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# Stress and Loss Experiences of Families of Survivors of Traumatic Brain Injury

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Stress and Loss Experiences of Families of Survivors of Traumatic Brain Injury

Submitted by Tracy J. Ketzbeck  
May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee, and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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**Abstract**

The purpose of this research study was to explore how traumatic brain injuries affected families in which there was a survivor. It was the researcher's desire to learn what stress and loss looked like in families with a traumatic brain injury survivor. Data was gathered in a qualitative study in which nine individual family members of survivors of traumatic brain injury were interviewed. The family members were asked 13 questions in a semi-structured interview style. The qualitative data was analyzed using content analysis. Emerging findings indicated that stress and loss is very different for each family. Another emerging finding was financial assistance, discharge assistance, and mental health services were difficult to obtain in rural areas. Future research should consider the effects of the gender of the survivor on how the family system adapts, as well as whether the relationship of the caregiver to the survivor affects the family system. This study also highlights a potential need for a professional association concerning traumatic brain injury in order for better training and collaboration of social workers who work with survivors of traumatic brain injury and their families.

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Traumatic brain injury (TBI) is a hidden disability that affects millions of people. Every 15 seconds someone in the United States sustains a traumatic brain injury (Shore, 1995). This means every 15 seconds a family's life could change because of a motor vehicle crash, a fall, or injury due to a firearm (Shore, 1995). Traumatic brain injury is now the leading cause of death in adults under the age of 40, and is becoming a significant economic and physical cost to society (Gentleman, 2001). It is estimated that the life time cost to survive a TBI is \$4.5 million per individual (Degeneffe, 2001).

The special nature of traumatic brain injury presents challenges for the medical personnel and the families of the survivors. According to the Center for Disease Control and Prevention (CDC, 2011), there is an estimated 1.7 million people who sustain a traumatic brain injury (TBI) yearly. Out of those millions, 52,000 die and over 1.5 million of them are either treated and released from emergency rooms or are hospitalized with the possibilities of lifelong disabilities. Children adolescents and adults from 0 to 4 years, 15 to 19 years and over 75 years of age are most likely to experience a TBI. Males have higher rates of TBI, often during years when they are most productive in society and in many cases where they are contributing the most to the family income. This loss of productivity cost almost \$60 billion in 2003 (CDC, 2011).

According to Bishop, Degeneffe, and Mast (2006), a traumatic brain injury occurs when an external force acts on the skull causing. A traumatic brain injury includes damage to the brain either through external or internal insult such as a blow to the head, excessive force, bleeding, or a virus is a brain injury. The external force can either be penetrating or cause the brain to move back and forth. Brain injuries can be caused by falls, motor vehicle accidents, lack of oxygen, strokes, tumors, illness, or violence such as



through abusive head trauma or a gunshot wound (Brain Injury Association of Minnesota, n.d.). Brain injuries can range from mild to severe. TBI can result in lifelong neurobiological and neuropsychological damage with lifelong deficits.

Families are rarely prepared or fully informed about the nature of the TBI. This may be due to a variety of reasons. In part this could be attributable to the different expressions of a TBI based on the various areas in which the brain can be injured (Degeneffe, 2001). However, another major reason may be the focus on the present crisis in the context of emergency room. If the families start in an emergency room, many of their long-term questions may not be answered due to the focus of the medical team on the immediate injury. Families often comment to staff about lack of communication in the critical stages that underline long term effects. Some of that may be because many medical professionals are not trained in giving bad news (Fineberg, Kawashima, & Asch, 2011; Lefebvre & Levert, 2006).

Research is showing that families may experience psychological distress, marital discord, and poor family functioning immediately after the TBI and it may continue for years (Carnes & Quinn, 2005). Bishop, Degeneffe, and Mast (2006) assert, it is important for social workers to intervene early in the acute and rehabilitation stages because of unintended family discord could affect the survivor's rehabilitation prognosis.

The survivor of the TBI and their family may not only undergo the trauma of the brain injury, they may also experience a variety of social and emotional strains, including complicated grief and ambiguous loss. According to Worden (2009), complicated grief is when one experiences numbness, detachment from others, and difficulty in accepting the death of a loved one. In the case of the TBI, the death is not physical death of the

survivor, but the loss of their job, hobbies, or other family functions the survivor and family members may no longer be able to do.

Ambiguous loss is when the survivor or family members are experiencing the psychological loss of a person through some event or illness such as a TBI (Boss, 2006). The survivor of a TBI physical present in their family's life, but they may not be there psychologically due to memory loss or coma. The survivor may no longer be able to participate in family activities such as holiday events or even as simply as joining the family at the dinner table and discussing the days events. There also could be role changes such as the survivor no longer able to balance the check book or take the garbage out to the trash can. This type of loss can traumatize a survivor, friend, or family member to the point in which they lose all coping skills and their "resilience is lost in a frozen iceberg of grief" (Boss, 2006, p 26).

According to Landau and Hissett (2008), ambiguous loss is an important concepts for clinical social workers to know because of the implications on family relationships and how important it is for family involvement in the treatment of TBI survivors. It is also important to clinical social workers because the family of a survivor may describe the survivor as a "stranger" which could have effects of grief on the entire family (Gosling & Oddy, 1999). This grief is different than a traditional death because of the lack of official notice or ritual for this unclear loss, so traditional therapies used in grief may not work (Boss, 2010).

Due to the issues related to TBI, the purpose of this research is to examine the special nature of TBI, how TBI affects the family system and caregivers, and what are the current and promising practices and promises for families and their survivors after a TBI.

### **Literature Review**

The families of survivors who suffer a traumatic brain injury encounter many challenges greater than they could ever imagine when they first learn of the traumatic brain injury. There is much literature available regarding the issues families face after they learn about this life changing event (Duff, 2006; Bishop, Degeneffe, & Mast, 2006; & Serio, Kreutzer, & Gervasio, 1995). There are many studies specific to survivors of traumatic brain injuries and their families, while other information has come from hospital and rehabilitation staff, grief/loss counselors.

