back to the home. Themes common among interviewees suggested that the initial transition from the hospital went well, as the majority of patients had the opportunity to have their loved one at home for a weekend prior to discharge to raise confidence and awareness of what the return home might look like. However, as the transition progressed caregivers reported feeling overwhelmed and sometimes felt they were unable to cope, which led to the end of the relationship. At this phase, 4 out of the 9 couples separated. In addition, caregivers reported that although there was a range of services available during inpatient rehabilitation to assist in the transitional phase, many felt frustrated when ongoing community and outpatient services proved scarce. In particular, those individuals who lived in rural settings had limited access to services in general and indicated that they did not receive support they required.

Another significant barrier during the transition phase is lack of financial assistance (McCarthy et al., 2006). Caregivers report that their loved ones are frequently unable to return to work, and to care for their spouse the caregiver had to increase their workload (Jacobs, 1988; Turner et al., 2007). Because financial resources were strained, and available resources often carry financial costs, support services that were suggested during previous phases became unaffordable (Degeneffe & Olney, 2008; Mellick, Gerhart, & Whiteneck, 2003). As a TBI occurs through accident or trauma, caregivers are often involved in negotiating compensation settlements, which caregivers frequently find confrontational, overwhelming, and cause greater financial strain (Turner et al., 2007). Transportation is also noted as a barrier, because many individuals with a TBI are not recommended to drive (Fraas, Balz, & Degrauw, 2007; Turner et al., 2007). Often

individuals with a TBI reported not feeling comfortable taking the bus, as they are unfamiliar with public transportation, and/or are concerned about getting lost or taking the wrong route (Turner et al., 2007). As such, reintegration into the community was largely dependent on caregivers. Although caregivers often actively seek out information, the information they frequently receive is inadequate (Lezak, 1987; 1986; 1996; Turner et al., 2008). They may also feel misinformed or ill-prepared about the prognosis and limitations of their loved one.

### The Reintegration Phase

Family members' point of reference is of their loved one before the injury, and although the loved one has transitioned back into the home, former roles remain in a state of transition (Cavallo & Kay, 2005). The reintegration phase is the long term, evolving state of the family and the injured individual. Family members continue the process of fully integrating their experiences of the TBI and its long term effects, which impact their daily life. As previously mentioned, caregivers may have unrealistic expectations for their loved ones' recovery, and may feel that since their loved one has regained some aspects of their abilities that a full recovery still possible (Lezak, 1986; 1987; 1996; Turner et al., 2008). For example, Turner et al. (2008) compiled a literature review of 50 articles from 1987 to 2007 focusing on the transition from the hospital to the home for individuals with a TBI. Search terms were based on compilations of TBI, rehabilitation, transition from hospital to home, discharge, and integration with community and home. The researchers suggest that the common theme in the literature is the transition from the hospital to home is a challenging and stressful time for both the caregivers and the

survivor of TBI. As recovery progresses, caregivers become more aware of the realities of their loved one's injury and adjustment to new familial roles begins.

### Transition to New Roles within the Family

Caregivers, during the transition phase and beyond, reported higher rates of depression, anxiety, and increased isolation (King, Shade-Zeldow, Carlson, Feldman, & Phillip, 2002; Kreutzer, Gervasio, & Camplair, 1994; Machamer, Temkin, & Dikmen, 2002; Marsh, Kersel, Havill, & Sleigh, 1988; Marsh, Kersel, Havill, & Sleigh, 2002; Oddy et al., 1978; Semlyen, Summers, & Barnes, 1998; Turner et al., 2008). Along with these symptoms, caregivers may feel burdened by the new construction of their role within the relationship. For example, Hanks, Rapport, and Vangel (2007) investigated appraisals of caregiver burden and relationship satisfaction by of caregivers of individuals with a moderate to severe TBI (n=60) through administration of the Disability Rating Scale (DRS), Functional Independence Measure, Social Provisions Scale, Coping Inventory for Stressful Situations, Family Assessment Device (FAD), and the Caregiver Appraisal Scale. The majority of participants reported feeling overwhelmed by the level of support their spouses needed. In addition, caregivers felt they lacked the skills needed to fully assist their loved one. In the research literature, spouses have been referred to as the "hidden patients;" as they will more frequently take on the role of a primary caregiver with little access to resources or external assistance (Fengler & Goodrich, 1979, p. 175). Jacobs (1988) surveyed 142 families with a loved one who had acquired a severe TBI to identify the primary stressors on family members. Family members reported high levels of burden even years after the injury. Participants in the study reported feeling guilty and inadequate to provide the support their loved one

needs. Additionally, caregivers reported that as services within the community were not available, they took on the role needed to provide rehabilitative care even though they had not received formal training. Jacobs indicated that 28% of participants reported that the payments for medical and rehabilitative services created significant financial burden on the family, and an additional 38% reported leaving the workforce because their loved one needed continuous support due to the severity of symptoms. Caregivers also indicated decreased social interactions outside the home, took additional time off of work, and had limited ability to engage in activities within the community (Livingston, Brooks, & Bond, 1985; Machamer et al., 2002).

Family members and spouses assume changes in familial roles to care for the individual with the TBI. For example, assuming average marital roles, before the injury the married individuals may have shared the responsibilities of the family and household together (e.g. helping with household chores, assisting with income, caring for children). Zasler and Kreutzer (1991) reported that post-injury the spouse who acquired the TBI is no longer able to fulfill their roles and responsibilities and, depending on the severity of injuries, may have become dependent on the other spouse to fulfill these previously held roles as well as assist in their care. The caregiving spouse may need to supplement income, by either working longer hours or obtaining another job, taking care of household chores, and providing support and care to other family members, especially if children are involved (Turner et al., 2007). The support that partners previously obtained from their spouses is missing and, depending on the severity of injury, the caregiver's role may change from that of a spouse to one similar to that of a parent (Kreutzer et al., 1994; Zasler & Kreutzer, 1991; Zeigler, 1987). For example, the spouse may provide

structure, feedback on behavior, and assistance with daily activities. As the level of responsibility rises with little to no external support, spouses have higher likelihood of physiological and psychological distress, and studies report that spouses are the most significantly impacted of all family members by their partner's injury (Gervasio & Kreutzer, 1997; Kreutzer et al., 1994; Mauss-Clum & Ryan, 1981; Panting & Merry, 1972; Rosenbaum & Najenson, 1976; Zeigler, 1987).

Spouses, even two years after the transition back home, continue to report a significant level of anxiety and depressive symptoms. For example, Weddell, Oddy, and Jenkins (1980) surveyed 44 males with a severe closed-head injury two years post-injury. The results suggest the majority of participants continue to experience difficulties within their families and job settings, and have reduced social interactions. In a follow-up study of this sample, Oddy et al. (1985) was able to interview 34 males of the original sample and 24 caregivers, seven years post-injury. Their findings suggest that participants' level of functioning and difficulties remained stable over time. Additional research by Brooks et al. (1986) interviewed close relatives (n=42) of an individual who had sustained a TBI 5 years previously and also had participated in follow-ups at 3, 6, and 12 months. The interviews conducted with caregivers suggest that the symptoms of the TBI continued to persist, and were sometimes even more severe than what caregivers had reported at the one year follow-up. In addition, caregivers reported a greater level of stress than the first year. Brooks et al. (1987) conducted a follow-up study at seven years post-injury and expanded the sample to include additional caregivers (e.g. spouses, siblings, children, parents, and others) (n=134). Participants were again interviewed and similar results suggest that even seven years post-injury those who had sustained a TBI continued to



have difficulties in areas of behavior, cognition, and social interactions. The majority (85%) of caregivers reported a moderate to high level of burden and stress, suggesting that stress among caregivers remains stable overtime. Thomsen (1984) conducted a follow-up study of 40 patients who had sustained a severe TBI through an impact injury with a blunt object. Participants of the study had been evaluated at 4-5 months post injury and then 2-5 years after the injury. This study administered questionnaires to the individuals with a TBI, his or her caregivers, and/or medical staff. Results from the surveys suggested that for two thirds of the patients the physical, behavioral, and psychological symptoms of the TBI continued. Taken together, these research studies suggest that changes resulting from a TBI tend to grow slightly worse within the first year post-injury, which may be due in part to the multiple changes the individual is experiencing, and do not appear to resolve over time. Similarly, caregivers indicate that levels of stress did not improve with time, suggesting that services even a decade later are relevant for family members

The role from a spouse to a caregiver has been associated with moderate to severe physical illness and long term psychological distress. For example, a study of caregivers of individuals with a TBI exhibiting symptoms of amnesia, which lasted between 1 and 7 days or longer, suggested that of the 14 spouses and 40 mothers, the majority of participants endorsed higher levels of depressive symptoms in the first month post-injury and lesser levels of depressive symptoms 6 to 12 months later (Oddy et al., 1978). This study further suggests that the depressive symptoms are not associated with the level of severity of the head injury, or with the type of caregiver (i.e. spouse vs. parent or close relative). Participants did, however, indicate that when depressive

symptoms are severe they also experienced memory loss, difficulty making decisions, and difficulty engaging in conversation in social settings due to trouble with word finding. Similar results were obtained in a study that focused on the experiences of female caregivers (i.e. spouse, mother, or daughter) of males who sustained a severe TBI (n=41) compared to those males who acquired a mild TBI (n=42). Female caregivers with loved ones who sustained a severe brain injury continued to report higher levels of anxiety and lower levels of family and marital cohesion at the one year follow-up than the follow-up at 3 and 6 months (Livingston et al., 1985). Caregiver role was not related to symptom severity, although the severity of the injury was associated with higher levels of symptoms and dissatisfaction within the family and marital unit. In contrast, other studies within the research literature do suggest that spouses of injured loved ones report higher levels of stress and psychological distress than do parents of individuals with a TBI (Gervasio & Kreutzer, 1997; Kreutzer et al., 1994; Mauss-Clum & Ryan, 1981). This may be due to the large number of changes that the family unit undergoes through the recovery and transitional period. For example, a study of 20 female spouses within 6 months of their veteran husband's acquired TBI, indicated that more the half of the participants (60%) reported undergoing significant stressful family unit alterations due to the event. Those spouses within the study that were identified as having a "balanced" (i.e. cohesive and flexible relationship) prior to the acquisition of TBI endorsed the greatest number of changes compared to those who were identified as moderately stable or unstable families. This means that previously well-balanced families reported higher levels of separateness, higher levels of rigidity, and greater difficulty making

compromises with husbands whose injuries were severe (Curtiss, Klemz, & Vanderploeg, 2000).

### Effects of TBI on the Spouse

Spouses experience thoughts of separation or divorce, loss of affection, and an increase in marital conflict (Chwalisz & Strak-Wroblewski, 1996; Panting & Merry, 1972; Tate, Lulham, Broe, Strettles, & Pfaff, 1989). Additionally, spouses report loss of intimacy resulting from post-injury sexual difficulties (Gosling & Oddy, 1999). Lezak (1978), based on her extensive clinical work with families and patients of TBI, indicates that sexual dysfunction frequently occurs after an individual sustains a TBI, either in an increased or completely absent level of sexual interest. She further suggests that marital distress also occurs from diminished interpersonal skills and lack of empathy.

Caregivers also indicate that their health changed due to their current life situation. Turner et al. (2007) examined the reintegration of individuals with a TBI into the home by interviewing 13 individuals with a TBI and 11 of the patient's caregivers. Caregivers within this study reported becoming sick more frequently. They also indicated being more emotional and felt a loss of control over their life, as well as an increase in stress over the financial standing of their family. Other stressors endorsed by spousal participants included other hospitalizations that occurred post-injury but were not related to the original brain injury of their spouses. Panting and Merry (1972) found that within a sample of family members of individuals with a severe TBI, 61% indicate that post-injury they began taking psychotropic medication to assist them in coping with the multiple stressors that occurred due to their family member's injury. Similar results were indicated by Mauss-Clum and Ryan (1981), in which spouses and mothers of individuals

with a TBI (n=40) reported an increase in depressive and anxiety symptoms, to the extent that caregivers began to receive psychotropic treatment to better cope with their loved one's injury.

Social isolation is well documented within the research literature (Bardach, 1969; Lefebvre, Cloutier, & Levert, 2008). Prevailing theories suggest that within a few years of the transition to the home, the primary caregiver will have few to no social interactions other than contact with immediate family (Brooks et al., 1986; 1987; Thomsen, 1984). The trend toward social isolation occurs as the primary caregiver needs to devote a high amount of time taking care of the family member with the TBI. Additionally, the unpredictability of personality changes, impulsivity, inappropriate behavior, fear of new situations, etc., may create awkward social interactions and embarrassment at social gatherings, all of which may cause the caregiver to withdraw from interactions with others (Lezak, 1978). Social isolation and feeling alone may occur independently of interacting with others, as caregivers frequently report that those outside the immediate family are unable to understand their experiences and the day-to-day life of living with a spouse or family member with a TBI (Johnson & Catalano, 1983). Lezak (1988), based on extensive clinical work with spouses and other caregivers of an individual with a TBI, discusses the multiple traumas and systems impacting the un-injured spouse. For example, prior to the injury, couples with healthy relationships care and support one another, especially during times of stress. The un-injured spouse continues on through the stages of healing without his or her primary support mechanism. In addition, the emotions and associations of the previous relationship continue even though the remembered partner is no longer in the relationship. Moreover, Lezak (1978) describes,

spouses enter a kind of “social limbo” as the marriage continues to deteriorate, and areas of social support also diminish as the usual niches such as outings with other married couples or even outings as a single person are not usually viable (p. 593). Longitudinal studies have indicated that social isolation and feeling alone tend to continue over the long term instead of improving (Brooks, 1991).

The hidden side of living with an individual with a brain injury is the potential experience of abuse. Family members, especially the primary caretaker or the spouse of the individual with a brain injury, may be the target for physical, verbal, and emotional abuse (Lezak, 1978). Lezak (1988), based on further experience working with families, children, and spouses of individuals with a TBI, reported that the un-injured partner, in addition to taking care of the spouse with the TBI, taking on additional responsibilities of the household and income, and diminished social opportunities and support, is frequently the target of irrational and unpredictable emotions and impulsive decisions. The spouses of individuals with TBI may also be victims of verbal and physical abuse. Despite violence happening behind the walls of the house, family members and spouses do not report these incidences to others out of fear of being misunderstood or being told that they need to leave the relationship. Spouses are often torn in different emotional directions, between the responsibility they feel to the partner they remember and the guilt they have of disliking or being unhappy with the partner they now have. Family members and spouses may become fearful, resentful, or repulsed by the individual with the injury (Miller, 1994). Mauss-Clum and Ryan (1981), in their survey of 40 female spouses and mothers of individuals with a TBI, asked questions specifically about abuse in the home and found that one fourth of the sample experienced verbal abuse and

additional threats of physical violence. Additionally, Brooks et al. (1986) followed 42 family members one year and five years post-injury of a spouse with a severe brain injury. Results of the study indicated that the majority of relatives found that their loved one had difficulty controlling their anger and easily became irritable. Additionally, individuals with a severe TBI either threaten or engage in violent behavior with the passage of time: 15% of participants' report threatening and/or violent behavior at 1 year post-injury, and 54% at 5 years. Furthermore, 20% of family members have been physically assaulted one or more times.

Lezak (1978), in her work with family members, finds that caretakers reported one to two instances of physical violence being threatened, but that smaller acts of physical violence are more common, such as slapping, tripping, hitting someone with objects, or pushing. Lezak suggested that this could be because the individual with the acquired brain injury grieves his or her loss of ability and may feel frustrated, unworthy, incompetent, and/or scared of their condition. Lezak (1978) described the consequences of a TBI as a demeaning experience for individuals, wrought with feelings of being trapped and unable to recover previous functioning and aware that they will be dependent on others for the rest of their lives. The individual with a TBI may feel resentment and become angry when his or her ideas, needs, or desires are challenged, or when confronted with issues that fall outside of their range of ability (Zeigler, 1987). Feelings of bitterness, humiliation, and loss of self-esteem become tied to the caretakers and provide the progression for the abuse. Family members report the individual with the TBI as being chronically unhappy (Lezak, 1978; 1988; Sachs, 1991). In conjunction with this state of unhappiness, individuals with TBI may frequently make repetitive demands, set

unrealistic expectations and tend to do so with expressions laden with criticism, ridicule, accusations of unfaithfulness, hostility, and rejection of family members; typically, these responses are focused towards the caregiving spouse (Lezak, 1978). Physical violence may occur, especially in individuals who have difficulty controlling emotions, are highly impulsive, and lack empathy. Violence may also manifest by the individual against him or herself, and in the process of caregivers trying to stop self-harm, the individual with a TBI may strike to prevent getting help. Caregivers and spouses may feel obligated to tolerate and defend abuse and aggressive behavior due to the symptoms of brain injury (Zasler & Kreutzer, 1991). The research literature is limited with regard to violence and abuse within the home in the case of a TBI. Additional research within this area is needed to further understand how caretakers and families cope with abuse within the home.

Spouses also indicate that their ability to parent has been altered due to their spouses TBI. Children and the issues of parenting, in general within the TBI research literature, have been and continue to remain scant. Although, the experiences of children are beyond the scope of this paper, several considerations are important to understand the experiences of spouses. Given the aforementioned aftermath of TBI on the family system (e.g., social isolation, potential for abuse, resentment, and feelings of guilt), the caregiving spouse may be overwhelmed by the additional roles and responsibilities within the family; therefore his or her relationship and well-being of the children within the family system will be affected (Urbach, Sonenklar, & Culbert, 1994).

For example, Uysal, Hibbard, Robillard, Pappadopulos, and Jaffe (1998) examined the parenting skills of individuals with a TBI and their spouses. Out of a total

of 32 couples who participated in the study, half of the families reported that one parent had sustained a TBI while the other half denied TBIs in both parents. In addition, this study interviewed children from each group to explore the child's perception of the parental relationship. The spouses and children of individuals who sustained a TBI reported a higher frequency of depressive symptoms than couples without a TBI. In addition, spouses of individuals with a TBI, when compared to spouses without TBI, reported a decrease in feeling of warmth, love, and acceptance towards their children. In addition, children with a parent who sustained a TBI reported that the parent was less involved with providing discipline and was less engaged within the parenting role. Both children and spouses of individuals with a TBI reported higher levels of depressive symptomology than the control group. This study was one of the first to examine the experiences of children and spouses within the marriage nine years post-injury.

In addition to changes spouses perceive in their ability to parent, spouses may find themselves in the middle of arguments or issues between their children and the parent with a TBI. Cavallo and Kay (2005), based on clinical experience and review of the research literature, suggested that children may experience their formerly dependable parent as unpredictable, irrational, and moody. Additionally, the injured parent may view their children as competition when perceiving a need for the attention of their spouse. In this instance, the spouse may find him or herself becoming the mediator between the injured parent and the children. Moreover, they may also serve as the primary parent, especially if children refuse to interact with or withdrawal from their parent with the TBI. Given that there are relatively few studies that focus addressing the impact of children with parents who have sustained a TBI, it is largely unknown the contribution and



additional stress on the marital relationship spouses encounter in attempting to assist both their children and their spouse.

### Changes within the Marriage

The experience of coping and recovering from a TBI is one that is shared by the spouse and the rest of the family. As such, the dynamics of the marital relationship are also in a state of transition and adaptation. The classic study by Rosenbaum and Najenson (1976) is one of the first to specifically focus on the experiences of female spouses of husbands who sustained severe brain injury as a result of their military duty. Rosenbaum and Najenson (1976) compared the experiences of spouses with a partner who had a severe TBI one year post-injury to those whose husbands were paraplegic and those whose husbands did not have any injury. The spouses of husbands who had sustained a TBI reported higher levels of depression, isolation, role-reversal, and adjustment than those whose husbands were paraplegic or in good health. In addition, spouses of husbands who acquired a TBI also reported lack of sexual intimacy with their husbands as a result of the shift in personality and temperament; spouses felt they no longer were married to the same individual (Miller, 1994; Zasler & Kreutzer, 1991).

Similar results were found in a study by Mauss-Clum and Ryan (1981), wherein the majority of wives report feeling that they are married to a stranger or that they are married but no longer had a spouse. Additionally, Gosling and Oddy (1999) used a mixed method design to examine female spouse's perception of the quality of their marriage 1 to 7 years after their male partner sustained a severe TBI. Results suggest that the majority of participants (n=18 couples) felt the quality of their marriage had profoundly deteriorated post injury and 10 participants indicated that their spouse currently "felt like

a stranger” (p. 789). In addition, female spouses reported a loss of equality and sharing within the marriage, and felt they had lost their partner. Regarding their sexual relationship, spouses felt disconnected from their partner and six participants indicated that “it felt wrong” (p. 790). Although the female spouses of the study described significant changes within their marriage, 14 of the participant reported limited to no assistance and felt that the majority of services were focused solely on the partner with the TBI. Moreover, 8 of the participants indicated that counseling services or more information would have been helpful. Given the small sample size of this study, results may not be generalizable, especially in understanding experiences of male spouses when their female partner has been injured. However, few studies exist to date which focus on the experiences of spouses five years or more post injury.

The reactions of a caregiving spouse toward the recovery process may be one of mixed emotions, especially as caregivers often feel guilt surrounding their emotions and reactions toward their recovering spouse (Chwalisz & Strak-Wroblewski, 1996). When a spouse dies, the living spouse is given the opportunity to grieve for his/her loss and often other family members and friends assist the individual in coping with the changes that occur in life after the funeral. However, in the case of a caregiver who has a spouse with a TBI, they may feel it is not socially acceptable to mourn the loss of their loved one’s abilities and personality (Lezak, 1978). Chwalisz and Strak-Wroblewski (1996), through their study of the subjective experiences of caregivers, sought to identify the most salient issues concerning spouses while caring for a loved one with a brain injury. Reported themes shared by the 27 participants who care for a spouse with a TBI suggested that caregivers feel they have a lot to be thankful for, especially that their spouse survived

their injuries. However, the spouses also indicated needing more information to assist in the adjustment process. Although caregivers felt that there is much to be thankful for, they reported wishing that the “old spouse would return” (p.33).

Spouses, through the recovery process and beyond, continue to mourn the loss of their partner’s previous state of being and desire to talk about the loss and difficulties experienced due to the injury to their loved one. For example, family members and spouses may feel that the afflicted spouse has passed on (Lezak, 1978; Zeigler, 1987) due to the personality, behavior, and cognitive changes which make their loved one unrecognizable from the person still remembered (MacFarlane, 1999). Ambiguous loss has been cited as the most difficult type of loss to cope with because there is no sense of closure (Boss, 1999; 2006; Landau & Hissett, 2008). Boss (1999) defines ambiguous loss as a phenomenon that defies closure and paralyzes the grieving and coping processes, since the type of loss is unclear. Ambiguous loss may manifest through either by a family member being psychologically present, but physically absent, or by a family member who is physically present but psychologically absent (Boss, 1999; 2006). In the case of severe TBI, the outward body may heal, but pieces of the individual’s personality may be permanently altered. As such, family members grieve the loss of the unique characteristics that defined their loved one’s personality. Family members may feel guilt and shame as they mourn the loss of the person who they knew, especially when society within American culture often praises the life saved and dismisses the importance of processing the loss of a loved one’s characteristics and personality when he or she is still living (Lezak, 1986).

In the immediate family, members may hesitate to discuss feelings of bereavement among each other out of fear of amplifying emotions of alienation, guilt, rejection, and anger within the family. Additionally, spouses of an individual with a severe TBI may fear that by disclosing feelings of grief and loss to others, he or she is betraying his or her spouse's progress. Spouses, by concealing their grief, may feel a heightened sense of separation and loss of intimacy from their partner (Landau & Hissett, 2008). Landau and Hissett (2008) examined feelings of ambiguous loss in family members (spouse, partner, parent, or adult children) when a family member sustained a mild to moderate TBI, through the research method of phenomenology. Participants of the study included the individual with a TBI and two family members or care providers. The researchers conducted three interviews: one with the individual with the TBI alone; one with the caregivers/family members alone; and one with both parties together. The total number of participants was not reported within the study. Themes gathered through the interviews suggested that family members, in attempting to protect other members of the family, choose to not fully disclose the extent of their feelings because the member of the family who is being grieved is still alive. To date there is no cohesive intervention or established method for ambiguous loss therapy within the research literature (Collins & Kennedy, 2008).

To investigate the emotional process of grief and loss that caregivers experience, researchers have established similar theories of adjustment (Cavallo & Kay, 2005; Degeneffe, 2001; Lezak, 1986; Ridley, 1989). The majority of these theories have applied similar methodology to that of Kübler-Ross's stages of grief model and Lezak's (1986) six factor model, which is based on her work with families of TBI. The process

Kübler-Ross (1969) outlines begins with the shock or realization that the loved one has experienced an injury, although the full extent of their condition is not fully realized or believed by caregivers. This initial stage is focused on feelings of denial and shock. During this time family members are not able to fully comprehend or process what has happened to their loved one; many approach the situation with hope that their loved one will recover to their pre-injury self. However, Lezak (1986) suggests this term may be problematic as in general the meaning of recovery is “returning to normal” whereas physicians use the term “recovery,” within the case of moderate to severe TBI to mean “improvement” from the survivors current status, not a return to pre-morbid functioning, yet this may not be clearly communicated to the survivors family (p. 243). Caregivers may also see their loved one making gains on a daily basis and not realize that eventually these gains will slow. Subsequently, these factors may further contribute to caregivers not fully understanding the extent of TBI (Lezak, 1986). As the afflicted individual becomes stable, awareness begins to set in, and caregivers began to accept that their loved one is no longer the same, that they now have deficits in areas of cognition, behavior, physical abilities, and social interactions. Although caregivers realize that their loved one has difficulties, hope prevails that, with time, they can return to previous standing. This stage, of hope despite counter evidence, has been termed bargaining.

As family members continue interacting with the individual with a TBI, the realization of the permanence of their loved one’s condition can no longer be bargained or denied and caregivers may feel a range emotions, including grief, depression, anger, and resentment. They may also feel trapped within their new role (Mauss-Clum & Ryan, 1981). It is common within this stage for spouses and other caregivers to begin having

increasing thoughts of divorce or separation from their spouse (Mauss-Clum & Ryan, 1981). Lezak (1986) found in her work with spouses that the decision to either leave the marriage or relationship and accepting what it would mean to become a caregiver enhanced feelings of grief and loss. Once the spouse “accepted” the new role or came to a decision about what they would do with the relationship, they were better able to come to a state of resolution. The caregiver begins to set more realistic goals for their loved one and learns to accept the changes in his or her spouse. It is important to note that not all families will process through all the stages, nor will they all find commonalities within each phase (Verhaeghe, Defloor, & Grypdonck, 2005). The stages are not meant to be done chronologically, and it is common that families may experience several phases at once or will cycle back through the phases. Verhaeghe et al. (2005) suggested that acceptance may never be established, because living with an individual with a brain injury requires continuous adaptation. This may be especially relevant as the individual with the brain injury ages and roles within the family continue to shift.

### Marital Satisfaction

The impact of TBI on the marriage is difficult for both the injured and uninjured spouse. Several studies have examined marital outcomes of partnerships where one spouse acquires a severe TBI. Panting and Merry (1972), the first researchers to study this phenomenon, surveyed 10 couples where one partner acquired a TBI, and found that 40% of the couples divorced or separated within seven years after the injury; the most common occurring reason for the divorce was accumulated burden and increased stress due to the spouse’s injury. Thomsen (1984) completed a fifteen year longitudinal study of individuals with severe head trauma examining the rates of divorce and found that only

two out of the 9 originally married couples were able to sustain their marriage within the duration of the study (Thomsen, 1984). Tate et al. (1989) reported that 54% of 31 individuals with a severe TBI divorced within six years after sustaining their injury. Similarly, a study by Wood, Lioffi, and Wood (2005) indicated that of the original 48 couples in their study, 48% divorced or separated within a six year time period.

A study examining divorce rates in relationships with a severe TBI found that of the 131 participants recruited from a Brain Injury Rehabilitation Trust program between the years of 1991-1995 who had lived with the spouse at least one year post-injury, approximately half of the relationships dissolved within a five year period (Wood & Yurdakul, 1997). The study suggested that duration of the relationship, or how long the couples had been married prior to the injury, was related to divorce rates: those who were married longer before the injury was sustained had a greater likelihood of remaining married. For example, only 15% of marriages dissolved among those that had lasted 43 years or longer. However, the study further indicated that marriages that did dissolve were more likely to end within five to six years post-injury. In addition, results suggested that divorce and separation are more related to the sequelae of the TBI, rather than the severity of the injury, such as selfishness, inappropriate behavior, and frequent fluctuations in mood. This study, however, did not address the resources or supports that may contribute to marriages being sustained. The researchers suggest that further understanding of the variables that impact the marital relationship continue to remain largely unknown, especially those that are subtle and lead to increased stress and caregiver burden.

Kreutzer, Marwitz, Hsu, Williams, and Riddick (2007) designed a replication study based on research conducted by Woods and Yurdakul (1997), which further examined risk factors and rates of divorce and separation in individuals with mild, moderate, or severe TBI. This study surveyed 120 survivors of TBIs between 30 and 96 months after their injury and found that the divorce rate was 17% and the separation rate was 8%. The researchers indicated that gender, ethnicity, education level, time since injury occurred, and employment status post-injury were not associated with divorce or separation. The greatest predictor of marital success, in this study, was level of severity of the injury, meaning that those with more mild TBI's tended to have higher rates of sustained marriage than those with severe head injuries. Their findings suggested that those who are married longer before the injury occurred, those who are older, those whose injuries are acquired through non-violent means, and those with less severe injuries are more likely to remain married (Kreutzer et al., 2007). Notably, this study was limited as other variables which impact the quality of the marital relationship were not investigated, nor was the input of caregiving spouses. The authors of the study further recommended use of measures of marital adjustment to investigate marital satisfaction in those relationships which have remained together. Notably, although the researchers replicated the study by Woods and Yurdakul (1997), this study was significantly shorter by 4 years and may not be generalizable to long-term marital stability.

The reduction in divorce rate in couples where one individual has sustained a TBI has been investigated in another study by Anderson-Parenté, DeCesare, and Parenté (1990). They examined the contributing factors to sustaining marriage when one partner sustains a TBI. The study recruited 23 couples that had been married two years post-



injury and who reported intending to remain married. Notably, five out of the seven couples had been married between 3 and 14 years, one couple had been married 21 years, and another couple had been married for 42 years. However, the range of time between the marriage and the onset of injury ranged from two to 17 years. All but one of the spouses with a head injury was male. Of the couples recruited at the time of the survey, only 10 of the original 23 remained married by the end. Participants completed a survey via phone interview that contained questions about demographic information, economic status, work history, quality of the marriage, changes in daily living, and psychosocial problems due to the TBI. Results suggested that age and length of time married, respect for their partner, long-term friendship, and mutual support were positively associated with marriage stability. Regrettably, how results were obtained was not reported and the time between when subjects were recruited to the study and when the survey took place is unclear. Results are also limited by the small sample size, and the range of time that participants had been married varied. The study was unable to interview those couples who had divorced or separated. The study also was unable to ascertain what resources or support that participants utilized that helped sustain the marriage.

Cavallo and Kay (2005) suggested that the decision to stay married may also be impacted by the age of the couple and whether or not there are young children within the home. Studies examining marital stability when one partner has sustained a moderate to severe brain injury are limited by small sample size, and participants tend to be middle class Caucasian American heterosexual marriages. As such, the results may not be generalizable, especially in regards to minority families within the United States. Arango-Lasprilla et al. (2008) examined the moderating effects of race on marital

stability two years post-injury in a sample of 977 (226 identified as minorities) participants. Their results indicated that 85% of the participants were still married at two years and 15% were divorced or separated. Similar to previous studies, marital distress was associated with injury severity, violent injuries, younger age, and being male with a TBI. Counter to previous results, the researchers found that among minority participants, marital stability was related to the level of disability. Further research is needed to better understand the influence of cultural values, religion, guilt, and family traditions on marital stability in families of TBI.

### Models of Stress and Burden

Marriages that have remained together have overcome multiple challenges within the relationship when one spouse acquires a TBI. Research has begun to focus on the how caregivers perceive stress and burden on the relationship, as well as finding methods to assist in coping with living with a spouse with a TBI. Chwalisz (1996) defined caregiver burden from two perspectives: the objective burden and the subjective burden. Objective burden is described as an individual experiencing an observable change in personality and behavior that is related to changes within their personal environment. For example, injury to their loved one creates financial burden, role changes, and isolation from social activities for caregivers. Subjective burden is the individual's personal negative reaction to a stressful event. When subjective burden is experienced, an individual must decide how stressful the situation is based on their emotional and physiological reaction to the event. Chwalisz (1996) created a model to describe the interaction of perceived stress and caregiver burden based on the experiences of 135 spouses of partners who sustained a TBI. Results of the study showed that the greatest

predictor of burden is the stress perceived by the spouse of the afflicted individual. For example, those who felt overwhelmed caring for their spouses may perceive this stress as a type of burden. Perceived stress is also associated with the degree of injury severity, types of social support and coping strategies utilized. However, variables such as gender, age, previous marital history, and appraisal do not appear predictive of caregiver burden. To date this is the first model developed which seeks to examine the experience of stress and burden specifically in spouses with a partner who sustained a TBI; further research is needed within this area to understand the perceptions of stress, and how caregivers conceptualize and view the role of a caregiver.