For the purpose of this research, the literature is reviewed in four categories: 1) the special nature of traumatic brain injury; 2) the effects family and caregivers; 3) grief and losses within the family; 4) resilience of the family caregivers; and 5) current practices and promising options regarding the support of family caregivers.

#### **The Special Nature of Traumatic Brain Injury**

Brain injuries are unlike broken arms because the cells do not regenerate. People who survive a traumatic brain injury and their families may go through years of physical, cognitive and emotional changes. Some of the lasting physical effects of a TBI can be seizures, blurred vision, fatigue, headaches, muscle control problems, sexual dysfunction, and trouble with balance and dizziness. There are also psychological impacts including behavioral and personality changes, cognitive changes and emotional changes. In terms of the behavioral and personality changes impulsivity, anger outbursts, and inappropriate social behavior are common (Uomoto & Uomoto, 2011), however, the behavioral and personality changes are less understood and less researched (Brooks &

McKinlay, 1983). Some of the cognitive changes are short-term or long-term memory loss, word finding troubles, difficulty in speech, difficulty in organization or problem-solving, and trouble with concentration. Some of the emotional changes are depression, grief over losses, impatience, impulsiveness, emotional flatness, and lower tolerance of stress (Brain Injury Association of Minnesota, n.d.).

The survivor and families are not only going to be cognizant of the physical, psychological, cognitive changes, and emotional changes they are also going to learn about how a brain injury is defined. The Glasgow Coma Scale is based on a 15 point scale for estimating and categorizing the outcome of a TBI. The test measures the motor response, verbal response, and eye movement. There are four levels medical professionals use to rate how well the survivors will succeed after a TBI. The mild traumatic brain injury has a score of 13-15 which many people distinguish as a concussion. The mild traumatic brain injury is a loss of consciousness of less than 30 minutes with the possibility of headaches, confusion, and memory loss. In the mild brain injury it may take days to months for these symptoms to appear (Lenrow, n.d.). The moderate TBI has a score of 9-12 and is rated on a loss of consciousness for greater than 30 minutes with physical and cognitive impairments which may resolve with rehabilitation. A severe TBI has a Glasgow Score of 3-8 which leaves the survivor in an unconscious state who has no meaningful responses or voluntary activities. The vegetative state has a Glasgow Score of less than 3 and has the survivor living in a vegetative state with only sleep wake cycle, no interaction with their environment and no local response to pain. The persistent vegetative state is when the vegetative state last over a month and brain death occurs when there are no brain functions (Lenrow, n.d.).

Due to the injury the survivor sustains the families are propelled into the unfamiliar territories of emergency rooms, acute care, and rehabilitation.

A moderate brain injury is usually defined as having a loss of consciousness from 20 minutes to six hours with a Glasgow Coma Scale, a scale which measures the severity of the brain injury, of 9 to 12 and a severe brain injury is defined as having a loss of consciousness of greater than six hours and having a Glasgow Coma Scale of 3 to 8 (Lenrow, n.d.). The impact of a moderate to severe brain injury depends on the severity of the initial injury, area of brain function not affected by the TBI, and the areas of the brain that are affected by the injury. The impact of a moderate to severe TBI can result in cognitive deficits and changes in speech and language, senses, vision, physical abilities and emotions (Lenrow, n.d.).

Besides all of the physical and psychological terminology the families learn throughout the acute hospitalization, they will also learn about modern equipment technologies of emergency rooms and the Intensive Care Unit (ICU). The modern medical technology of an ICU can have families have a difficult time with distinguishing between the purpose of the technology and the expectations and hopes of their family member's survival and recovery (Kean, 2010). With the increased survival rates may come, lifelong disabilities which can have a profound effect on the all concerned. While the TBI can have drastic changes in quality of life for the survivor, the TBI can also have drastic consequences in the lives of the family members of the survivor.

### **Effect on Family and Caregivers**

Traumatic brain injury can be one of the most disruptive and devastating events that can happen to families. With nine out of every 10 being discharged home, much of the

care giving responsibility of care giving is left to family members. It can produce a wide and varied list of family and caregiver need, involving many hours of work and attention (Kreutzer et al., 2009). Furthermore, many of these additional duties are unknown to friends, family and colleagues as the survivor may show no physical evidence of their injury (Chamberlain, 2006). The list of survivor, family and caregiver needs are so varied due to the variability of the TBI. Depending on the needs of the survivor a parent, partner, children, or siblings may need to assist with bathing, feeding, meal preparation, or monitoring medications.

These responsibilities may change how the survivor and family members relate to each other, as well as how the family members relate to each other (Bishop, Degeneffe, & Mast, 2006). Personality changes of the survivor can have an impact on relationships according to Brooks and McKinlay (1983), which states that the personality changes can cause distress on the caregiver as well as other family members. It also states that rehabilitation for the survivor is as important as it is for the family member to reduce caregiver stress due to teaching the family members to recognize and to be able to manage personality and behavioral changes. This is crucial in the rehabilitation process.

Family roles may also change. Parents may now need to extend their parental duties into their years of retirement and domestic partners may now face their intimate partners who are substantially different than prior to the survivor's TBI (Degeneffe, 2001). Regarding caregiver stress, there is difference in opinion whether the relationship of the caregiver to the survivor affects how well the caregiver will cope. In Kreutzer, Marwitz, and Kepler (1992) concluded there is no difference between the caregiver being a spouse or a parent as to how the caregiver copes. However, Collin and

Kennedy (2008) concluded there is more of a burden on the partner than on parents. The families which can accept all of these changes may have a better outlook for themselves as well as the survivor (Uomoto & Uomoto, 2009). It is reported by Ergh, Rapport, Coleman, and Hanks (2002) most families with the survivor having severe neuropsychological and neurobehavioral functioning to have the least support and feel the most distress. Whereas, those families with the least neuropsychological and neurobehavioral difficulties continued to have a great support system and have adjusted well to their new caregiver role.