To further understand coping strategies of caregivers, Monat and Lazarus (1985) developed the stress-coping theory and systems theory. Stress-coping theory describes stress as resulting from feeling underprepared or inadequate to sufficiently react to a stimulus. To reduce or resolve stress an individual must choose a strategy to cope with the situation. Monat and Lazarus (1985) described coping as adapting cognitive and behavioral knowledge to manage a situation that is deemed to be outside the individual's ability level. In stress-coping theory, coping strategies are used to dismantle negative emotions and reduce or resolve the effects of stress. System's theory, which is developed over an individuals' life span, is unique to each family and is based on 4 components or "pillars" that interact with one another and encompass an infinite number of relationships. The "system" adapts and shifts as other individuals and experiences enter the course of a person's life; no part of the system can remain untouched--if one part of the system changes, so do all the parts. In the case of brain injury, the family may be conceptualized as the system. As one individual in the system changes, all of the family

members within the system must also adapt and evolve as a result of the change. For example, consider the case of a married couple with three children where the husband worked outside the home and the mother was a homemaker. If the injured spouse is the husband, and, due to his severe TBI he is no longer able to work outside the home, the wife, in order to support the family, may seek out opportunities for work outside the home. As the wife is no longer able to spend time within the home, the children take on the role of caring for their father when their mother is not in the home. The children also become caregivers to each other, as well as to their parents, to maintain the structure of the immediate family and to cover the lost role of the father as caretaker.

### Coping Strategies

Although researchers have begun exploring the coping mechanisms and strengths that couples use to sustain the marriage, much is still unknown regarding what types of support, resiliency, and coping mechanisms contribute to sustaining marriages in the case of severe TBI. Research does, however; suggest that families and spouses who cope and adjust to the multiple changes with positive strategies result in a more positive outcome for the loved one with the TBI (Florian, Katz, & Lahav, 1989). Health care providers and psychologists have suggested several methods for assisting families and caregivers in coping with and adjusting to stressors related to their family member with a TBI. These strategies may include learning reciprocal communication (Florian et al., 1989), reading self-help books and information about TBI, developing a relationship with community support (such as social workers), long term follow-up, and peer support groups. Family members may also distance themselves from the effects of TBI by seeking out resources within the community to assist the family, actively seeking out methods to alleviate

stress, and using cognitive behavioral strategies to reframe negative experiences (Kosciulek & Lustig, 1998). A qualitative study examining common coping strategies utilized by both caregivers and those who acquired a TBI found that the most common coping strategies used by female spouses is remaining optimistic, developing realistic goals for the future, using assertive communication, helping their spouse become more independent, creating time for self, and joining support groups (Willer, Allen, Liss, & Zicht, 1991). Zarski, DePompei, and Zook (1988) surveyed 45 parents and spouses who had a family member with a TBI, and the results of their study suggest that caregivers who view their spouse or child with a TBI positively are better able to make decisions and re-establish roles within the family.

Social support and a sense of community may also assist spouses and family members to better cope with the long term consequences of TBI. Hanks et al. (2007) examined negative and positive appraisals of 60 caregivers whose family member sustained a TBI within the last 6 months to 15 years. Results of the study found that caregivers of individuals with moderate to severe brain injury reported the higher levels of stress in areas of perceived burden and mastery of caregiving. Caregivers in the study who reported satisfaction with social support had better outcomes in regards to their perception of the relationship and ability to care for their loved one. Social support and strong friendships are also associated with better transitions from the hospital to home, with feeling more comfortable in public and engaging in social activities both within the home and community, as well as providing rest and emotional support for caregivers (Turner et al., 2007).

Loved ones of individuals with acquired brain injury seek out information to assist them in preparing and coping with the multiple changes that are occurring in their lives. Jumisko, Lexell and Söderberg (2007) interviewed eight family members who cared for a close family member who acquired a moderate to severe TBI. Results of the interviews suggested common themes expressed by caregivers in terms of what gave them comfort, hope, and strength; these include support received by family members—including the immediate and extended family. Caregivers expressed feeling that relationships became closer within the family and appreciation for life and for loved ones increased. They were appreciative of the good days their family member had, especially in looking back at his or her progress. Family caregivers expressed joy and happiness at being able to make plans for the future, and felt that although they were caregivers, they had become stronger as individuals. Additionally, although sharing feelings about losing their loved one was difficult, family members who confided in others about their experience felt a sense of relief and felt more hopeful about coping with the changes. Finding meaning within the experience was helpful in sustain caregivers. Faith and religious belief may also alleviate levels of stress and create feelings of peace and comfort as well as the opportunity to increase levels of social support. Although this study revealed common experiences and coping methods of caregivers, results are limited by the fact that the role of the caregiver was not reported (i.e. whether uninjured individuals were partners, spouses, parents, siblings, children, etc. to the individual with a TBI). In addition, participants to the study provided care for varying lengths of time, and predominantly those interviewed were female caregivers. This study suggests that professionals, who provide caregivers with open and honest communication, actively

listen to the needs and concerns of caregivers, and assert a willingness to assist caregivers to learn affective coping strategies not only provide hope to caregivers, but also alleviate some of the burden.

Research into interventions and resources provided by the community are scarce within the literature. Boschen, Gargaro, Gan, Gerber, and Brandys (2007) reviewed interventions targeted at providing support to family caregivers and found that there was a lack of evidence within the research literature that supports any particular method of intervention for family members, as the majority of research was not evaluated with empirical measures. The researchers suggested that additional pilot studies and more thorough evaluations of program effectiveness are needed. Interventions that are clinically based and non-research focused, although few in number, provide mental health care providers suggestions for working with family members. DePompei and Williams (1994) developed a family-focused rehabilitation program that provides family member's support in processing loss and grief as well as provides assistance for preparing for changes in the future. Other interventions focus on training for providers to assist caregivers in developing coping strategies (Blosser & DePompei, 1995), understanding and adapting to role changes within the family structure (Maitz & Sachs, 1995), and processing grief and loss and adjustment (MacFarlane, 1999). Due to the increased number of veterans with combat related injuries, the Veterans Health Administration developed interventions that target the emotional impact on families when their loved one survives a TBI (Collins & Kennedy, 2008). These interventions focus on creating a system of care where services to the family and individual are integrated and focus on rehabilitation with an interdisciplinary team, medical family therapy, and

individual therapy focused on assisting in processing ambiguous loss; however, outcomes from this approach have not yet been published.

### Summary and Conclusions

Although health care professionals, rehabilitation specialists, mental health care providers, and specifically counseling psychologists can extrapolate the symptoms and severity of traumatic brain injury, the lived experience, especially longitudinally, is lacking within the research literature. Studies that examine the effects of TBI indicate that individuals who sustain a TBI have changes in multiple areas of functioning. The majority of these changes may improve within the first few years, but a return to pre-morbid levels of functioning may not be possible. The research literature documents the multiple impacts of traumatic brain injury within the family system (King et al., 2002; Machamer et al., 2002; Marsh, Kersel, Havill, & Sleigh, 1988; Marsh et al., 2002; Oddy et al., 1978; Semlyen et al., 1998; Turner et al., 2008), particularly the negative impacts on spouses (Gervasio & Kreutzer, 1997; Zeigler, 1987).

Caregivers are most acutely challenged by the personality changes in their loved ones and with the problems they experience coping with the loss of a remembered loved one while the individual is still alive (Landau & Hissett, 2008; Lezak, 1978; Zeigler, 1987). Divorce and separation post-injury has been shown to be higher than the general population, although the coping mechanisms and resiliency of spouses within marriages that are sustained are not clearly understood. Previous studies focusing on risk factors for divorce have mainly focused on the severity of injury, gender, how injury was acquired, length of marriage, age of spouses, and length of time post-injury (Anderson-Parenté et al., 1990; Arango-Lasprilla et al., 2008; Brooks et al., 1987; Kreutzer et al., 2007). The



majority of studies examining marital stability of individuals with TBI have use structured questionnaires and archival data as well as tend to have small sample sizes. Additionally, previous studies tend to lump caregivers into one group, even when the relationship to the individual with a brain injury is not clearly known.

Despite the multiple negative impacts that TBI has on family members and spouses, family members and spouses also report positive feelings associated with their loved one. Chwalisz and Strak-Wroblewski (1996) identify that family members feel thankful, and that there is appreciation for the family member with a brain injury. Additionally, family members may feel that relationships within the family have been strengthened as a result of caring for a family member with a brain injury (Jumisko et al., 2007). Sustaining hope, obtaining support, and maintaining a positive outlook have all been associated with lower levels of stress and greater feelings of confidence in being a caregiver (Carson, 1993; Smith & Smith, 2000). Social support has also been associated with a reduction in perceived burden (Chwalisz, 1996).

Zarski et al. (1988) posited that spouses who focus on the positive aspects of their relationships tend to stay together, although the experience of these spouses and how they conceptualize their relationship with their partner is unknown. Typically, studies have focused on predictors of marital distress and usually are within a time frame of 5-6 years post-injury. Little is known about the marriages that do last, and it is uncertain how spouses cope through the ever changing adjustment cycle of their spouse's brain injury, especially as both partners age.

### Purpose of the Study

To assist and support spouses who have a partner with a TBI for 10 years or more, it is important to first understand how the individual experiences this major life transition as well as how spouses continue to cope with the ongoing consequences of TBI as their partner continues to age. Anchored in the findings and recommendations of the literature, the overall purpose of the present study was to understand the experience of spouses who have remained married to their partner who sustained a TBI. Specifically, indicators focused on the relationship between quality of life and coping strategies on marital satisfaction.

The first aim of this study was to provide a description of spouses who have remained married 10 years post injury or longer. Few studies have focused on the marital relationship of spouses beyond 5 years post injury. The majority of studies tended to focus on the first few years of recovery; specifically, they have focused on time frames within the first five years after transitioning back to the home. Moreover, most of the previous studies have focused on the primary caregiver, but do not distinguish between those who are spouses or other family members. This study examined the coping strategies and marital satisfaction of spouses as its primary focus using psychometrically sound instruments. Further examination of marital satisfaction and coping will guide those within the health care professions to better determine the long-term resources and supports that spouses and the overall family may need to continue providing care to their injured loved one. In addition, this study also provided information to further our understanding of the evolving circumstances, stressors, and coping strategies of spouses.

As a result, practitioners will be able to better determine treatment modalities and resources for families and spouses impacted by TBI.

The second aim of this study was to examine the correlates of marital satisfaction interference by examining demographic variables, quality of life and coping strategies associated with marital satisfaction. While studies have examined the impact of TBI on marital satisfaction (Anderson-Parenté et al., 1990; Gosling & Oddy, 1999; Panting & Merry, 1972; Rosenbaum & Najenson, 1976; Wood & Yurdakul, 1997) this study furthers our understanding of that impact by examining factors associated with marital satisfaction. Thus, this research may provide insight to long-term coping strategies and quality of life as well as how psychologists might better intervene within the marital relationship as spouses continue to cope with the ongoing consequences of TBI, especially as their partner continues to age.

Lastly, this study examined stressor types among spouses with a partner who has sustained a severe TBI. Though studies in the extant literature have identified the negative impact on relationships after TBI, few have identified the perceived stressors among spouses who remain married 10 years or longer (Panting & Merry, 1972). Some authors have indicated that there is a potential link between accumulated burden and increased stress due to the TBI injury (Panting & Merry, 1972; Rosenbaum & Najenson, 1976); however, others indicated that variables impacting the marital relationship continue to remain largely unknown, especially those that are subtle and lead to increased stress for the spouse (Wood & Yurdakul, 1997). This study addressed these aims and adds to current literature base by furthering our knowledge regarding the evolving experiences of spouses who have continued to remain married beyond 10 years to

partners with severe TBI. The next chapter will detail the methods and procedures of the study.

## CHAPTER II

### METHODOLOGY

The purpose of this study was to explore the current experiences and coping strategies of spouses whose partner sustained a severe traumatic brain injury (TBI) and who have continued to remain married 10 years post injury. This chapter provides a description of the methods and procedures used to recruit participants. The chapter concludes with a description of the measures and the psychometric properties of the instruments chosen for this study.

#### Participants

Participants were adults over the age of 28 who were partners or spouses of individuals with severe TBI, which was sustained at least 10 years ago; who had remained married at least ten years post injury. Participants were recruited through multiple online media: an email invitation distributed by The Brain Injury Association of Iowa to its membership listserv (Please see Appendix A for a letter to the Brain Injury Association and email invitation) and an ad posted on the organization's webpage; ads distributed through the listserv of the The University of Iowa Mass Email System; the Eastwind Healing Center listserv, and the Brain Injury Alliance of Minnesota; postings in online support groups on facebook and Caring.com; and a survey posting on ResearchMatch.org. Caring.com and the Eastwind Healing Center also posted the same ad on their Facebook pages.

The Brain Injury Association and the Brain Injury Alliance are non-profit organizations that provide information and support to professionals, families, and communities who have been affected by TBI; membership to the BIA is voluntary. The

Brain Injury Alliance of Iowa currently has over 1,500 active members and the Brain Injury Alliance of Minnesota has over 2,000 active members who access the website site and receive emails via the listserv. Caring.com is an online website and Facebook page which provides information, support, online resources, and support groups to assist caregivers as they care for their aging parents, spouses, and other loved ones. Currently, the Facebook page of Caring.com has over 20,655 followers and online group memberships are estimated to include over 4,000 individuals. To assist researchers and those interested in participating in research, Researchmatch.Org is an online research tool developed by major research institutions to facilitate connecting volunteers and researchers. Currently, ResearchMatch has approximately 32,656 active volunteers who access the website and receive emails about potential research studies for which they may qualify. To access individuals within the community who may be interested in research, the University of Iowa developed a listserv to assist researchers in recruitment that allows researchers to send a brief email to all faculty, staff, students, and retirees who may be interested in participating. The Eastwind Healing Center of Iowa City, IA is a private holistic health center which specializes in various psychological as well as chronic health conditions within the Iowa City Community. The current email membership is approximately 473 individuals.

Only spouses and partners of individuals who survived a severe traumatic brain injury were able to participate in this survey. TBI severity was determined by participants confirming that his or her spouse had lost consciousness for 6 hours or more as a result of his or her injury (Alfano, Neilson, Paniak, & Finlayson, 1992). The primary care giving spouse within this study is defined as the husband or wife who has provided the greatest

number of hours of care and has been married to the same individual from the time of the injury to at least 10 years post injury and continues to remain married at the time of his or her participation in the study. Therefore, participants had to meet the following inclusion criteria before they were allowed to proceed with the online survey: (1) Must be at least 28 years-old; (2) Have been married, engaged, or within a committed relationship to his or her spouse/partner prior to onset of the TBI, and must continue to be partnered/ married to that same individual for at least 10 years when the study commences; and (3) Participant's husband or wife must have been diagnosed with a severe TBI (Alfano et al., 1992) as an individual who has lost consciousness for 6 hours or more as a result of his or her injury.

Once participants clicked on the provided link, they had the opportunity to review the informed consent (Please see Appendix B for the full informed consent document) as well as affirm that they met inclusion criteria. Once a participant accepted and affirmed both the informed consent and inclusion criteria of the study, the participant was then directed to the survey questions. If an individual indicated that he or she either did not agree to the consent or inclusion criteria, the individual was directed to another page and was thanked for his or her time, and was informed that requirements to participate in the study were not met.

The online survey contained measures of demographic information, physical and mental health, marital satisfaction, and coping mechanisms. Within the survey were rank order designs regarding primary stressors as well as open-ended response questions intended to allow participants to share stressor information not accounted for within the rank ordered design. In addition, an optional open ended response question was also

provided at the end of the survey for spousal caregivers who wanted to share additional information either about this study or regarding their personal experiences as a spousal caregiver.

### Measures

#### Demographics

Demographic information collected included: age, gender, ethnicity, age at the time of spouse injury; whether or not there are children within the home, employment status, education level, income level, how the TBI occurred, and the level of injury severity. See Appendix C for the complete questionnaire.

#### Physical and Mental Health

The SF-12v2 was used in the current study to assess the spouse's physical and emotional health as well as quality of life (QoL). The SF-12v2 Health Survey is a widely used measure of physical and mental health in research and clinical settings as well as a generic measure of quality of life (QoL) (Lee, Oakley-Browne, & Villanueva, 2008; Ware, Kosinski, & Keller, 1996; Ware, Kosinski, Turner-Bowker, & Gandek, 2002). The SF-12v2 is the short version of the SF-36 (Ware et al., 2002; Ware et al., 2010), which was developed from the original SF-36 (Ware et al., 2007; Ware et al., 1996) as a condensed measure of an individual's general health and well-being (Ware, Kosinski, & Keller, 1995).

The SF-12v2 is a 12-item self-report measure with eight domain scales (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health) and two summary components: Physical Component Summary (PCS) and Mental Health Component Summary (MCS). The PCS is



comprised of the subscales physical functioning, role-physical, bodily pain, and general health; whereas vitality, social functioning, role-emotional, and mental health domains are addressed in the MCS. An example item for the PCS is: “Does your health limit you in moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf (yes, limited a lot, yes, limited a little, or no, not at all limited). An example item for the MCS is: “How much time during the last four weeks, have you felt calm and peaceful (all of the time, most of the time, some of the time, a little of the time, none of the time)?”

The SF-12v2 was scored using the computer-based scoring services by QualityMetric Incorporated. Composite summary scores range from 0 to 100 ( $M=50$ ,  $SD=10$ ). Composite summary scores of 45 or greater indicate at least average overall functioning in well-being and physical functioning, and 40-44 represents below average functioning, and scores below 40 indicate significant impairment in well-being and physical health (Ware et al., 2010).

The SF-12v2 has demonstrated acceptable psychometric properties in various populations (Fleishman et al., 2010; Lee et al., 2008; Ware et al., 1996), including caregivers of spouses with dementia (Fauth et al., 2012; McLennon, Habermann, & Rice, 2011) and informal caretakers (spouses and adult children) of individuals with Alzheimer’s disease (Bonnet, Cole, Chen, Bodhani, & Ito, 2011). Ware et al. (2010) report a coefficient alpha for the PCS of .91 and for the MCS of .87; test-retest reliability (two week) of the PCS was .89 and of the MCS .76. The SF-12v2 has also shown excellent correspondence and good criterion validity between summary scores compared to the SF-36 (PCS= .90 to .99; MCS= .84 to .99).

## Stressors

To better understand the unique and common stressors that partners/spouses are managing within their relationships, each participant was asked to rank order a list of potential stressors that couples may experience due to one partner surviving a severe TBI (See Appendix D). The list of potential common stressors was based on the findings from previous research of spousal caregivers of TBI. In addition, participants were asked to describe the one stressor that had the most impact on their relationship/marriage since his or her spouse's injury. Participants were given a narrative space to define the stressor with as much detail as he or she desired.

## Coping

The Brief COPE Scale is a self-report measure of coping strategies an individual may use to adjust to a present or reoccurring stressor within one's life (Carver, 1997). The Brief COPE is based on dimensions of coping proposed by Lazarus and Folkman (1984) and Carver and Scheier (1981; 1990). Respondents were asked to think of their experiences dealing with a specific stressor or situation when responding to items. Participants' responses are anchored on a four-point Likert scale ranging from "I usually don't do this at all" to "I usually do this a lot." This 28-item measure has 14 subscales with 2 items per scale. The scales are: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. The Brief COPE is scored by summing the response items. Higher scores on the COPE suggest higher usage of a particular coping response. Examples of items on the Brief

COPE include: “I turn to work or other activities to take my mind off things;” “I get emotional support from others”; and “I learn to live with it.”

Coolidge, Segal, Hook, & Stewart (2000) were the first researchers to group the scales into three category scales of coping: emotion-focused strategies (e.g., acceptance, emotional support, humor, positive reframing, religion), problem-focused strategies (e.g., active coping, instrumental support, planning), and dysfunctional coping strategies (e.g., self-distraction, denial, substance use, behavioral disengagement, venting, and self-blame) based on the factor analysis described by Carver, Scheier, and Weintraub (1989). Several other studies have also applied this three factor approach when using the Brief COPE in samples of caregivers (Cooper, Balamurali, & Livingston, 2007; Cooper, Katona, & Livingston, 2008a; Cooper, Katona, & Livingston, 2008b; Cooper, Katona, Orrell, & Livingston, 2006). The three dimensional factor loadings have shown adequate psychometric properties among family caregivers of loved ones with Alzheimer’s disease (n=125) in a longitudinal study evaluating the internal consistency of the subscales and test-retest reliability (Cooper et al., 2008a) as Cronbach’s alpha was reported above .70 in each of the three factors (emotion focused  $\alpha=.72$ , problem focused  $\alpha=.84$ , and dysfunctional coping  $\alpha=.75$ ). Test-retest reliability at one year and two years later also demonstrated adequate stability as was no significant difference in emotion-focused, problem-focused, or dysfunctional coping strategies ( $r=.58$ ,  $r=.72$ ,  $r=0.68$ ;  $p<0.001$ ) reported over time. In the current study, the internal consistency for the three scale scoring method was acceptable for emotion-focused coping strategies ( $\alpha=.83$ ) and problem-focused strategies ( $\alpha=.73$ ). Although, the internal consistency for dysfunctional coping strategies ( $\alpha=.62$ ) was lower than the recommended alpha level of .70

(Nunnally, 1978), this level is still within the guidelines for use of the Brief COPE for alpha levels above .50 for two item scales as being satisfactory (Carver, 1997).

### Marital Satisfaction

The Dyadic Adjustment Scale (DAS) has been widely used within research literature to assess marital satisfaction and adjustment as self-reported by either dyads or individual spouses (Spanier, 1976). Spouses within this study completed the DAS to determine satisfaction within one's marriage. The DAS is a 32-item self-report measure. The majority of items (28) are rated on a Likert scale with response sets ranging in value from 0 to 4, 0 to 5, and 0 to 6. Response choices may range from "always agree" to "always disagree." Other items of the DAS include multiple choice (two items) and yes/no (two items). Example questions are: "Do you ever regret that you married?" "Do you confide in your mate?" and "Do you and your mate engage in outside interests together?" The DAS has four subscales: Dyadic Cohesion, Dyadic Satisfaction, Dyadic Consensus, and Affectional Expression; for the purposes of this study, marital satisfaction was assessed by the total DAS score.

The DAS is scored by summing the responses to items and the total score can range from 0 to 151, with scores above 107 indicating marital adjustment and scores below 92 indicating marital distress (Graham, Liu, & Jeziorski, 2006). The internal reliability for the DAS is adequate as the coefficient alpha for the total score is .96. Additionally, the internal reliability for the DAS subscales is also adequate with coefficient alphas ranging from .94 to .73 (Dyadic Satisfaction  $\alpha=.94$ , Dyadic Cohesion  $\alpha=.81$ , Dyadic Consensus  $\alpha=.90$ , and Affectional Expression  $\alpha=.73$ ) (Spanier, 1976). Test-re-test reliability of the DAS after 11 weeks is .96. The convergent validity of the

DAS has also demonstrated significant correlations ( $p < .001$ ) with the Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1959) as correlations for married and divorced couples between these scales were reported as .86 and .88, respectively (Spanier, 1976).

## CHAPTER III

### RESULTS

The results of the study are presented in this chapter. The first section provides a description of the study sample. In the second section, descriptive statistics for the measures are reported, including data on reliability and comparable samples. In the third section, stressors are analyzed and presented both qualitatively and quantitatively. Lastly, the profiles of spouses, given the compilation of quantitative and qualitative data, are summarized in light of initial research questions.

#### Sample Characteristics

A total of 109 participants accessed the online survey distributed through the Brain Injury Association of Iowa, the Brain Injury Alliance of Minnesota, ResearchMatch, UI Mass Email System, Caring.com, and the Eastwind Healing Center. Of the participants who accessed the online survey, 69 indicated that they did not meet study criteria or consent to participate in the study; 16 individuals consented to the study, but did not complete any of the online surveys; and a total of 3 participants were excluded as they identified as the survivor of a TBI, rather than being the spouse or partner of an individual who survived a severe TBI. Three participants were eliminated from analysis on a particular measure due to more than 10% of the items missing on that measure, but were included within the study for other measures. If demographic information and one measure was completed, that measure was included within the data set and analyzed. A total of 21 participants met inclusionary criteria.

A summary of the demographic characteristics of the sample participants is provided in Table 1. Of the 21 participants included in the analyses, the mean age was

55.2 years ( $SD=10.3$ ) and ranged between 40 and 75 years. Similar to previous studies of TBI spousal caregivers, the majority of participants were female (71.4%) as there were 15 females and 6 males (Gervasio & Kreutzer, 1997; Gosling & Oddy, 1999; Livingston et al., 1985; Mauss-Clum & Ryan, 1981; Miller, 1993; Rosenbaum & Najenson, 1976; Zasler & Kreutzer, 1991). The vast majority of spousal caregivers (85.7%) identified as Caucasian, with 4.8% of the sample identifying as African American, 4.8% Asian/Asian-America, and 4.8% Hispanic. Of the sample, 9.5% had obtained a high school diploma/GED or an associate's degree, 28.6% had attended some college or earned a bachelor's degree, while an additional 23.8% obtained a graduate degree. Regarding employment, the vast majority of participants were employed full time (76.2%), while 9.5% were either employed part-time or retired, and 4.8% were unemployed. Occupations across participants varied in vocational settings.

Table 2 provides a summary of the demographic characteristics of the spouse survivor of TBI as reported by the caregiving spouse. Similar to the caregiver spouses the mean age was 56.81 years ( $SD=10.98$ ) and ranged between 37 and 74 years. The majority of spouses identified as Caucasian (90.5%) while 4.8% were either African-American/Black or Hispanic. Of the survivor spouses 38.1% had obtained a bachelor's degree, 23.8% earned a high school diploma/GED, and 14.3% obtained an associate's degree. Fewer spouses earned a graduate degree or had less than a high school education (9.5% and 4.8% respectively). Similar to caregiving spouses, occupations varied considerably between surviving spouses; however, the vast majority of spouses (61.9%) were unable to return to work after obtaining a TBI. The cause of injury reported also varied between spouses; however the most common cause of TBI within this sample was

Table 1. *Demographic Characteristics of the Spouse Caregiver Sample*

VARIABLES	n	%
Sample size	21	
Age	55.52*	10.3*
Age at time spouse was injured	34.57*	11.9*
Gender		
Male	6	28.6
Female	15	71.4
Ethnicity		
African-American/Black	1	4.8
Asian/Asian-American	1	4.8
Caucasian	18	85.7
Hispanic	1	4.8
Education		
High School/GED	2	9.5
Some College	6	28.6
Associate's Degree	2	9.5
Bachelor's Degree	6	28.6
Graduate Degree	5	23.8
Occupation		
Administrative/Clerical	4	19.0
Construction/Skill Trades/Labor	2	9.5
Editorial/Writing	1	4.8
Engineering	1	4.8
Finance/Insurance	1	4.8
Healthcare/Social Service	3	14.3
Professional/Scientific	2	9.5
Real Estate	1	4.8
Retired	3	14.3
Sales/Retail	1	4.8
Unemployed/Disabled	1	4.8
Employment Status		
Employed full time	16	76.2
Employed part time	2	9.5
Retired	2	9.5
Unemployed	1	4.8

*Note.* \*These values are mean and standard deviation, respectively



Table 2. *Demographic Characteristics of the Spouse Survivor of TBI Sample*

VARIABLES	n	%
Sample size	21	
Age	56.81*	10.98*
Age at Injury	35.81*	10.7*
Gender		
Male	15	71.4
Female	6	28.6
Ethnicity		
African-American/Black	1	4.8
Caucasian	19	90.5
Hispanic	1	4.8
Education		
Less than High School	1	4.8
High School/GED	5	23.8
Some College	2	9.5
Associate's Degree	3	14.3
Bachelor's Degree	8	38.1
Graduate Degree	2	9.5
Occupation Prior to Injury		
Administrative/Clerical	1	4.8
Agriculture	1	4.8
College Student	2	9.5
Construction/Skill Trades/Labor	5	23.8
Engineering	3	14.3
Finance/Insurance	1	4.8
Healthcare/Social Service	3	14.3
Military	2	9.5
Retired	1	4.8
Sales/Retail	2	9.5
Ability to Work		
Yes	8	38.1
No	13	61.9
Cause of Injury		
Vehicle Accident	10	47.6
Fall	2	9.5
Assault	2	9.5
Industrial Accident	2	9.5
Combat/Gunshot wound	2	9.5
Brain aneurysm/Stroke	3	14.3

*Note.* \*These values are mean and standard deviation, respectively.

vehicle accidents (47.6%) (The grouping of vehicle accidents included: car accidents (n=6), bicycle accidents (n=2); snowmobile accident (n=1), and a skiing accident (n=1)), which is consistent with the research literature of the major causes of TBI within the United States (Annegers et al., 1980; CDC, 2010; Jager et al., 2000; Kalsbeek et al., 1980; Kraus et al., 1984; Sosin et al., 1996), followed by stroke/brain aneurysm (14.3%), and assault (9.5%), falling (9.5%), industrial accidents (9.5%), and combat/gunshot wound (9.5%).

Table 3 provides a summary of the demographic characteristics of the marital relationship. The mean total number of years the couple has been married was 31.19 years ( $SD=11.3$ ) and ranged between 14 and 54 years. More specifically, the mean total number of years the couple had remained married since their spouse's injury was 19.28 years ( $SD=8.34$ ). The majority of caregiving spouses had been in a committed relationship with their partner for a significant amount of time when his or her spouse had been injured, as the mean years within the relationship at the time of injury was 12.28 years ( $SD=10$ ). In addition, responses ranged from dating their spouse to being married for 54 years. Only 4 participants indicated having been married previously. Two-thirds of the participants reported having children (66.7%) and 57.1% indicated that their children were living with them at least half-time when their partner sustained his or her injury. In contrast, 9.5% indicated that their children lived with them less than half-time at the time of his or her spouse's injury. Three participants indicated that their children had not been born at the time the injury occurred. At the time of the injury, 28.6% indicated that they had two children, 14.3% reported having 4 children, and 9.5% indicated having three children. For the participants whose children were born and living

Table 3. *Demographic Characteristics of the Marital Relationship by Caregiving Spouse*

VARIABLES	n	%
Sample size	21	
Previously Married	4	19.0
Years in Relationship		
Total years married	31.19*	11.3*
Years married at the time of injury	12.06*	10.1*
Years married since the injury	19.28*	8.34*
Dating at the time of injury	3	14.3
Children		
Yes	14	66.7
No	7	33.3
Number of Children		
2	6	28.6
3	2	9.5
4	3	14.3
6	1	4.8
7	1	4.8
Children living at home at least ½ at time of injury		
Yes	12	57.1
No	2	9.5
Children's Age at the time of Injury		
Not yet born	3	14.3
Age 1-4 years	4	19.0
Age 5-9 years	5	23.8
Age 10-14 years	5	23.8
Age 15-22 years of age	4	19.0
Annual Household Income		
Below \$20,000	2	9.5
\$20,000-29,999	3	14.3
\$30,000-39,999	3	14.3
\$40,000-49,999	3	14.3
\$50,000-59,999	2	9.5
\$70,000-79,999	2	9.5
\$80,000-89,999	2	9.5
\$90,000 or more	4	19.0

*Note.* \*These values are mean and standard deviation, respectively

with them at least half-time at the time of the injury, 19% had children between the ages of 1-4 years, 23.8% 5-9 years, 23.8% 10-14 years, and 19% had teenagers and young adults between the ages of 15-22 years. The total household income varied across participants; however, the majority of this sample (61.9%) had household incomes at or below the income bracket of \$40,000-\$49,999, while 19% of the sample had household incomes of \$90,000 or above.

### Descriptive Statistics

Table 4 provides a summary of the ranges, means, standard deviations, and Cronbach's alpha for all measures. The quality of life scores, as measured by the SF-12v2, were generally within the average range. T-scores of 45 or greater on the SF-12v2 are considered at least average overall physical or mental health. For example, although the lowest quality of life was reported in the area of role emotional (M=47.12), a measure of the degree to which emotional problems limit the ability to work or engage in daily activities to the typical level of care, the value was still within the average range for overall functioning. The highest quality of life was reported in the area of general health (M=53.15), which suggests that participants found the least amount of quality of life interference in the area of their general health. In addition, overall physical health (PCS) was generally above average (M=53.26), more specifically 50% (n= 12) of the sample indicated having overall higher quality of life in regards to their physical well-being (physical functioning, general health, bodily pain, and vitality) than the general population norm, 35% (n=6) indicated health quality of life at the norm, and 15% (n=3) reported overall physical health below the norm. Mental health quality of life was generally reported within the average range (M=47.16), which suggests that participants within this

sample indicated that their mental health quality of life was similar to that of the general population. More specifically, 60% of the sample indicated their mental health quality of life was at the general population norm ( $n=12$ ), 10% above the mean ( $n=2$ ), and 30% lower than the general population ( $n=7$ ).

In terms of coping, participants' coping strategy scores were somewhat variable; in general, participant's scores were higher in the areas of emotion-focused ( $M=23.60$ ) and problem-focused coping strategies ( $M=13.81$ ) than dysfunctional coping strategies ( $M=19.60$ ). In addition, individual scales of the Brief COPE indicated higher scores on the scales of active coping ( $M=5.00$ ), use of emotional support ( $M=4.55$ ), use of instrumental support ( $M=4.45$ ), positive reframing ( $M=4.55$ ), planning ( $M=5.30$ ), acceptance ( $M=6.60$ ), and religion ( $M=4.85$ ) with mean scores above 4 based on a score of 8 as the maximal score. Denial ( $M=2.40$ ) and substance use ( $M=2.65$ ) were the least used coping strategies as mean scores were less than 3 with a maximal score of 8, while self-distraction ( $M=4.80$ ) was the highest mean score within the dysfunctional coping strategy category.