Carnes and Quinn (2005) state with the changing roles the domestic partners also experience significant emotional distress and less satisfaction with the partner. Stillwell and Stillwell (1997) report that brain injury has an impact on intimacy; 30% of married couples divorce within seven years after the TBI, whereas, the general public as being at 14-18% after seven years of marriage. According to Mills and Turnbull (2004), some of the reasons for the marriage ending could be sexual dysfunction due to lack of interest because of pain or fatigue, altered body image, or the survivor' inability to not be able to pick up cues given by their partner.

The role of intimate partner may suddenly change to one of caretaker after a TBI. A study done by Henry et al. (2011) showed that 10 participants have taken on an instrumental role following a traumatic experience. An instrumental role is a role taking a specific issue related to the traumatic experience. Many of the participants have taken on the role of "caretaker" or "provider". The participants also view themselves as having the role of protecting the relationship and/or family. Fourteen of the participants in a study on the impacts of traumatic events stated, as the non-traumatized partner they may try to

compensate by exaggerating their roles by becoming more involved in care and supportive roles. In addition some of the participants state they have experienced emotional and physical disengagement in their relationship (Henry et al., 2011). In studies on the effects on children, younger siblings may now be taking care of by older sibling because the parents are now attending to the survivor of the TBI (Uomoto & Uomoto, 2009).

These changes can add more caregiver stress and lead the caregiver to find coping strategies. Degeneffe (2001), states how well the family copes with the grief and caregiver stress may have to do with the financial stability of the family, the ages of caregivers, coping resources, and the caregiver's support system. The new family roles and stressors can be ever changing. This is because the brain injury can vary from mild (concussion) to severe (deep coma). Some of the survivors recover after a short rest period while other require life-long support (Gan, Campbell, Gemeinhardt, & McFadden, 2006). Many of the families feel ill prepared for this new and many times long term role of caregiver (Gan et al., 2006; Uomoto & Uomoto, 2001; & DePompei & Williams, 1994).

Many families have not had extensive experience with the medical system prior to the phone call that a family member has experienced a fall, motor vehicle accident, an injury due to a firearm, physical abuse, or a stroke. The medical system can be confusing and frustrating and before families can even think about the possibility of long term care giving and related implications there are several issues the literature states must be addressed for both the family and the survivor. These include family denial; lack of information from the medical team; working through transitioning the patient to different



units of care; and providing information and resources for long term caregivers. Utomoto and Utomoto (2011), state that many families first try to cope by denying the seriousness of the situation. It can be an effective coping tool especially for the partner of the injured person. Denial may be adaptive when it preserves family stability and keeps families from becoming overwhelmed (Miller, 1993). Soon though, families may discover denial may impede the progress of planning for the future and their feelings soon turn to hope (Miller, 1993; Carnes & Quinn, 2005; Molter, 1979).

Hope as well as changes in the daily activities are matters which may consume a survivor's family in the early days and weeks of the acute hospital stay. In a study of 25 family members many of whom were mothers and wives, hold onto hope. In the first few weeks after the injury due to the uncertainty was what was going to happen or if their family member would survive. Researchers found that this lengthy and uncertain waits often led families to postpone and delegate their usual responsibilities often leading them to feel guilty for leaving chores and other family member needs unmet (Lefebvre, Pechat, and Levert, 2007; Grahame, 1991). The uncertainty of a traumatic brain injury, its disruptive effects on the survivor's family and friends, and the uncertain prognosis makes it difficult and uncomfortable for physicians and other health care professionals to intervene in the everyday lives of the survivor and families.

Researchers have found that after the initial crisis is over the patient improves to the point of transitioning to a rehabilitation hospital unit or a long term care facility, the family may have another difficult period (Lefebver, Pechat, & Levert, 2007). It is hard because families have to adjust to change: change in the care providers they have come to trust, change in the work pace, and change in assessment procedures in that there could

be a delay in assessment by the medical professionals. These changes can feel like meet family's needs are dismissed and can have families grieving and feeling uncertain about the future. Furthermore, they may feel anger because of miscommunication in the acute setting (Lefebver, Pechat, & Levert, 2007; & Grahame, 1991).

Researchers have recommended that the family be informed even though the medical crisis may be over the rehabilitation can be a long, slow process (Uomoto & Uomoto, 2009). It is also important for the family member to recognize signs of fatigue, depression and despair. Harris et al. (2001) had a study with 58 caregivers and discovered that caregiver depression is linked to whether the caregiver feels supported. The depression also effected how the family adjusted to the survivor and the survivor adjusted to the long term effects of the TBI. In another study Rivera et al. (2007) report 60 caregivers completed the Centers for Epidemiological Studies Depression Scale and concluded if the caregiver had physical problems or ineffective problem solving the caregiver was at greater risk for depression. It was also reported that family members were using tranquilizers, sleeping pills and alcohol to cope with the new and long term stress (Kreutzer, Marwitz, & Kepler, 1992).

### **Grief and Loss**

Grief is a common emotion experience by people who experience trauma. In the literature regarding traumatic brain injury and the grief the survivors and their families experience, it was discovered there is not any one definition of grief that authors have agreed upon. Bonanno and Kaltman (2001) stated the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) sees grief is a stressor that produces distress but does not allow for a diagnostic category regarding complicated grief, but some of the symptoms

under some of the other diagnosis such as Major Depression or Post Traumatic Stress Disorder. A group of experts in the fields of grief, trauma, and psychiatry identified a unidimensional cluster of symptoms which is distinctive from depressive and anxiety and this cluster is associated with disability such as impaired role performance, sleep disturbances, and low self-esteem which can last for years. This group would like to label this type of grief as traumatic grief (Jacobs, Mazure, & Prigerson, 2000). Traumatic grief is just one of the other types of grief families that survivors of TBI may experience. Another type of grief is ‘complicated grief’ which can have symptoms of intensive grief, which does not lead to assimilation of the loss and produces an impaired functioning (Chamberlain, 2006).