Overall marital satisfaction for spousal caregivers, as measured by the DAS, suggested that participants were slightly less satisfied with their marriages ( $M=99.79$ ,  $SD=25.19$ ) than the general population as higher scores indicate greater marital adjustment (Spanier, 1979). Graham et al. (2006) recommended general guidelines: scores of 107 are suggestive of marital satisfaction with normal levels of concern, while scores below 92 indicate moderate levels of distress within the marriage. In this study, the majority of participants (57.5%) rated their overall marital satisfaction as average to markedly above average, while a lesser percentage of the sample (23.9%) rated their

Table 4. *Descriptive Data for Psychometric Instruments*

Measure	n	Range	Mean	SD	Alpha
Quality of Life (SF-12v.2)	21				
Physical Functioning		25-100	52.94	6.87	NA
Role-Physical		38-100	50.81	7.52	NA
Bodily Pain		25-100	50.00	9.15	NA
General Health		25-100	53.15	7.52	NA
Vitality		0-100	50.47	7.80	NA
Social Functioning		25-100	48.01	8.43	NA
Role-Emotional		38-88	47.12	8.68	NA
Mental Health		0-100	48.36	7.24	NA
Physical Health Scale (PCS)		37-65	53.26	7.35	.82
Mental Health Scale (MCS)		28-59	46.71	7.78	.81
Coping (Brief COPE)	20				
Self-Distraction		3-8	4.80	1.28	NA
Active Coping		3-7	5.00	1.26	NA
Denial		2-4	2.40	.75	NA
Substance Use		2-6	2.65	1.14	NA
Use of Emotional Support		2-7	4.55	1.50	NA
Use of Instrumental Support		2-8	4.45	1.57	NA
Behavioral Disengagement		2-6	2.80	1.20	NA
Venting		2-6	3.75	.85	NA
Positive Reframing		2-8	4.55	1.88	NA
Planning		3-8	5.30	1.30	NA
Humor		2-6	3.05	1.23	NA
Acceptance		3-8	6.60	1.73	NA
Religion		2-8	4.85	2.43	NA
Self-Blame		2-8	3.20	1.40	NA
Emotion-Focused Strategies		12-36	23.60	6.15	.83
Problem-Focused Strategies		10-20	14.75	3.43	.73
Dysfunctional Coping Strategies		13-27	19.60	3.50	.62
Marital Satisfaction (DAS)	19				
Dyadic Consensus		15-60	44.47	9.77	.93
Dyadic Satisfaction		9-47	33.32	10.44	.93
Affectional Expression		2-12	7.58	2.27	.77
Dyadic Cohesion		5-23	13.81	5.53	.89
Dyadic Adjustment		34-140	99.79	25.19	.96

marital satisfaction as having significant indicators of concern ( $T < 34$ ) to the degree that thoughts of the marriage dissolving are likely to be present. The majority of study measures showed satisfactory reliability with the exception of dysfunctional coping strategies from the Brief COPE, which although below the traditionally recommended alpha level of .70 (Nunnally, 1978), is within the Carver's (1997) guidelines of alpha levels above .50 for two item scales as being acceptable.

Table 5 provides a comparison of the means and standard deviations of these participants to available published data. A series of independent group t-tests were used to compare the means of the study sample with those of comparable published data of spousal caregivers. Spousal caregivers in this study reported similar levels of marital satisfaction as spousal caregivers of partners with chronic illness ( $t(109)=0.70, p=0.24$ ) (Badr & Acitelli, 2005). With regard to coping, emotion-focused ( $t(143)=3.22, p<.001$ ), problem-focused ( $t(143)=2.90, p=.002$ ), and dysfunctional coping ( $t(143)=3.39, p<.001$ ) were used to a significantly greater degree than published data of spousal caregivers of individuals with dementia (Cooper, Katona, & Livingston, 2008a). There was no difference between physical health quality of life when compared to the spousal caregivers of partners with Parkinson disease ([PCS: $t(115)=.773, p=.220$ ]) (Tanji et al., 2008). However, in terms of mental health quality of life, the study population had lower scores than the spousal caregivers population ([MCS: $t(115)=2.56, p=.006$ ]) (Tanji et al., 2008). These findings were expected given the nature of this select population of spousal caregivers as they have chosen to remain married on average nearly two decades after their spouse's injury, which is well beyond the years of caregiving within previous research studies. Given the length of their marriage and dedication to the caregiving of

their spouse, it is likely they have adapted and added coping strategies over time which have sustained their marriage; however, in terms of mental health quality of life, similar to previous research literature, long term caregiving spouses have a greater likelihood of experiencing symptoms of depression and anxiety than the general population (Cavallo & Kay, 2005; Lezak, 1978; 1986; 1988; 1996; Mauss-Clum & Ryan, 1981; Panting & Merry, 1972; Turner et al., 2007).

### Research Questions

Prior to data analysis, an a priori power analysis estimated that a minimum of 97 participants were necessary to achieve a power level of .80 assuming a moderate effect to achieve significance at the  $p < .05$  level. Although attempts were made to meet the stated criteria for power, barriers to achieving this sample size were due to stringent inclusion criteria as well as participants not fully completing the study questions. As such, research questions for this study have been modified.

The first research question pertained to the descriptive profile of spouses who have remained married ten years post injury or longer. Given the above descriptive analysis presented earlier in this chapter, spousal caregivers in this study endorsed generally average levels of physical and mental quality of life compared to population based data and indicated greater likelihood of using emotion-focused and planning focused coping strategies, more specifically within the coping areas of acceptance, religion, planning, and active coping. Regarding marital adjustment, spouses endorsed slightly lower levels of marital satisfaction compared to published data. However, compared to other populations of spousal caregivers, participants in this study reported significantly lower mental health quality of life, and greater usage of emotional-focused,



Table 5. Scores and Published Data Comparisons for Measures

Measure	<u>Sample</u>				<u>Published Data</u>			<u>T Test</u>	
	n	N	M	SD	N	M	SD	T	Sig.
Marital Satisfaction (DAS)	151	19	99.79	25.19	92	104.10 <sup>1</sup>	24.18	.70	.24
Coping (Brief COPE)									
Emotion-Focused Strategies	10	20	23.60	6.15	125	19.40 <sup>2</sup>	5.3	3.40	<.001
Problem-Focused Strategies	6	20	14.75	3.43	125	11.70 <sup>2</sup>	4.5	3.22	.002
Dysfunctional Coping Strategies	12	20	19.60	3.50	125	16.10 <sup>2</sup>	4.4	3.39	<.001
Quality of Life (SF12v2)									
Physical Health Scale (PCS)	6	21	53.26	7.35	96	51.58 <sup>3</sup>	9.33	0.77	.22
Mental Health Scale (MCS)	6	21	46.21	7.78	96	51.92 <sup>3</sup>	8.57	2.56	.006

*Note.* n= Number of items in a scale, N=Sample

<sup>1</sup>=Published data with mean and standard deviations based on dyadic adjustment in couples of chronic illness (N=92). Badr, H. & Acitelli, L. (2005). Dyadic adjustment in chronic illness: Does relationship talk matter? *Journal of Family Psychology, 19*, 465-469.

<sup>2</sup>=Published data with means and standard deviations based on the LASER-AD study of carers of people with Dementia (N=125). Cooper, C., Katona, M., & Livingston, G. (2008b). Screening for elder abuse in dementia in the LASER-AD study: Prevalence, correlates, and validation of instruments. *International Journal of Geriatric Psychiatry, 23*, 283-288.

<sup>3</sup> = Means and standard deviations based on published data of spousal caregivers of individuals with Parkinson's disease (N=96). Tanji, H., Anderson, K., Gruber-Baldini, A., Fishman, P., Reich, S., Weiner, W., & Shulman, L. (2008). Mutuality of marital relationship in Parkinson's disease. *Movement Disorders, 23*, 1843-1849.

planning-focused, and dysfunctional coping. Levels of marital satisfaction and physical quality of life were not significantly different between the sample and published data.

The second research question was to examine the relationship of marital satisfaction with demographic variables and coping strategies. Table 6 summarizes selected inter-correlations between demographic variables and the main study measures. Bivariate correlations were calculated to explore the relationships between demographic variables and measures of marital satisfaction (DAS total) with health-related quality of life (SF-12v2: PCS & MCS), and coping (Brief COPE, emotion-focused, problem-focused, and dysfunctional coping strategies scales). In regards to quality of life measures, the Physical and Mental Component Summary of the SF-12v2 were not significantly correlated with any of the selected demographic variables. However, although not statistically significant, the age of the spousal caregiver was positively associated with mental health quality of life ( $r=.35$ ) while higher income level was also related to higher levels of mental health quality of life ( $r=.39$ ). Dysfunctional Strategies Coping strategies were most strongly related to income level ( $r= -.54$ ;  $p < .05$ ) and the educational level of the spousal caregiver ( $r= -.57$ ;  $p < .001$ ). These results suggest increased use of dysfunctional coping strategies with lower financial means and lower levels of educational attainment. When examining the relationships between emotion focused and planning focused coping strategies with demographic variables, findings indicate that emotion focused and planning focused coping strategies were not significantly related to any of the selected demographic variables. Although not statistically significant, relationships emerged between emotion focused and problem focused coping strategies. For example emotion focused strategies were positively

associated with years married at the time of the injury ( $r=.35$ ) and the total years the couple has remained married (.42) while use of problem focused coping approaches was negatively associated with reported income level ( $r=-.43$ ).

Marital adjustment (DAS-total) was strongly associated with the spouses who indicated they were older at the time of their spouse's injury (age of the spousal caregiver;  $r=.47$ ,  $p<.05$ ), the number of years the couple was married at the time of the spouse's injury ( $r=.62$ ,  $p<.001$ ), and the total number of years that couple has remained married ( $r=.60$ ,  $p<.001$ ). Thus, results suggest that higher levels of marital satisfaction are associated with longer term marriages, the age of the spouse at the time of the injury, more specifically if the caregiving was older, and the duration of the marriage at the time of the injury.

The third research question pertains to the relationship of marital satisfaction with mental and physical health quality of life and coping strategies (emotion-focused, problem focused, and dysfunctional coping approaches). Bivariate correlations were conducted to examine the relationships between several study variables and these correlations are presented on Table 7. The majority of measures were not correlated with one another with several exceptions. In regards to mental health quality of life, a couple of significant associations emerged. Participants with higher use of dysfunctional coping strategies reported significantly lower mental health quality of life (SF-12MCS;  $r=-.57$ ,  $p<.001$ ) and participants who indicated higher levels of marital satisfaction (DAS total) tended to report better levels of mental health quality of life ( $r=.46$ ,  $p<.05$ ). Relationships between marital satisfaction (DAS total) and emotion focused coping strategies

Table 6. *Inter-correlations Between Demographic Variables and Selected Study Variables*

Scale	SF-12PCS	SF12-MCS	EFCoping	PF Coping	DCoping	DAS
1. Age of Spouse caregiver	-.22	.39	.19	.03	-.22	.47*
2. Years married at time of injury	-.32	.25	.35	.32	.01	.62**
3. Total Years Married	-.04	.34	.42	.25	-.22	.60**
4. Income level	.35	.09	.05	-.43	-.54*	.25
5. Education level of spouse caregiver	.32	.16	-.16	-.41	-.57**	.02

*Note.* SF-PCS= SF-12v2 Health Survey Physical Component Summary; SF-12MCS=SF-12v2 Health Survey Mental Component Summary; EFCoping=BriefCOPE Emotion-Focused Strategies Scale; PFCope=BriefCOPE Problem-Focused Strategies Scale; DCoping=BriefCOPE Dysfunctional Strategies Scale; DAS=Dyadic Adjustment Scale.

\*p<.05; \*\*p<.001

Table 7. *Selected Inter-correlations Among Variables*

Scale	1	2	3	4	5	6
1. SF-12PCS	-					
2. SF-12MCS	-.05	-				
3. EFCoping	.34	.06	-			
4. PFCoping	.14	.08	.53*	-		
5. DCoping	-.41	-.57**	-.01	.19	-	
6. DAS	.25	.46*	.78**	.40	-.33	-

*Note.* SF-PCS= SF-12v2 Health Survey Physical Component Summary; SF-12MCS=SF-12v2 Health Survey Mental Component Summary; EFCoping=BriefCOPE Emotion-Focused Strategies Scale; PFCope=BriefCOPE Problem-Focused Strategies Scale; DCoping=BriefCOPE Dysfunctional Strategies Scale; DAS=Dyadic Adjustment Scale.

\* $p < .05$ ; \*\* $p < .001$

(EFCoping) were similar in direction and magnitude. More specifically, caregiving spouses with higher levels of marital satisfaction also reported significantly higher usage of emotion focused coping strategies ( $r=.78$ ;  $p<.001$ ). Although, the following were not statistically significant, given the sample size of the current study, the following relationships between variables may be relevant and deserving of further research inquiry. For example, caregiving spouses who used higher levels of dysfunctional coping strategies (DCoping) reported lower levels of physical health quality of life (SF-12PCS;  $r=-.41$ ) whereas those who indicated higher usage of problem-focused coping strategies (EFCoping) also indicated higher levels of marital satisfaction (DAS total;  $r=.40$ ).

#### Analysis of Stressors

One of the research questions of this study was to better understand long-term stressors of enduring marriages when one partner had a severe TBI. As such, each participant was asked to give a narrative response of the stressor that he or she felt had the greatest impact on their marriage throughout the time of their spouse's recovery until the present time. The principle investigator generated thematic categories for responses provided by the participants. These categories were then reviewed and defined for accuracy and are included in the outline below. There was a 95% agreement between the two raters who were knowledgeable within the field for categorizing the narrative response items. The final categories derived from this analysis were: Symptoms Resulting from TBI (e.g., cognitive changes, memory difficulty, communication, etc.), Personality Changes (e.g., unpredictable behavior), Caregiver Worries (e.g., tasks/household duties, caring for spouse), Financial Concerns (e.g., lack of money or resources for needs), Isolation (e.g.,

unable to maintain friendships/connection with family), and Existential/Religious Concerns (e.g. why is this happening to me?).

For example, one spouse reported “*her inability to learn and remember*” while another spouse noted “*short term memory loss.*” Yet another participant noted that the spouse had an “[*in]ability to communicate effectively.*” Another spouse indicated “*he had some post traumatic symptoms for several years after his injury*” while another noted “*His inability to get a full nights sleep on most nights.*” Given these responses within this theme, it appears spousal caregivers continue to navigate long-term and possible permanent emotional and cognitive symptoms of TBI within their relationship.

For the theme of “Personality Changes” (e.g., unpredictable behavior) 3 spouses indicated that changes in their spouse’s personality were most stressful, specifically that the spouse engaged in behaviors that were surprising or unlike how he or she would have usually behaved prior to his or her injury. For example, one spouses reported, “*personality changes and his inability to make decisions and the problems with ego associated with that*” while another spouse indicated “*personality change which results in unpredictable behavior.*” Given the responses within this theme, it seems caregiving spouses, despite the length of time after the injury, continue to struggle with trying to make sense of their spouses behaviors, which at times may be illogical and/or irrational and therefore create situations and experiences which appear to create a stressful dynamic with in the relationship.

Caregiver Worries (e.g., tasks/household duties, caring for a spouse) as a theme was characteristic of 2 spouses. Caregiver worries included assistance in completing general household tasks and concerns regarding the well-being/safe keeping of their

spouse. For example, one spouse noted “*keeping him safe and healthy*” and the other reported “*lack of work on his part.*” The responses within this theme appear to indicate spouses continue to worry about their partner’s well-being and ability to balance the roles and responsibilities without additional assistance from their spouse.

The theme of “Financial Concerns” (e.g., lack of money or resources for needs) was described by 4 spouses. Financial concerns included worries about income and money. For example, one spouse reported “*his inability to work as many hours as we need*” while another spouse noted “*limited income.*” Another spouse simply indicated “*financial concerns.*” Given the responses within this theme, it appears financial concerns are long term stressors and continue to impact the marital relationship.

The theme of “Isolation” (e.g., unable to maintain friendships/connection with family), 3 spouses’ responses suggested feeling stressed due to their inability to connect with friends/family or engage in interests due to caring for their spouse and maintaining work responsibilities. In addition, this theme also includes their spouses loss of friends and support after sustaining his or her injury. For example, one spouse stated, “*I haven’t felt free to travel or engage in evening activities.*” Another spouse reported, “*physical exercise.*” Another spouse noted, “*loss of my wife’s support system.*” Responses within this theme suggest spouses continue to struggle with the loss of their ability to engage in personal relationships/self-care as well as the loss and difficulty of their spouses to also access support and companionship outside of the marital relationships.

The theme of “Future Worries” (e.g. will this happen to me again?) included the unanswered questions and unknowns of spousal caregivers and the path of caring for their injured partner. One participant’s responses indicated this theme as the participant



reported “*worry[ing] about it happening again.*” The response within this theme suggests that spousal caregivers also have worries about their spouse potentially becoming reinjured.

In addition to the above themes coded for stressors, participants were also asked an open ended question stated: “Is there anything else about your experience that you’d like to share?” A total of 6 participants provided responses to this question. These responses were not coded given the depth of each response about the impact of stressors, information about daily life and time spent with their spouse, as well as limitations and implications for future research. The responses included additional information on stressors and potential recommendations for future research. Specifically, one participant stated,

*“I would add that my husband's injury was severe enough that he is not independent, with many of the limitations of a TBI survivor including compromised speech and swallowing, short-term memory deficits and Parkinsonism. I make all decisions and am solely responsible for his care and well-being. He attends an adult daycare in [town], which he and I appreciate very much. We do not have a sexual relationship. He retains a sense of humor and very much enjoys puzzles, word games of all sorts, cards, and a good game of Scrabble. He mostly wins.”*

A second participant reported, “*Caregiving after this many years has worn me out.*” The third participant stated “*It has been a long recovery but very positive outcomes.*” The fourth spouse reported,

*“Brain injury is a very serious life sentence. People do not realize the toll it takes on the patient and especially the caregiver. We've lived with this for over 25 years and the natural progression of life does not make it any easier on either of us.”*

The fifth spouse indicated, *“I do feel that the doctor who operated on my husband should be sued but have never taken steps to make this a reality.”* And finally, the sixth spouse said,

*“We both feel lucky that the head injury happened to us (and I mean both of us) rather than our children. We both are very committed to each other as partners in life and have faith in each other that we will survive. We are now in our twentieth year of head injury and 45th year of marriage. The kids have grown and gone and we are closer now than we were when we had to deal with growing children. We agree more now. My wife has been in nursing home for the past two years, and I see her 3 or 4 times a week (she is 50 miles away). When I go down, I pick her up and we usually sit along the Mississippi River in mostly silence feeling comfortable with each other.”*

To further understand caregiving spouses' stressors over the course of their relationship after their spouse survived a severe TBI, participants rank ordered a list of potential stressors developed on findings from previous research studies of caregivers of TBI. They were also provided a space to define a stressor that was not on the list in as much detail as desired to better define their unique experience. A frequency table was developed based on responses. Table 8 provides the highest rankings. The top ranked

stressor, consistent with narrative response provided by participants, was the unpredictable behavior and was rated as the number one stressor by 7 participants. The second ranked stressor was changes in the injured partner's personality. The third ranked stressor was changes in the injured partner's personality. The third ranked stressor was work responsibilities. Finances/Income was the fourth most ranked stressor and notably was ranked as the number one stressor for 6 participants. Feeling disconnected from their spouse/partner was the fifth most ranked stressor, while continued navigation of the healthcare system and sex/intimacy were tied for the sixth ranked stressor. Surprisingly, continued role as a caregiver was the 7<sup>th</sup> most ranked stressor. Two participants provided responses of other stressors not identified on the list. These responses were: "*sex*," "*communicat[ion]*," "*household help*," "*loneliness*," "*unable to have intimate (non-sexual) conversations about life and the future*," and "*collapse of wife's social network outside of family*." Given these responses, the additional stressors which were added by participants indicates that spousal caregivers may feel loneliness, have difficulty communicating with their spouse, and have desire to have in-depth conversations with their spouse, which is separate from the category of isolation and is perhaps a cause of significant stress within the relationship.

Table 8. *Frequency of Stressors*

<u>Stressor</u>	<u>Rankings</u>										<u>Avg. Rank*</u>
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	
Changes in Personality	2	4	1	1	1	3	1	1	0	1	3.10
Unpredictable behavior	7	4	0	1	1	1	1	0	1	0	2.19
Work Responsibilities	1	4	4	1	3	1	1	2	1	0	3.71
Household Responsibilities	0	2	4	4	2	0	3	2	3	0	5.05
Finances/Income	6	0	2	1	4	1	1	1	1	2	4.10
Healthcare	1	0	2	0	2	3	1	2	4	1	4.95
Continued Role of Caregiver	1	3	2	2	1	4	3	2	1	1	5.05
Disconnected from Spouse/Partner	1	0	2	2	0	2	4	2	1	2	4.76
Sex/Intimacy	0	2	0	1	2	1	3	5	1	1	4.95
Strained Family Relationships	0	0	1	2	1	0	1	0	3	6	5.24

*Note.* N=21. Not every participant ranked each stressor 1-10. For example a couple participants ranked 1-7.

## CHAPTER IV

### DISCUSSION

This chapter will discuss the implications of the results presented in Chapter III. First, the findings of the study will be discussed in context of the major themes of the research questions. Second, the limitations of the study will be reviewed. Third, suggestions for further clinical implications and continuation of future research will be offered. Last, a brief summary of the general conclusions will be presented.

#### Discussion of Results

Prior research studies exploring relationship wellbeing and marital satisfaction in spousal caregivers of surviving individuals with TBI mainly have examined the couple relationship within the first 5 to 8 years after injury. In addition, those studies focusing on the marital relationship were also dedicated to the factors which cause the break-down of a marriage rather than exploring marital satisfaction and long-term marital adjustment. Previous research has explored rates of separation and divorce following TBI by investigating the association between marital stability and the severity of injury, cause of injury, and duration of marriage pre and post-injury (Kreutzer et al., 2007; Vanderploeg, Curtiss, Duchnick, & Luis, 2003). However, the literature is not well developed in terms of marital dynamics and adjustment in enduring relationships of couples with severe TBI and for long-term stressors and coping strategies, which potentially impact marital satisfaction and quality of life. Increasing our understanding of these long-term marital relationships by describing the demographics of the long-term caregiving spouse and clarifying the relationship between marital satisfaction, quality of life, coping strategies, and primary continued stressors is fundamental to expanding understanding of couples

living with TBI. Additionally, this research may assist in the development of appropriate interventions and supports for couples affected by TBI beyond a decade after a spouse has sustained his or her injury. Thus, the purpose of this study was: (1) to provide a profile of spouses, including demographic information regarding their marital relationship, who have been long term caregivers to their spouses who survived a severe TBI and provide comparisons to similar caregiving populations, (2) to explore the relationship between demographic variables and spouses' health-related quality of life, coping strategies, and marital satisfaction, and (3) to develop better understanding of the continued long-term stressors that caregiving spouses experience within their marriage.

The results of the present study show that long-term caregiving spouses of individuals with severe TBI, for the most part, experience good physical and mental health quality of life, tend to use positive coping strategies (i.e. emotion-focused and planning-focused coping strategies), but experience mild dissatisfaction with their marriage. Caregiving spouses' experience of long-term stressors which impact their marriage suggest that stressors previously reported in the research literature impact the marriages of the current participants as well. These findings support the research literature and also serve to extend and inform the existing research literature about the long-term impact of severe TBI on marital satisfaction for enduring spousal caregivers.

### Demographic Characteristics

The sample in this study was predominately female (71.4%) and the mean age of participants was 55 years. Both values are consistent with the literature on the percentage of female to male caregivers as well as the expected age range of typical caregivers (Family Caregiver Alliance, 2010). Previous literature on spousal caregivers of TBI has

also predominantly focused on the female caregiving spouse (Gervasio & Kreutzer, 1997; Gosling & Oddy, 1999), which may be attributed to men being at a higher risk for sustaining a TBI than women (CDC, 2010). The major cause of injury survived by spouses in this sample was vehicle accidents, followed by falls, which is consistent with the research literature on primary cause of TBI in the general population (CDC, 2010; Sosin et al., 1996). Notably, the majority of the participants within the sample was Caucasian, educated, and had been working full-time.

Similar to other studies of spousal caregivers (Jacobs, 1988; Turner et al., 2007), the majority of spouses within this sample reported that, after their spouse survived his or her injury, he or she was unable to return to work. Financial concerns are frequently discussed within the research literature as continuing stressors for caregivers and families of TBI. In this sample, the majority of participants indicated having household incomes at or below \$49,999, while less than 20% of the sample reported household incomes of \$90,000 or above. Kreutzer, Davany-Serio, and Berquist (1994) reported, based on their sample of 119 family members of TBI, the majority of participants (54%) indicated having annual incomes of \$30,000 or less, while a third of the study (32%) reported annual incomes of \$40,000 or greater. Peters, Stambrook, Moore, and Esses (1990) examined the marital relationship of 55 male survivors of mild, moderate, and severe TBI. Time since the accident, at the time of their participation in the study, ranged from a few months to 8 years post injury. In this study, female spouses with husbands who survived a severe TBI (n=20) reported annual incomes of between \$20,000 to \$25,000 prior to their spouses' injury and \$15,000 to \$20,000 after the injury.

These studies in conjunction with the current study suggest that financial concerns of families may be a long term stressor, especially given the majority of injured spouses are unable to return to work. Although caregiving spouses tend to work full time, only one spouse in the family is able to work and subsequently unable to significantly raise the family income level. Notably, the average family income of families with brain injury continues to be significantly lower than the national median household income (U.S. Census Bureau, 2013). Long term stressors, including financial concerns, will be discussed in detail later in this chapter.

### Health Quality of Life Characteristics

As mentioned in the review of literature, spousal caregivers of individuals with TBI report negative changes in physical and mental health due to caregiving for their spouse. For example, spousal caregivers of individuals with TBI report higher levels of anxiety and depressive symptoms than parent caregivers (Mauss-Clum & Ryan, 1981; Kretuzer et al., 1994) to the extent that caregivers seek treatment and take sick days to a greater extent than prior to their spouse's injury (Turner et al., 2007). Given the research literature, it was expected that the current sample would experience lower physical and mental health quality of life than the general population. In addition, it was thought that spouses in the current sample would experience lower physical and mental health quality of life compared to a similar long term caregiving sample, since the injured spouses had received a severe TBI.

In regards to physical health quality of life, there were no significant differences between spousal caregivers of TBI in this study and spousal caregivers of Parkinson's disease (See Chapter III). However, there were significant differences between the mental



health quality of life for spousal caregivers of TBI and spousal caregivers of individuals with Parkinson's disease. It should be noted, that participants in the current study endorsed average levels of physical health and mental health quality of life. The lowest quality of life domain was in the area of role-emotional (i.e., the degree to which emotional problems limit the ability to work or engage in daily activities), yet this domain was still within the average range. The highest rated domain was in the area of general health, which suggests spousal caregivers in this study have equivalent quality of life to the general population.

This surprising result is inconsistent with the literature and counters the supposition that caregivers' physical and mental health quality of life decreases while caring for a spouse. For example, Perlesz, Kinsella, and Crowe's (1999) review of 23 studies addressing family psychosocial outcome after TBI noted that the majority of studies indicated caregivers (primarily spouses and family members) were negatively impacted by caregiving, with higher levels of anxiety and depression. However, this review of studies also posited that positive outcomes for caregiving were largely unaccounted for as researchers tended to focus only on negative impact of stress and burden, neglecting measures which provide opportunities for participants to report caregiving benefits. In this regard, a more recent study of 72 long-term caregivers of TBI (years since injury  $M=9.64$ ;  $SD=7.76$ ; range of 1 to 40 years post injury) exploring the relationships among coping, attitudes towards caregiving, distress, mood ratings, and quality of life revealed that the majority of caregivers endorsed more positive feelings towards caregiving; negative outcomes related to caregiving appeared to be mediated by access to a supportive social network (Wells, Dywan, & Dumas, 2005).

It is important to account for the unique qualities of the current sample. First, the average length of time post-injury the couple remained married was much higher than previous research averages. Second, the majority of participants within this study were recruited from agencies or online support groups which provide long-term resources and community support to individuals, couples, and families impacted by brain injury. As such, it is highly probable that these spousal caregivers represent a sample which has over time found resources and coping strategies that protect against negative outcomes of long term caregiving as well as have had a considerable amount of time to process their spouses' injury.

#### Coping Strategies Characteristics

Investigating the coping strategies of long-term spousal caregivers of severe TBI was another focus of the current study as research literature suggests that long term marriages after TBI undergo multiple challenges. Given the research literature, it was thought that the current sample would use more functional (emotion-focused and planning focused) strategies than dysfunctional (avoidance) strategies given the choice to remain in a long-term marriage. Spousal caregivers in this sample used more emotion-focused and planning focused strategies than dysfunctional coping strategies. More specifically, spouses used the coping strategies of acceptance, planning, active coping and religion to a higher degree than other types of coping strategies while the least frequently used coping strategies were denial and substance use.

Similar to studies investigating coping among caregivers of TBI, the present study showed that long term caregiving spouses use more positive approaches to coping which appear to alleviate negative psychosocial outcomes, and may provide opportunities for more positive appraisal towards caregiving (Wells et al., 2005; Verhaeghe et al., 2005). In addition, this study also is in alignment with Monat and Lazarus's (1985) theory of stress and coping, as caregivers in this study demonstrated use of functional coping to reduce the impact of stress on long-term caregiving. As previously mentioned, this

conclusion needs to be interpreted with caution, given the nature of this sample since accessing the survey means that participants were using an online support network, which in and of itself is a positive coping strategy.

### Marital Relationship and Satisfaction

As discussed previously in this chapter, research literature on marital stability after TBI has primarily focused on the relationship within the first decade of marriage. For example, Wood and Yurdakul (1997) investigated relationship stability among individuals (n=131) who had a spouse survive a TBI (76% survived a severe TBI), were together at least one year prior to the injury, and were married an average of 8 years post-injury. The study reported that nearly half of all married couples were divorced at the conclusion of the study. The longest study to date examining long-term stability and marital breakdown in couples surviving severe TBI was Thomsen's (1984) study, which followed 9 married couples over the course of 10 to 15 years; at the conclusion of this study, only 2 couples remained married. Kreutzer et al. (2007) completed a follow-up evaluation of 120 individuals between 2.5 and 8 years post injury that had survived a mild, moderate, or severe TBI and had been married at the time of injury. Results indicated that the average years since injury was 4 years and the majority of participants had remained married (75%), while a small percentage divorced (17%) or separated (8%).

This particular sample of participants is perhaps the only to date to have gleaned information from spouses of severe TBI 20 years post injury; albeit the small sample size and difficulty generalizing results, this sample provides a unique opportunity to investigate variables associated with long-term marriages and the adjustment to stressors

within the relationship. Surprisingly, and contrary to predictions, findings revealed similar levels of marital satisfaction in this study as spousal caregivers of partners with chronic illness. This result is in contrast to the research literature which suggests that spousal caregivers are mostly unsatisfied with their marriage, given separation and divorce rate from studies ranging from 8% to 74% (Kreutzer et al., 2007; Thomsen, 1984). For example, Peters et al. (1990) examined marital satisfaction in 55 female spousal caregivers of male spouses with mild, moderate, and severe TBI. Results showed that as injury severity increased, marital satisfaction declined: for spouses whose spouse had mild (n=10) to moderate injuries (n=25), marital satisfaction was average; however, for spouses whose spouse had severe injuries (n=20), scores were indicative of moderate levels of dissatisfaction. The marital satisfaction and adjustment within this sample is high and suggests that more information is needed to understand the complex variables which impact marital satisfaction.

Findings also revealed that marital satisfaction was strongly and positively associated to age of the spousal caregiver, number of years the couple was married at the time of the spouse's injury, and total number of years the couple has remained married. This finding is consistent with the research literature which suggests marital longevity may protect the marriage despite changes in personality, cognition, and behaviors (Kreutzer et al., 2007).

Results from this study indicated that marital satisfaction was positively associated with emotion-focused coping strategies, suggesting that caregiving spouses who used more emotion-focused coping strategies (e.g., acceptance, active coping, and religion) reported more satisfaction and adjustment within their relationship. In regard to

mental health quality of life, marital satisfaction was also positively associated with mental health quality of life, suggesting that spouses who indicate better satisfaction with their marriage have higher mental health quality of life. In contrast, participants who used more dysfunctional coping strategies endorsed significantly lower mental health quality of life. Physical health quality of life did not have a significant relationship to other study variables.