Grief is a relatively new research subject in the field of traumatic brain injury. It is a subject that allows clinicians to move from symptom-based model to to a more functional hypothesis model regarding grief and loss. According to Mills and Turnbull (2004) people in intimate relationships can have serious disruptions in these as a result of a TBI, and may need to reestablish that relationship on a frequent basis. This disruption they call a “grief cycle”. It starts with the initial shock and emotional numbing which can give way to denial followed by anger, shame and guilt.

The losses a family and survivor can have following a TBI are potentially countless. A few of the loss each of them could experience are relationships, family roles and being able to participate in family activities. Some family members state the survivor’s personality changes in such a way that the family member they knew and loved is “dead” (Gosling & Oddy, 1999). In a study of 46 survivors of a TBI take the Brain Injury Grief Inventory, and found that younger people adjusted to the TBI much better, females

scored higher as did single people, which is not what was expected. It was thought marriage was a protective factor. The one thing the study did show was that survivors and their families suffer grief over their losses. Assessing these losses may only enhance recovery and rehabilitation for both the survivor and family members (Ruddle, Coetzer, & Vaughan, 2005).

One of the concepts family and friends need to adjust is ambiguous loss. Boss (2004,) states ambiguous loss is when “a loved one is physically present, but psychologically absent” (p. 554). It is a common term applied to persons whose family member is diagnosed with Alzheimer's. It can also be used to describe the experience of the family member of a survivor of a traumatic brain injury. The grieving may start while the survivor is still in the hospital or rehabilitation center due to the personality and psychosocial changes (Degeneffe, 2001). Boss (2009) further states traditional grief therapies will not work with these families because the survivor is physically alive.

With no closure or social validation, the persistent ambiguity begets confusion, immobilization and exhaustion which can lead the family into a traumatic response. The family may need to set some therapeutic goals to manage the stress, find meaning in the ambiguity of the survivor being a part of the family system, and rediscovering hope (Collins & Kennedy, 2008). The ambiguity of a TBI can make people feel helpless and therefore can make family members feel depressed, anxious, and have relationship conflicts. First the ambiguity surrounding the outcome of the survivor can make family members cognitively immobilized and unable to make decisions. Second ambiguity surrounding the prognosis may prevent reorganization of family roles, rituals, and rules. Third there are no customary markers of a loss therefore there are no changes and

everything is frozen. Fourth the ambiguity has the survivor and family questioning the world as just and fair place. Fifth ambiguous loss has a long duration which is physically and psychologically exhausting (Boss & Couden, 2002).

### **Resilience**

The concept of resilience is becoming important for the understanding, management, and governing complex systems in the area of trauma and grief especially as it relates to TBI. Resilience is different from recovery. Resilience is the ability for people who experience a potentially highly disruptive event, such as life-threatening situation, and continue to maintain a relatively stable life with some flexibility. Whereas, recovery states that one is exposed and then return to pre-exposure life (Bonanno, 2004). Trauma researchers are now discovering the importance of the individual's ability to go through difficulties and regain a satisfactory life (Bonanno, 2004). This is very true for the survivor of a TBI as well as their family members.

As family members roles change from partner, sibling, or parent to caregiver, family members become resilient due in part to their ability to cope (Carnes & Quinn, 2005). Families cope best by having long term support. It is also important for family members and caregivers to have respite which can furnish them with the opportunity to seek and experience adequate support (Ergh et al., 2002). Boss (2010) also believes that in order for people to have resiliency they must learn how to adapt to the new life and to make sure one takes care of their health. Boss (2010) continues by stating that in the face of ambivalent losses one must finding new meaning in life, reconstruct our identities, normalize the ambivalence and discover hope.

### **Current Practices and Promising Changes**

There are many current practices when working with families of survivors of TBI. Some of the practices are working with the basic needs in the early days, weeks, and months following the injury. Molter (1979) states there are four basic needs of family members. Those four needs were to “speak to the doctor at least once a day”, “to be told about chaplain services”, “a place to be alone in the hospital”, and “to have someone assist with financial problems”. Molter (1979) also states that approximately 40% of the 40 relatives interviewed stated only four other needs were only met 50% of the time when the survivor was critically ill. Also in a study of 21 parents of children who have survived a TBI stated their top needs were “explanations done in language I can understand”, “my child is given the best medical care”, and “my spouse understands how difficult this is for me”. The needs of parents are different than the study done by Molter (1979) for adults (Armstrong & Kerns, 2002). Several authors stated, one of the top needs of the families is clear, concise, and honest information regarding the traumatic brain injury (Kreutzer et al., 2009; Armstrong & Kerns, 2002). Another family need in the hours and days following the TBI is emotional support which could benefit from mental health treatment even in the early days (Kreutzer et al., 2009), this is important because after a traumatic brain injury how the survivor adjusts to the changes in their life depends greatly on the support of their families.

The family’s ability to respond to the traumatic brain injury can be dependent on its communication style, family’s organizational pattern, family’s ethnic and cultural background, and the family’s willingness to access community resources (DePompei & Williams, 1994; Spina, Ziviani & Nixon, 2005). The family systems perspective states it is important to not only look at the survivor but also look at the health and functioning

abilities of each member of the family as well as the family as a whole. This is very helpful if the family enters family therapy to assist in coping with all of the stress for this does not have one family member as “the problem” instead the therapist can examine how the family system is operating (Gan et al., 2006).

During the rehabilitation process family members can play a variety of different roles. First they can be information providers which can help in assessment and therapy. Second families can be active participants in the assessment and treatment of the survivor. Third families can be advocates for community resources and support systems. Fourth families can be communication experts for medical professionals and therapists. Finally families can be goal developers by relating their fears, desires, and needs. It is important for the survivor and their family members to coordinate information between medical professionals and therapists (DePompei & Williams, 1994).

Along with the early needs of the family currently not being met. It has been found that discharge planning can also cause increase stress on the family and the caregiver. Currently, many areas of the country do not have professional assistance for rehabilitation or mental health services for family support (Serio, Kreutzer, & Gervasio, 1995; Blake, 2008). The literature also states that in current practice there are a lack of financial resources to assist with making homes handicapped accessible or assist with caring for the survivor of the TBI (Gentleman, 2001). Without these financial services the families become the primary caregiver often without training or support. According to Kreutzer et al. (2009) over 90% of survivors of TBI are discharged home with relatives being the primary caregivers for years after the injury. The family may also not get any formal training to care for the survivor of the TBI (Serio, Kreutzer, & Gervasio, 1995). It

is very important for families to be well trained and have a good support system because it will affect the outcome of the survivor (Bishop, Degeneffe, & Mast, 2006). The families also then often start to experience anxiety, frustration, grief, ambiguous loss and denial which can negatively affect the survivor (Degeneffe, 2001). How families survive the changes depends greatly on the support they feel from the time they learn about the traumatic brain injury all the way thru the rehabilitation process, access to community and financial resources (Molter, 1979; Gan et al., 2006; Degeneffe, 2001).

Survivors and families often find that things are not the same and many survivors may not return to their jobs, family roles, or may not be able to leave home and be independent at the rate of their peers if an adolescent. The most appropriate intervention to assist families from the hospital to discharge and aftercare is the one in which realistically assists families in appraising the impact of the injury on the entire family system including the survivor (Rosenthal & Young, 1988). One of the aftercare events the family can participate is a family support group such as with a state agency such as a brain injury association or rehabilitation center, which can assist families cope with all the difficulties (Armstrong & Kerns, 2002). A second after care event is to have the family attend family therapy which also can assist the family in dealing with the families feelings of loss and helplessness as well as adapt to the disability itself and potential family and long term consequences (Rosenthal & Young, 1988).

The survivors, family members and caregivers are not the only person who may need education regarding how to interact after a TBI. The literature also discusses how medical professionals need to be trained in family interventions. Physicians and professionals often feel powerless and like a failure when they have to be the bearer of bad news. The



physicians and professionals are trying to better themselves through interdisciplinary approaches and care conferences. Some rehabilitation centers have started to use an ecological approach by concentrating on the needs of the survivor and family (Lefebvre, Pelchat, & Levert, 2007; Duff, 2006; Finberg, Kawashima, & Asch, 2011; Lefebvre & Levert, 2006).

The lack of training of physicians and professionals on how to give support after delivering news about the TBI can have effects on how the family copes with the news. Some of the lack of coping can be because families are in shock and not able to comprehend the long term nature of the disorder, the long term state of the uncertainty regarding the injury, or the fact the questions cannot be answered currently or maybe never answered (Bishop, Degeneffe, & Mast, 2006; Lefebvre & Levert, 2006). In one study, five of seven relatives expressed the wish for uniform, condensed information by a single doctor (Sady et al., 2010). In fact in a qualitative study of 49 family members of a person with TBI regarding a family conference was found to be a valuable tool as it got everyone “on the same page” (Fineberg, Kawashima, & Asch, 2011; Duff, 2006). While many people who sustained a TBI are now surviving their brain injury due to medical improvements such as better trained trauma care specialists, CT scans availability and sophisticated Neuro-intensive care (Gentleman, 2001). There are a number of long-term consequences for family caregivers.

Three of the most important psycho-social intervention to allow for good coping skills is access to accurate information about TBI (Grahame, 1991). The information needs to be provided in a concrete manner with key facts in language that is understandable to a non-medical person (Grahame, 1991). The information also need to

be given in a supportive climate for learning and adjusting which may mean giving hope or allowing family and friends of the survivor to vent how they are feeling. The family members also feel it is important to allow the family and other care givers physical time with the survivor in order to give them a sense of what it is going to take to care for the survivor and allow for some skill building time (Grahame, 1991). Family and caregivers may need assistance from a short period of time to extensive participation to allow for all family's members needs to be met and assistance with the adjustment (Bishop, Degeneffe, & Mast, 2006).

### **Conceptual Framework**

Issues involving family needs and losses following a traumatic brain injury are complex. This research project was developed on a number of theories and assumptions related to families. This study was completed using the lens of the family systems perspectives and ecological perspective.

#### **Family Systems**

The family systems perspective emphasizes how the family system affects the individual and family functioning across the life-span (Maitz & Sachs, 1995). Family system perspective also considers the experience of the person with the injury as well as each member of the family. It is important to visualize the family as a whole instead of individual family members when doing the most effective family interventions (Gan et al., 2006). It is important for all medical professional, rehabilitation staff, and other professionals working with families and the survivor of a TBI to understand that despite the many different definitions of family. Family to the survivor will be psychologically and behaviorally connected to each other. This connection happens over the life cycle of

the family and can be lawfully described. If there is a significant change in one member then it produces a change in all of the members and these changes can have effect on the survivor's outcome (Maitz & Sachs, 1995). It is also important to remember each survivor, each family member and situation is unique (Rosenthal & Young, 1988).

### **Ecological Perspective**

The ecological perspective emphasizes the reciprocity between an individual or group and its environments. There is special attention paid to the goodness of fit between the individual or group and the environments in which they live (Sands, 2001).

Individuals do not live in a vacuum and how individuals handle traumatic events and recovery is a result of how they interact with their environment (Sorsoli, 2007).

According to Ungar (2002), social work has expanded this perspective to explain that an individual and their environment is constantly changing to adapt to each other. This perspective helps to understand the relationship between the social worker, the traumatic brain injury survivor, and their family and how each has to pull information from their environment to determine the best working relationship.

The research question that this research project has addressed is : What does stress and loss look like in families with survivors of traumatic brain injury?

## **Methods**

### **Research Design**

A qualitative study was conducted due to the nature of this research project. Qualitative research allows for the participants to share their experiences through their own words. Qualitative research allows researchers to develop a fuller understanding of the experiences and needs of family members of traumatic brain injury survivors. A

qualitative research design allows for the researcher to examine an individual's life-world by focusing on their language, symbols and their meaning, empathy, and other subjective aspects within the lives of individuals and groups (Berg, 2009).