It is important to note that the majority of the research literature has focused on marital stability, which is separate from the construct of marital satisfaction and adjustment. The dynamics within the relationships of caregivers of TBI appear to be complex and not well understood (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). Therefore, findings need to be interpreted with caution given the limits of the methodology of this study and available comparisons within the research literature. To date, there are three studies which have used the Dyadic Adjustment Scale (DAS total score) in investigating marital satisfaction in spousal caregivers of TBI (Kieffer-Kristensen & Teasdale, 2011; Moore, Stambrook, Peters, & Lubusko, 1991; Peters et al., 1990). The study by Moore et al. (1991) examined coping strategies and marital adjustment of 46 families of severe (n=13), moderate (n=22), and mild (n =11) TBI. Consistent with the current study, results suggested that families who used more coping strategies as measured by the F-COPES had better marital satisfaction (DAS total score); however, the researchers found significant differences in coping strategies based on demographic variables of the three groups. More specifically, families who are younger and have financial strain may have under used coping skills, which was associated with lower marital satisfaction and adjustment. The study by Peters et al., (1990) described

earlier in this chapter, suggested that marital satisfaction (DAS total score) was impacted by the severity of their husband's injury, as wives of spouses' with severe TBI reported lower scores in dyadic consensus (e.g., extent of agreement between partners on issues that impact the relationship), affectional expression (e.g., spouses' level of satisfaction with sex and affection within the relationship), and overall satisfaction within the relationship (i.e., DAS total score). In addition, researchers indicated higher levels of marital adjustment appeared to be associated with lower levels of financial concerns and psychological symptoms due to the TBI as well as milder TBIs. Kieffer-Kristensen and Teasdale (2011) investigated marital adjustment (DAS) and psychological well-being by comparing a parent surviving a TBI to another parent diagnosed with diabetes (type I or II). To participate, parents had to be married and also have school aged children living within the home. Results of this study indicated that the caregiving spouses of TBI reported lower levels of marital satisfaction; more specifically nearly half of these caregiving spouses reported pronounced problems within their marriage compared to only 10% of the caregiving spouse of individuals with diabetes. Both of these studies were limited by small sample sizes, restricted inclusion criteria, and that participants were only surveyed at one point in time. These limitations similar to the current study restrict the generalizability of results. Future research which includes larger sample sizes of couples of TBI is needed to further confirm these findings.

### Long-term Stressors

The last research question sought to better understand the long-term stressors that spouses continue to report as their marriage has endured. A unique aspect of the current study was using two methods to assess stressors, as participants responded to two

narrative prompts and rank ordered a list of common stressors of caregivers of TBI. The themes gathered from participants' responses support the existing research literature as well as provide new information on long-term stressors.

The theme of "Symptoms Resulting from TBI" was the primary stressor reported by 7 spouses. Participants described continued challenges with long-term symptoms of TBI including cognitive changes, memory loss, and communication and also emotional changes in their spouse including depression and symptoms of post-traumatic stress. Three spouses described primary stressors in "Personality Changes" (e.g., unpredictable behavior) in their spouse who survived severe TBI. Spouses described continued difficulty coping with unusual and unpredictable behaviors of their spouses, which may be illogical or irrational. The caregiving spouse may have needed to adjust care or deal with a decision or an action their spouse took which was uncharacteristic of their husband or wife.

"Caregiver Worries" (e.g., tasks/household duties, caring for a spouse) was primary for 2 spouses. Participants indicated having difficulty in completing general household tasks and concerns regarding the well-being/safe keeping of their spouse. Spouses' responses within this theme appeared to suggest that spouses worried about their partner's wellbeing as well as balancing the roles and responsibilities without assistance from their spouse.

The themes of "Symptoms Resulting from TBI," "Personality Changes," and "Caregiver Worries" support the research literature documenting the difficulties spouses experience due to multiple and permanent changes in the domains of cognition, personality, and behavior after TBI. It has been well documented with the research

literature that caregivers report long-standing difficulties with the often permanent changes to their spouses' cognitive functioning, most specifically attention, concentration, processing speed, memory, communication, initiation, and reasoning (Brooks, 1984; Oddy et al., 1985). In her historic contribution to the research literature on caregiver's experience with individuals with TBI, Lezak (1978) described the many personality changes, often unpredictable in nature, given the permanent injury to the brain. In addition, Lezak (1978) documented that caregivers frequently report having difficulty coping with their spouses' impulsivity, inappropriate behavior, fear of new situations, and embarrassing behavior at social gatherings. Furthermore, in her work based on interacting with families, children, and spouses, she indicated that due to these cognitive changes, caregivers take on responsibilities of the household, work responsibilities, have diminished social support, and on top of their caregiving role, often receive the brunt of their spouses' irrational and unpredictable emotions and impulsive decisions.

“Financial Concerns” (e.g., lack of money or resources for needs) was the primary stressor of 4 spouses. Financial concerns included worries about income and money. Participants' responses within this category as well as average income reported agrees with the research literature that spouses have difficulty given the potential loss of income from the injured spouse and continue to have concerns that the family will be able to meet all financial obligations. As mentioned earlier, participants within this study reported annual incomes significantly lower than the national average. In addition, spouses reported that the majority of their spouses were unable to return to work and thus the caregiving spouses within this sample work full time jobs in addition to their roles as



caregiver. It is unclear whether caregivers are accessing services within their community, which may also place another financial responsibility on the caregivers.

This theme supports other recent research on relational stressors within marriages after TBI. For example, Hammond et al. (2011) conducted two gender-specific focus groups, each consisting of five spousal caregivers of individuals who survived a TBI. Time since injury for wife caregivers ranged 6 to 12 years and husband caregivers 4 to 9 years. Spouses in both groups discussed feeling overwhelmed by financial responsibilities, specifically that they had increased responsibility managing finances, paying bills, and the added fear that their spouse due to their unpredictability and after their injury were no longer able to understand or have the ability to control spending. In addition, spouses reported fear that their surviving spouse may place them in larger financial debt. Wife caregivers also expressed concerns at having to shoulder the bulk of employment responsibilities.

The theme of “Isolation” (e.g., unable to maintain friendships/connection with family) was primary for 3 spouses. Responses within in this theme revealed that spousal caregivers had few opportunities to engage with friends/family or spend time on hobbies or leisure activities. In addition, this theme also included the loss of friends for their injured spouse. This theme is also consistent with the research literature which suggests both surviving spouses of TBI and caregivers are trying to cope not only with changes in their spouse, but also with a loss of social support and having limited ability to engage in activities within the community (Livingston et al., 1985; Machamer et al., 2002).

The theme of “Future Worries” (e.g., will this happen to me again?) included the unanswered questions of spousal caregivers and the potential ambiguous path of caring

for their injured partner. The one response within this theme suggests that spousal caregivers also have worries about their spouse becoming reinjured. This theme may be an important consideration to future research of long-term caregiving spouses, given this concern is novel to the research literature of spousal stressors. Given the dearth of studies focused on the long-term consequences of brain injury with loss of consciousness and long-term stressors of caregivers of severe TBI, these concerns of both caregiving spouses and TBI survivors remain largely unknown. For example, there are only two studies to date focusing on the risk for re-injury among individuals who survived a severe TBI. In addition, a growing body of research examining aging TBI survivors suggest this population is more at risk for Alzheimer's Disease (Fleminger, Oliver, Lovestone, Rabe-Hesketh, & Giora, 2003), dementia (Lye & Shores, 2000), Parkinson's disease (Lee, Bordelon, Bronstein, & Ritz, 2012) and medical morbidity (Harrison-Felix, Whiteneck, DeVivo, Hammond, & Jha, 2006). Given the limitations in methodology of this study, these results should be interpreted with caution; however, this information is suggestive for future contributions about long-term care and continued worries of caregivers to both re-injury and possible emerging illness with age that may be associated with survivors of TBI.

In addition to the open-ended responses coded for primary stressor, participants also provided responses to an open ended question asking for "any additional information that they would like to share." These responses reflect the continued toll that caregiving has had on the caregiving spouse who in general is feeling "worn out." In addition, responses also raises questions regarding how both spouses are coping not only with the TBI, but increased health concerns as they and their spouses' age. Two of the caregiving

spouses indicated their spouses need additional care outside of the home, one at an adult day center and another in a nursing home. One of the spouses indicated that she is solely responsible for decision making. Spouses also mentioned additional coping strategies such as relaxing with their spouse, playing games together, having faith, expressing appreciation for their spouse and support systems as well as continued commitment to the relationship.

Consistent with reported primary stresses themes, the ranked stressors show that multiple stressors continue to have lasting impact on the marital relationship. The top ranked stressor was unpredictable behavior, followed by changes in personality. The third ranked stressor was work responsibilities; followed by finances/income, feeling disconnected from their spouse/partner, sex/intimacy, and their continued role of being a caregiver. These results are consistent with findings from previous investigations (Zasler & Kreutzer, 1991). Additional responses written in by participants suggest spousal caregivers may feel emotionally and intimately disconnected from their spouse given difficulty communicating and lack of in-depth conversation. Spouses, although in a relationship, may feel an increased sense of loneliness as opportunities to connect are rare. These results were consistent with findings from previous investigations (Gosling & Oddy, 1999; Hammond et al., 2011). Although spouses in this study are unique in the length of time since their spouses' injury, despite the longevity of their relationship they continue to cope with stressors that have been documented since their spouse returned home from the hospital. Thus, the results of the analysis of stressors support the notion that caregiving stressors of individuals with TBI may not improve over time (Thomsen,

1984), which further provides encouragement for appropriate services to caregivers and families of TBI throughout the survivors' lifespan.

### Study Limitations

This study has several limitations in both measurement and design issues that need to be considered. Measurement limitations include issues with self-report instruments and internal consistency concerns. Regarding self-report instruments, several participants did not complete all items on the DAS as questions and response items did not describe their particular relationship situation (i.e., initial directions for the DAS ask participants about the extent they disagree with their spouse as well as items addressing their sexual relationship). A couple of participants provided feedback that their spouse's injury was so severe that the extent to which they disagree is a moot point. In addition, spouses who survived a severe TBI may lack the ability to engage in sexual relationships due to no longer living within the home, severity of the injury, or increased risk factors of developing neurodegenerative diseases.

There were also concerns with internal consistency levels of the Brief COPE-Dysfunctional scale with a coefficient alpha level of .62; as other studies using the Brief COPE with TBI samples report alpha levels for dysfunctional coping strategies as .75 (Cooper et al., 2008a). The lower than optimal alpha level within this study is an important limitation because of the low sample size and concerns regarding the items on this scale truly reflecting participants' coping approach within dysfunctional coping strategies given that items were not highly correlated with one another. This alpha level also suggests that findings regarding this scale should be interpreted with caution. This study is also limited as the Brief COPE was the only measure used to address coping

strategies by participants. Future research may also consider using additional measures to address coping approaches within marital and family relationships where one spouse has survived a TBI.

The other limitations include issues with sampling and generalizability. Regarding sampling, it should be noted that all participants of this study self-selected. Furthermore, participants were recruited solely through online methods, which require participants have technical knowledge and access to a computer. Given this requirement, the sample may be biased toward individuals who are more highly educated and have more financial means. In addition, participants were primarily recruited from the Brain Injury Alliance of Minnesota and the Brain Injury Association of Iowa as well as online support groups at Caring.Com, and their Facebook pages. Thus it is possible that this sample represents a segment of long term spousal caregivers who are more physically and mentally healthy, have more positive coping strategies, and have more stable and satisfying marriages. Limitations of the sample also include that the majority of the participants of this study are Caucasian, and thus the results do not include perspectives from caregiving spouses of other ethnic and racial groups. These factors contribute to increased concerns of generalizability of the results.

Another sampling concern was the strict criteria of the study, which required spouses to be married post-injury for at least 10 years and also their spouse had to have a loss of consciousness for at least 6 hours. Sixty-nine individuals indicated that they did not meet study criteria and only 21 participants were able to be included within the study. While these criteria provided opportunities to investigate an unusual and unique sample, it restricted the study to caregivers of more severe cases of TBI, and by default may have

excluded a majority of caregiving spouses who could have added further insights into caring for their spouse. A different sampling concern was also noted as 16 individuals who accessed the study did not complete any of the measures, suggesting interest in the study, but perhaps lack of time to complete.

More recent studies of spousal caregivers of TBI (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; Hammond et al., 2011), recommend a holistic approach to investigating marital adjustment in couples living with TBI. These researchers indicated a limitation to studies of marital stability and satisfaction in couples with TBI is that research typically gathers information on one spouse's perspective. Godwin et al., (2011) posits that research focused on only one spouse is more of an investigation of spousal perception regarding the quality of the marriage.

#### Implications for Clinical Practice

The findings of this study have significant clinical applications in providing resources, support, and interventions for long-term spousal caregivers of severe TBI. First, results suggest that caregiving spouses, although generally reporting good physical and mental health quality of life, indicate reduced marital satisfaction and describe numerous stressors which continue to impact the quality of their marriages. These factors suggest that spouses may experience chronic stress in their roles as both a caregiver and a spouse. Second, coping strategies, more specifically emotion-focused strategies, appeared to be associated with increased marital satisfaction while higher use of dysfunctional coping strategies seemed to be related to reduced mental health quality of life. Thus, it is vitally important to target interventions addressing stress and coping, rather than only addressing spouses' perception of the stability and quality of his or her marriage.

Interventions focusing on stress reduction while simultaneously creating new strategies for coping may assist spouses in obtaining more satisfaction with their marriages. For example, mindfulness meditation interventions may be particularly helpful in fostering acceptance and distancing one's self from distressing experiences, feelings, and negative emotions, while simultaneously deepening one's sense of self-compassion. Additionally, interventions which incorporate the union of yoga and meditation may be especially helpful for stress-reduction while also providing access to a supportive group of individuals within the community. Research evidence, albeit limited in regards to caregiving populations of individuals with cognitive disorders, suggests improvements in both psychological and physiological well-being of individuals who practice mindfulness for chronic stress (Kabat-Zinn et al., 1992) as well as among caregivers of individuals with dementia when individuals engage in a meditative practice which incorporates yoga (Waelde, Thompson, & Gallagher-Thompson, 2004) or using brief mindfulness approaches (Hoppes, Byrce, Hellman, & Finley, 2012). Notably, both Mindfulness Based Stress Reduction and the Inner Resources, a manual based a psychotherapeutic yoga and meditation intervention program, incorporate gentle yoga with meditative practices. To the author's knowledge there are no current research articles to date which focus on mindfulness based stress reduction or yoga for caregivers of individuals with severe TBI.

Counseling psychologists approach the therapeutic relationship from a holistic and strength based lens. Conceptualizing the results of this study from this perspective offers several implications. First, one of the most vital tools of psychologists and other helping professions is their ability to listen without judgment, the lens of acceptance. As

such, counselors have the ability to hear their clients' stories truly for the first time, and use their knowledge base of both clinical and research experience to inform their ability to "dig deeper." This skill is especially important, as, although there are commonalities in symptoms of TBI and among caregiving spouses, each individual may present with a unique constellation of symptoms, which occur in the context of the caregiving spouse's multiple roles. The ability to tell one's story, in the therapeutic relationship, is symbolic for the caregiving spouses to not only reach out for support, but also to begin testing whether or not "someone" can understand.

In addition, from this insider's perspective, psychologists will also be able to understand multicultural considerations and adjust psychotherapeutic interventions accordingly. Throughout the research literature, caregivers of TBI underscore the feelings that their unique situations are not understood and, similar to their surviving spouse, caregivers become more isolated as social interactions diminishes and others do not fully comprehend the experiences and obligations of being a caregiver (Johnson & Catalano, 1983; Lezak, 1978). For example, TBI being described as "the silent epidemic" is suggestive of the impact of TBI to be misperceived for both caregivers and survivors.

Robins (2012) conducted a qualitative study with 13 couples living with TBI. The themes established in this study suggested that couples need more comprehensive resources at all stages of adjustment as well as providers who have the knowledge, training, and ability to address the impact of TBI on relationships. Furthermore, participants desire professionals who have competency in family supports and resources for caregivers, as this not only increases interpersonal connections for both individuals in



the relationship but also is associated with the well-being and recovery of the survivor of TBI (Robins, 2012).

Second, through the development of a strong therapeutic alliance, which serves as a microcosm of the caregiving spouse's interactions with others—the psychologist may assist the client in connecting with others and engaging in emotion focused and active coping methods. The role of the psychologist may include: helping clients learn how to provide others psycho-education on their experience of being a caregiver for an individual with a severe TBI; providing opportunities for expansion of vulnerability and intimacy in connecting with others through interpersonal risks and challenges (i.e., Interpersonal Psychotherapy and Functional Analytical Psychotherapy techniques); giving interpersonal feedback on engaging in asking for help and also connecting with others more deeply; and begin enlisting the help and support of others through extended friends/family as well as their community. In addition, psychologists can reinforce caregivers to take time to engage in self-care (e.g., beginning a hobby, joining a book club, yoga). This self-care may be increasingly more possible if the spouse has been able to locate resources or enlist the help of others.