The researcher chose a semistructured interview style, which allowed flexibility during the interview. It also allowed for reordering of the questions, for the allowance of clarification and sub-questions, and the flexibility in the use of language (Berg, 2009). The interview questions were open-ended and intended to invite responses in which themes could be identified. There were 13 questions in total, and the interview method allowed for flexibility and the ability to remove any question the interviewer thought had been already answered.

Prior to the interview the participants were given a University of St. Thomas Institutional Review Board (IRB) approved consent form (see Appendix A). The consent form reviewed the background information of the study, the layout of the interview, the process of keeping everything confidential, and the voluntary nature of the study. The interviewer reviewed the consent form with the participants and then answered any and all questions the participant may have had regarding the research project.

The risk and benefits were also explained to the participants, which included that the participants may have felt some uncomfortable emotions during and after the interview regarding your family member's traumatic brain injury. The interviewer gave each of the participants' mental health resources after the interview in case the participant wanted to speak to someone regarding those emotions. All respondent information was kept confidential throughout the research project and all data will be destroyed upon completion of the research project.

**Sample**

The purpose of this study was to interview family members of survivors of a traumatic brain injury. There was a requirement that the injury had to happen 12 months or greater from the interview in order for the participants to participate in the study. The ideal sample size was eight to 10 family members and there were nine family members who participated in this study.

An availability sample method and snowballing method was utilized to draw family members from a readily available population (Monette, Sullivan, & DeJong, 2011). Flyers were laid out on a table prior to the brain injury support group meeting. The flyers explained who the researcher was, why the researcher was doing the research, that their participation was completely voluntary, and how the researcher was to be contacted. The researcher explained the flyer and participation would be kept confidential to the support group members. This process was designed to obtain eight to ten participants and nine participants were obtained.

**Protection of Human Subjects**

The proposal for this study was submitted, reviewed and approved by the researcher's research committee and the IRB at the University of St. Thomas. Data collection did not begin until the IRB had approved its protections of human subjects. Each participant was given an informed consent form (Appendix A) that was read and signed by the participant prior to the start of the interview. The consent form informed the participant of all of the components of the research that might have affected their willingness to have participated in the study.

This study was a voluntary study and participants were able to withdraw from the study up to seven days after their interview. All participants' information was kept confidential and no identifying information about the participants was in the final report. All tapes and transcripts were kept in a locked filing cabinet. The transcripts prior to printing were kept on a password protected file on the researcher's computer.

### **Data Collection**

The data collection for this study utilized nine in-depth, face to face qualitative interviews with family members of a survivor of a traumatic brain injury. All interviews were held in private in a location of the participants choosing. The researcher and participant were the only ones present at the time of the interview. Interviews were approximately 30 minutes in length, were recorded to aid in transcription and were 13 questions (Appendix B) in length. All tapes were destroyed on June 1, 2012. The interview obtained information regarding the family's experience regarding the hospital stay, any stress the family has felt, role changes and losses the family may have felt since the traumatic brain injury.

To insure all of the questions had at least face validity, the researcher completed a comprehensive literature review prior to the questions being written. All questions were read by two social workers and a faculty member. All questions were approved prior to the interviews. The interviewer collected observational notes of the surroundings and any non-verbal communication to allow for any additional information during the discussion.

### **Data Analysis**

After all the interviews were completed, the data was analyzed by using content analysis. According to Berg (2009, p 338), content analysis is a: "careful, detailed,

systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meaning”. Content analysis will be performed to objectively identify specific themes from the interviews and should retain, as much as possible, the exact wording used in the statements as it related to the family member’s hospital experience, any losses and role changes the family member may have experienced, and any promising practices that may have surfaced during the interview in relation to the family and survivor of a traumatic brain injury (Berg, 2009).

### **Findings**

This research study was conducted based on qualitative interviews with family members of survivors of a traumatic brain injury. The purpose of this study was to inquire as to what stress and loss looks like in families who have a survivor of a traumatic brain injury.

### **Participants’ Characteristics**

There were nine family members who were interviewed for this research study. Of those nine three were adult daughters (of survivor or survivor’s partner), three were adult granddaughters of the survivor, one was a wife of a survivor, one was an adult son and one was a daughter in law of a survivor. All of the interviews were conducted in person at a location and time set by the interviewee. Eight of the interviewees live in greater Minnesota and one of the interviewees’ lived in rural Wisconsin. Length of time from the injury was from one year to nine years. The length of time since the injury occurred may have given different perspectives on the stress and losses felt by the family members and how the traumatic brain injury has altered their lives.

Eight of the nine were family members within the primary support system of their survivor of the traumatic brain injury. Two of the survivors were admitted to an Intensive Care Unit on a ventilator for three or more days and the one survivor was in Neurological Progressive Units for greater than a week. All of the survivors experienced at least one inpatient rehabilitative stay during their initial recovery process. Direct quotes from the participants were used to provide insight into the situations faced by traumatic brain injury survivors and their families. The findings were broken down into effects on family, family role changes, losses, stress and medical personnel helpfulness. All names and identifying information have been removed in order to provide confidentiality all participants.

### **Preoccupied With Worries**

Many of the participants interchanged the word “worry” and “stress” during the interview regarding their hospital experiences and now living with the survivor of a traumatic brain injury as it has affected the family system. The family members also spoke about how they waned from hope to despair as the survivor health and behaviors fluctuated during the first year or so. The participants spoke about many worries such as whether their family member was going to survive, hospital decision making, financial, and worries about the survivor. The following are examples of how the participants discussed their worries.

**Worries about survival and hospital decision making.** Some of the participants spoke about the different types of hospital decisions they had to make during the acute treatment phase.