Third, counselors have a unique opportunity to reinforce positive aspects of caregiving as well as the spouses' resiliency and commitment to their partners. Several participants of the current study expressed appreciation for their spouses and provided descriptions of activities they enjoyed doing with their spouses. These descriptions shed light on how spouses who have remained married for longer than a decade post injury have adapted, and found activities to engage in with their spouses that were enjoyable. The majority of the spouses within the study expressed commitment to their marriage and

a willingness to continue within the relationship. Psychologists have the opportunity to further encourage and support not only the spouse, but the relationship through exploring relationship dynamics prior to the injury and how the spouse changed after the injury. This reflection may be especially important given that spouses continue to report difficulties with the cognitive, behavioral, and personality changes to their spouses.

### Implications for Future Research

Future research is needed to address the short-comings of this study and the relevant literature. This study provides evidence for further exploration of the relationship between marital satisfaction, adjustment, and stability, coping, continued stressors, and quality of life issues related to long-term spousal caregiving of individuals with severe TBI. Future research can expand upon these findings by focusing on variables that may mediate the relationship between marital satisfaction, coping, and stressors. Second, future studies should specifically investigate the effectiveness of certain measures to better investigate marital adjustment and satisfaction among severely injured populations.

The present study demonstrated that long term spousal caregivers of individuals of severe TBI are generally somewhat unsatisfied with their marriage. Past research has primarily focused on marital stability in caregivers of TBI within the first 5 to 8 years of marriage. As such, future research on marital satisfaction and adjustment with couples living with severe TBI could extend the perceptions of the relationship by including the surviving spouse. Given that in some cases of severe TBI the spouse has survived significant injuries, modifications in the study may be necessary to include appropriate measures or consideration of qualitative research or implementing mixed methods.

More recently, Hammond et al. (2011) conducted two gender specific focused groups to examine marital satisfaction and stability. This study provided interesting results suggesting that individuals' reactions and coping strategies towards TBI may be

influenced by gender differences. For example, the study indicated female caregiving spouses felt unappreciated since the surviving spouse's injury as they are unable to meet previous expectations of interactions with their caregiving spouse. In contrast, male caregivers endorsed more positive appraisals. In addition, positive feelings regarding caregiving may increase when the spouse's injuries are more visible. Robins (2012) investigated intimacy with couples living with TBI through semi-structured interviews as well as a follow-up semi-structured interview at 6 months. Results from this study, similar to the current study, suggest that couples are resilient, but marital quality was impacted by the couples' access to social support and resources, psychological history, pre-injury coping, and communication. In addition, participants also suggested that misconceptions of TBI as well as comparisons of the surviving spouse prior to the injury may negatively influence marital quality.

Both of these studies lend support to the increased richness of the data when both spouses are included in the investigation. Future research targeting both spouses could expand our understanding of how couples discuss and evaluate coping strategies collaboratively as well as how coping strategies may evolve as time after surviving the injury has increased. In addition, as the majority of studies have focused on female caregivers of husbands with TBI, studies which are able to increase participation of female survivors of TBI and their husbands will assist researchers in their ability to have more comparable samples to examine differences in marital adjustment and quality between genders. Researchers may also consider employing longitudinal design to help elucidate how adaption and flexibility in coping relates to marital satisfaction in couples surviving severe TBI. In addition, the most current studies within the literature suggest conceptualizing results within the framework of a theory of marital satisfaction, which would lead to deeper understanding of the "lived experience" of couples living with TBI as well as assist in the validation of measurements for research and clinical purposes (Godwin et al., 2011). For example, future researchers may wish to consider using The

Family Adjustment and Adaptation Response (FAAR) model developed by McCubbin and Patterson (1983) to better assess the marital relationship, especially if both spouses as well as other family members are included within future research. This model is especially appropriate for use within couples living with TBI given the frequent sudden, unexpected, and life altering course of surviving TBI on the family and marital relationship. McCubbin and Patterson's model suggests that the onset of a non-normative stressful event(s), which is sudden and/or unexpected combined with normative stressors (i.e., typically found in daily life, expected transitions within relationships and daily life roles) leads to the "pile up of demands" (Lavee, McCubbin, & Olsen, 1987, pp. 858). The pile up of demands are defined as the multiple stressors that families and couples may encounter as they adjust to the transitions resulting from the non-normative stressor as well as maintaining or adapting to changing circumstances within their previously established roles and experiences (Lavee et al., 1987). In addition the pile up of demands is directly influenced by the family's resources, previous family relationship strains (including the marital relationship), the strategies with which the family cope, and the inherent unanswered questions and life changes resulting from the non-normative event. The model described by McCubbin and Patterson (1983) has utility to assist researchers to better understand how couples and families use resources over the long term and how these coping strategies and resources may be flexible to adapt to the multiple normative and non-normative stressors that families and couples living with TBI continue to navigate throughout the rest of the family's life as well as the marital relationship. Future research of spousal caregivers of TBI would greatly benefit from increased sample sizes to further understand if results of smaller studies are generalizable to the population of long-term caregivers.

From an interventional perspective, there is a dearth of studies investigating implementation of interventions and resources to assist caregivers of TBI (Boschen et al., 2007; Kreutzer et al., 1994). To the author's knowledge, there are no pilot program

studies on long-term caregiving for spouses with TBI at the community level, although the majority of research suggests spousal caregivers continue to report needing on-going resources and support (Hammond et al., 2011; Robins, 2012). Future research, as discussed within this section, would provide valuable information to inform the development of pilot studies as well as provide increased opportunity to evaluate the effectiveness of psychological interventions (e.g., Mindfulness/Meditation Programs, Interpersonal Psychotherapy, Cognitive-Behavioral Therapy approaches) for long-term spousal caregivers of TBI.

### Conclusions

Several conclusions were drawn from this study. First, age of the caregiver, number of years married, and length of the marriage post-injury has a positive association with marital satisfaction. Second, long-term spousal caregivers of individuals with severe TBI typically use more positive coping strategies and tend to experience good physical and mental health quality of life, although endorse somewhat lower levels of satisfaction within their marriage. Results also indicate that long-term spousal caregiver's level of marital satisfaction is similar to that of other spousal caregivers of individuals with chronic illness. Third, the study also demonstrates that stressors reported within the first decade of marriage continue to be a challenge for long-term caregiving spouses of severe TBI. The present study also marks the first investigation known to the author that examines marital satisfaction in a sample of very long-term spousal caregivers of severe TBI. Taken together, further investigation of marital satisfaction and adjustment in enduring long-term caregivers of severe TBI is needed to better understand how caregivers adapt, and how flexibility in coping may impact positive appraisal of the relationship. In addition, clinicians and researchers need to further investigating types of resources utilized and how the need for resources, support, and access to support may change over time, especially as both caregiver and surviving spouse age.

APPENDIX A  
RECRUITMENT LETTER

Dear Executive Director of the Brain Injury Association of Iowa,

I am currently recruiting spouses and partners of individuals who are survivors of moderate to severe traumatic brain injury (TBI) to participate in my dissertation research. The study is investigating the relationship between stress and coping strategies related to relationship satisfaction. We hope that this research will assist health care professions to better understand the evolving circumstances, stressors, and coping strategies of spouses/partners who have remained within committed to their relationships for 10 years or more after the onset of their spouses or partner's injury. As a result, we hope practitioners will be able to improve treatment modalities and resources for families and spouses impacted by TBI. I would appreciate any help you can provide by passing the invitation along to potential participants. If you are eligible to participate in the study, you are also invited to participate.

Please distribute the email information and online survey link below to members of your organization. Thank you for any assistance you can provide. If you have any questions, please contact me using the information below.

*EMAIL SUBJECT LINE – Research Study about Relationship Satisfaction*

*Dear Spouse or Partner of TBI survivor,*

*You are invited to participate in a research study being conducted by investigators from the University of Iowa. The purpose of the study is to better understand the coping strategies and marital satisfaction of committed couples who have remained together for at least ten years since their partner or spouse sustained his or her moderate to severe TBI.*

*I am inviting spouses and partners of individuals who are survivors of moderate to severe TBI and who have remained married or within a committed relationship since the injury occurred. Approximately 100 people will take part in this study at the University of Iowa.*

*If you agree to participate, I would like you to complete several online questionnaires. It will take approximately 25 to 30 minutes to complete the questionnaires. You may skip any questions that you prefer not to answer. You will not be paid for being in this research study. After you complete the questionnaires, there will be no additional contact from any member of the research team.*

*If you have any questions about the research study itself, please contact JoAnna Argüello, 361 Lindquist Center, Iowa City, IA at 507-319-3134 or [joanna-arguello@uiowa.edu](mailto:joanna-arguello@uiowa.edu).*

*To access the study, please follow this link to the study website. You will be asked to read additional information about the study before beginning the study questionnaires:*

[https://uiowa.qualtrics.com/SE/?SID=SV\\_4GVT1xUfH2I7tRi](https://uiowa.qualtrics.com/SE/?SID=SV_4GVT1xUfH2I7tRi)

*Questions may be addressed to the Primary Investigator, JoAnna Argüello ([joanna-arguello@uiowa.edu](mailto:joanna-arguello@uiowa.edu)) or her adviser, Elizabeth Altmaier ([Elizabeth-altmaier@uiowa.edu](mailto:Elizabeth-altmaier@uiowa.edu)).*

*Thank you for your time and participation.*

*JoAnna Argüello*

*JoAnna Argüello, B.S.  
Doctoral Candidate  
University of Iowa  
Department of Psychological and Quantitative Foundations  
361 Lindquist Center  
Iowa City, IA  
507-319-3134  
[joanna-arguello@uiowa.edu](mailto:joanna-arguello@uiowa.edu)*

## APPENDIX B

## INFORMED CONSENT

**Informed Consent**

**Thank you for your interest in our study. To be eligible for participation in this study you agree that the following are TRUE for you:**

- 
- **You and your spouse/partner been married or have been in a committed relationship for 10 years or longer since he or she survived TBI**
- 
- **Your partner/spouse in a coma(unconscious) for at least 6 hours after his or her injury**
- 

**If both criteria are TRUE for you, then** you are eligible to participate in our study. Please read the following information about the study and, if you agree to participate, follow the instructions to access the study survey.

---

**Project Title:** The Other Side of the “Silent Epidemic”: Caring for a Spouse or Partner with a Moderate to Severe Traumatic Brain Injury Ten Years Later

**Project Investigator:** JoAnna Argüello

This is a research study. The purpose of this research study is to better understand the coping strategies and marital satisfaction of committed couples who have remained together for at least ten years after their partner or spouse sustained his or her traumatic brain injury (TBI). We hope that the information collected in the study will help researchers and clinicians better understand the experience of spouses and partners who care for their loved one and how spouses and partners cope with the changes of TBI throughout their MARRIAGE or committed relationship.

I am inviting spouses and partners of individuals who are survivors of moderate to severe TBI and who have remained married or within a committed relationship for at least 10 years since the injury of their spouse/partner occurred. Approximately 100 people will take part in this study conducted by researchers at the University of Iowa.

If you agree to participate, I would like you to answer an online survey with questions about mood, stressors, coping techniques, satisfaction with your relationship, and everyday life. We will also collect information about you and your spouse/partner including age, gender, education level, employment, and about your family. You are free to skip any questions that you prefer not to answer. It will take approximately 25 to 30 minutes to complete this survey.

I will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To help protect your confidentiality, we will not collect your name or any identifying information about you in the survey. It will not be possible to link you to your responses. We will store all study data in



password protected files and password protected computers. If I write a report or publish the results of this study I will do so in such a way that you cannot be identified.

Because the survey ask you about personal information, it is possible that you may feel uncomfortable answering some of the questions. You are free to skip any questions that you would prefer not to answer. If you have any concerns about your responses to the questions, please contact the Brain Injury Association of Iowa at 1-800-444-6443 or the Crisis Line of Johnson County 319-351-0140 to further discuss your concerns or to assist you in finding services and/or local support groups.

You will be asked to provide information over the internet. Information provided via the internet may be viewed by individuals who have access to the computers where the information is being collected or stored. It is also possible that your responses could be viewed by unauthorized persons. We will use a secure website for the online survey and the website will not collect any information that could identify you or link you to your responses.

You will not benefit personally from this study. However, I hope that others may benefit from the information learned in this study because the information will be used to improve treatment modalities and resources for families and spouses impacted by TBI.

You will not be paid for participating in this study. There are no costs to participating in the study.

Your participation in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify. You may withdraw from the study at any time by closing your web browser without submitting your survey.

If you have specific questions regarding this study or to report any research related problems, you may contact the principle investigator, JoAnna Argüello, BS, at 507-319-3134 or [joanna-arguello@uiowa.edu](mailto:joanna-arguello@uiowa.edu). You may also contact her faculty advisor Dr. Elizabeth Altmaier at 319-335-5566.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail [irb@uiowa.edu](mailto:irb@uiowa.edu). To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to complete the survey, please select "Yes" and click the ">>" button which take you to the study survey. By selecting "Yes" you indicate that you answered true to the eligibility questions and that you consent to participate in this research. If you wish to have a copy of this information for your records, please print this page before going to the survey. If you do not wish to participate in the study, you may close your web browser window now or at any time before submitting your survey responses. Thank you very much for your consideration of this research study.

Sincerely,

JoAnna Argüello  
Doctoral Candidate, Counseling Psychology Program  
Department of Psychological and Quantitative Foundations  
University of Iowa

APPENDIX C  
DEMOGRAPHIC QUESTIONNAIRE

To begin, I will be asking you some basic questions about yourself, your spouse, and your family.

1. Your Gender \_\_\_Female \_\_\_Male

2. Your Racial/Ethnic background?

\_\_\_Caucasian

\_\_\_African-American

\_\_\_Hispanic

\_\_\_Asian-American/Pacific Islander

\_\_\_Native American

\_\_\_Biracial, (please describe): \_\_\_\_\_

\_\_\_Other

3. Your current age \_\_\_

4. Your spouse's current age \_\_\_\_\_

5. Your spouse's gender \_\_\_\_\_

6. Your spouse's Racial/Ethnic Background

\_\_\_Caucasian

\_\_\_African-American

Hispanic

Asian-American/Pacific Islander

Native American

Biracial, (please describe): \_\_\_\_\_

Other

7. What is your spouse's highest level of education?

Grade School Completed

Some high school

High School Diploma / GED

Some College

College degree or higher

8. What was your spouse's occupation at the time of the injury?

\_\_\_\_\_

9. Is your spouse able to work at this time?

Yes

No

10. Your age at the time of your spouse's injury \_\_\_\_\_

11. Your spouse's age at the time of his or her injury \_\_\_\_\_

12. How was your spouse injured? \_\_\_\_\_

14. Do you have any children/stepchildren \_\_\_\_\_

a. If so, how many children/stepchildren do you have \_\_\_\_\_

b. How old are your children/stepchildren currently \_\_\_\_\_

c. How old were your children/stepchildren at the onset of your spouses' injury \_\_\_\_\_

d. Were your children/stepchildren living with you at least  $\frac{1}{2}$  time during your marriage?

\_\_\_ Yes

\_\_\_ No

15. How long have you and your spouse been married \_\_\_\_\_

a. How long had you been married at the time of your spouse's injury \_\_\_\_\_

b. Had you been married previously \_\_\_\_\_

c. What is your current living situation?

Describe \_\_\_\_\_

16. What is your highest level of education?

\_\_\_ Grade School Completed

\_\_\_ Some high school

High School Diploma / GED

Some College

College degree or higher

17. What is your current occupation?

---

18. What is your employment status?

Full-time

Part-time

Retired

Unemployed

19. Where you employed previous to your spouse's injury?

20. Which of the following best describes your household income?

Less than \$20,000

\$20,000 - \$29,999

\$30,000 - \$39,000

\$30,000 to \$39,999

\$40,000 to \$49,999

\$50,000 or 59,999

\_\_\_\$60,000 or 69,999

\_\_\_\$70,000 or 79,999

\_\_\_\$80,000 or 89,999

\_\_\_\$90,000 or more

APPENDIX D  
STRESS QUESTIONNAIRE

Please describe the one stressor that has had the most impact on your relationship / marriage since your partner / spouse's injury?

The following list represents potential stressors that a couple may experience due to one partner/spouse surviving a moderate to severe TBI. Please rank-order them in the best way that describes your actual situation. As your experience may be unique, not all stressors may apply. Please feel free to use the blank spaces to add your experience of stressors as needed. Rank 1-10, with 1 being the stressor that is most distressing and 10 being the least distressing.

1. Changes in your spouse/partner's personality
2. Dealing with your spouse/partner's unpredictable behavior or emotional changes
3. Work responsibilities
4. Household responsibilities
5. Finances/maintaining income
6. Dealing with health care/social service system
7. Continued roles as a caregiver to your spouse/partner
8. Parenting
9. Feeling disconnected to your partner/spouse
10. Sexuality/intimacy within the relationship/marriage
11. Strained relationship with extended family members (e.g., in-laws)
12. Social isolation/feeling that you have few or no one to talk to about your experience or situation
13. \_\_\_\_\_
14. \_\_\_\_\_
15. \_\_\_\_\_



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