*The first three nights after my husband was taken to the hospital, I did not sleep because I did not want him to die alone if he was not going to make it*

*We did not know if she was going to make it the first few days. She just kept seizing and they just kept giving her medications and hoping. They just kept telling us, “we don’t know how this is going to turn out”.*

*They kept telling us that he is going to need a feeding tube, but it was in his living will that he did not want one. We went with his wishes and now we are not sure if that hindered his recovery.*

*In the first few days we did not know if we would have to take her off life support*

**Worries about finances.** Acute and long term financial worries are a concern of the participants and their families.

*Our house is old and does not have a bathroom downstairs for my husband to use. It is stressful to think about how much money it has cost to get stuff for my husband.*

*... felt financial stress for the first times in our lives after all the hospital bills and now the clinic visits because of high deductibles*

**Worries about the survivor.** Family members wondering if the family decisions made on behalf of the survivor were the best.

*We wonder if we did the right thing because now the survivor is so depressed and angry at the whole world which causes a lot of family conflict, yet he is with us and that makes our family whole.*

*They found cancer during his brain work up, so now we worry that might come back and they also found another aneurysm in the front part of his brain.*

Many of the family members interchanged the words “worry” and “stress” to express what the family members went through during their hospital experience thru discharge. The participants spoke their worries regarding the decisions they made during their survivors hospitalization, the financial decisions they had to make at the hospital and what was happening at home, and the worries and stress about whether they made the correct decisions regarding the survivors medical decisions and how that is going to affect the survivor and their family.

### **Effects on Family**

In asking about what stress and loss looks like in a family who has a survivor of a traumatic brain injury, it was found that many family members addressed how the traumatic brain injury has affected their family system. Some of the participants described feeling forced out of their previous normal lives and trying to come to terms as a family with what the new normal is going to look like.

**Survivor Identity.** Many of the survivors were still working or were just starting to enjoy their retirement at the time of their traumatic brain injury. The injury changed how the survivor was now identified.

*Our son had to take over the farm. We have had to sell some sheep. I would say we have all gone downhill.*

*The neighbors did not know if they could ask for help anymore because he was home from the hospital but had not been out socially.*

*We had to get things squared away with the farm right away because we had to. It took until spring to really know how much this affected us all*

[the participant was talking about the effects on the family business]... *she is no longer going to be able to run the family business with her sisters*

[the participant was talking about the survivors injuries]...*and then getting that life had dramatically changed*

**Changes in the survivor.** Some of the survivors spoke of the difficulties behavioral changes in the survivors made to their everyday lives.

*My husband used to be so independent. When we first got home from inpatient rehab we could not leave my husband alone ever, so we had to have lots of family around. It was a burden to them and we lost all of our privacy. He is better now.*

*It didn't really make much sense until really spending time with Dad*

*Friends stopped coming over because of Dad's behaviors*

*It is hard to even go to a restaurant in the beginning because of the impatience waiting for food and the possible behaviors.*

The effects on the family who have a survivor of a traumatic brain injury are as varied as the injury itself, but many of the participants speak about how their family and lives are a new type of normal. They also speak of the different cognitive and behavioral changes in the survivor which may have changed the roles of the family members prior to the injury.

**Family Role Changes.** Many of the family members in this study were forced to take on responsibilities for which they were unprepared. Under pressure, many of the family members took on roles they never imagined, as they navigated the medical system,

insurance systems, financial responsibilities, and becoming caretakers. Female spouses and a few of the granddaughters were concerned about their role of the caretaker of the survivor or the household.

**Caregiver.** Some of the participants spoke about how their role of a wife, daughter, son or granddaughter had now changed to role of caregiver.

*They sent my husband home with a g tube that I had to flush every day.*

*I went from being the granddaughter to a caregiver of someone who was always very independent. It was weird seeing my grandfather naked the first time I helped him with a shower.*

*I thought I would have to move home and take care of Grandpa.*

*She had to be moved to an assisted living because she could not dress herself when she was first discharged from inpatient rehab and the family was not able to be their everyday*

**Role of family financier.** It was the first time for some of the participants had to be in control of the family finances as the survivor was the one who had been responsible.

*... I had to take over the whole farm*

*I had to become the bill payer and figure out all of this insurance stuff*

*The insurance was complicated. I almost need a degree in finance and social work.*

*There was so many things like food and gas we had to pay for during the hospital stay, but wanted to come everyday...couldn't really afford it.*

Role changes within a family after a traumatic brain injury are abundant. These roles changes are particularly visible amongst marital partnership and immediate family members. The participants spoke of how this really changed when they were suddenly

caregivers or the survivor needing to suddenly needing assistance with daily activities.

With these roles changes, it many times related to losses in their lives.

### **Losses within the Family System**

In the literature review there is a term described as ambiguous loss. Ambiguous loss for this research project as meant that the person or entity is physically present but maybe psychologically absent. A couple of the participants do a very good job of describing ambiguous loss and the affect this has had on them, while other describe cognitive and physical losses of the survivors.

**Ambiguous loss.** This was a family loss that the participants had a hard time naming what type of loss it was for them.

*I can't go to the hunting shack or fishing with Grandpa anymore. He can't see well enough or is safe with a firearm anymore. He is also unstable in his footing, so he would be unable to get into a boat from a dock without falling.*

*My dad used to make his own jelly and now he can't. It feels different.*

*Grandpa will never be able to go alone on vacation with Grandma again...they have lost their independence*

*He has stopped doing woodworking...I had hoped that we could sometime do this together, but that hope is gone.*

*...I can't take on extra jobs because I have to take care of the farm*

**Cognitive and physical losses within the survivor.** Due to cognitive and physical losses within the survivor it may have produced a kind of family stress that has not been seen before. It may also mean there has been some lost dreams.

*It is hard to communicate with him as he cannot track a conversation very well...his hearing is also poor*

*Hard to take her out because she has lost sight in her left eye. Too hard to have her go with her husband to Florida for the winter*

*Dad is unable to woodwork any longer*

*First, my dad isn't the same person he once was. His behaviors have gotten worse over time.*

*He has balance problems now and struggled with seizures so he is no longer able to drive.*

*Grandpa had started to become belligerent in the hospital and it has continued at home.*

The ambiguous losses the family members have experienced since the traumatic brain injury and the cognitive and physical losses within the survivor not only bring about many different losses that the family is only experiencing for the first time, but it also produces many new and different stressors.

### **How Stress Looks in the Family System**

The participants frequently used the word 'stress' when they spoke about the hospital experience and their current experiences living with the survivor of the traumatic brain injury. The participants spoke of a variety of stressors including those on other family members. The following are a few of the stressors family members have been feeling.

**Emotional/Physical stress within the family system.** Many family members felt they were ill-prepared for the stress they and the survivor felt after the survivor was home. There was the sense that family members did not know how to ask for assistance.

*Oh definitely, my father-in-law did all of that stuff and now my mother-in-law has to do it and take care of him too. I definitely think this is a great stress on the family.*

*It is really not stressful for me, but I wish I could put in a new bathroom downstairs, but my mother is a pack rat and she has too much stuff so there is no room. That is stressful that I can't do things for my dad.*

*This has been stressful for me because it is stressful for Grandma. When Grandpa first came home we had to have a commode in the living room because there is no down stairs bathroom...Grandma is a hoarder...we are going to need a therapist to clean out the house...Grandma got stressed over the thought of having to clean the house to put the bathroom in*

*I had to stay with my husband one night at the hospital to see if I could care for him... he got out of the room and was found down the hall...what if that would have been outside*

**Due to survivor's behaviors.** Survivor's behaviors not only produce stressed upon discharge but for many of the families continues to cause stress even several years out from the traumatic brain injury.

*He now causes issues where there aren't any. He doesn't take his medication properly which causes stress for everyone.*

*Grandpa yells at Grandma a lot regarding food. He doesn't always remember he has eaten. His behavior has changed a lot*

*...lost out on doing side jobs...can't ask for payment from my parents for doing their farm work because they don't have the money*

*It is stressful because our family dynamics have changed so much*

*She says mean things now that she never said or probably never would have said before.*

Some of the most emotionally stressful situations for the family members of a survivor are due to the survivor's behaviors. The participants spoke of how this was tearing apart their families. Their hopes were that the medical and social work personnel would assist in helping the families first adjust to the days of wondering if their survivor was going to live or die and then later, how to make their lives normal again or at least better.

### **Medical/ Social Work Personnel Helpfulness**

Relationships between the brain injury survivor, their family members and medical/ social work personnel are important to establish at the very beginning of the hospitalization and to maintain until discharge. This part of the findings describes the families views of the medical personnel/ social work helpfulness during the hospitalization until their family members discharge from an inpatient rehabilitation unit.

**Discharge Planning.** Many of the family members were grateful to the social workers for the assistance upon discharge planning. Some of the family members received little to know assistance for discharge planning and felt the social worker was too young. The survivors and their family members also discovered how little resources there were available in rural areas.

**Helpfulness.** The participants stated they were happy with the contacts they had with the medical professionals and were grateful for the assistance.

*The social workers were very helpful...helped set up home care*



*... include the whole family and then listen to the family, especially the primary caregivers*

*...it was helpful that they taught us how to get him out of the car*

*We were able to talk to the doctor everyday*

*The neurosurgeon would call my Mom everyday*

**Not so helpful.** The participants wanted medical professionals to understand what the family members experienced from start of the survivors hospitalization until discharge.

*The social worker assumed because we were there every day during the hospitalization that we were going to be able to do that for the rest of our lives*

*We had to find our own assisted living*

*They were going to discharge my Dad to his home with just my Mom and he had no memory of what room he was in. We were worried that he would get outside and get lost in the 40 acres around the house.*

*I was very upset that the nursing staff would not listen to us when we said he was more confused.*

*The social worker assumed that because we were there everyday during her hospitalization that we were going to be able to do that for the rest of our lives*

*[We]... wished there wasn't a new nurse every couple of hours and every day someone new in his room because that would make him so confused.*

Respondents recounted times when staff expected family members to take on more responsibility than they were ready for including extensive care for a person with TBI and accessing appropriate care for the survivor without any previous knowledge of the topic and without an education prior to discharge. Furthermore, when family members

stated that sometimes providers did not acknowledge family members' insistence on changes to the survivor during hospital care.

**Discharge Resources.** Survivors and family members were under the impression upon discharge that services would just continue once the survivor left inpatient rehabilitation.

*I wish there was a way the OT, Speech, and helpers could help my mom and dad. I mean longer than they did. I think my dad's speech would improve more, but he can't afford it.*

*Grandpa came home with a G-tube and I wish Grandma could have gotten some help with that.*

*I wish a social worker would follow up with families 3, 6, and 12 months and then yearly for 5 years after just to see how everything is doing*

*It was so nice to have the chaplains visit us both at the hospital and at home*

Social workers and other medical personnel need to be aware that families may not be ready to hear about these resources at a later date. This is to ensure family members feel support to know about such organizations as the Minnesota Brain Injury Association and home care agencies are there to assist with the transition for the survivor and their families from inpatient rehabilitation and home.

**Advice for other families.** The participants wanted others to know what they found through their triumphs and struggles.

*Remember you may be the only advocate for your family member upon discharge*

*Never give up*

*Inquire about how it is going to be at home*

*I wish I would have asked more questions, especially about the hospital workers roles so I would have known who to ask what questions*

All traumatic brain injuries are so different. All of my participants wanted to do this study to talk about the triumphs and struggles the survivor and their families had gone through to show future family members, social workers, and medical personnel that without the entire team the survival of the survivor may not be possible.

### **Discussion**

The research question of this study was how does stress and loss look like in families with a survivor of a traumatic brain injury. Because this question concerned the lived experience of family members, this study conducted qualitative interviews in order to gather rich information. Many of the participants were willing to participate in the hope that families could have better experiences when working with the medical systems and social workers who work with families who have a survivor of a traumatic brain injury.

#### **Preoccupied with Worries**

Despite the differences in the type of brain injury and the care needed for the survivor, all of the family members spoke about the need for communication, financial assistance, and education about and connection to community support. Good communication during the early days after the traumatic brain injury made those times less stressful for the family members as they knew how to plan for the day or week. Many of the families would have like to have known how to obtain information regarding financial assistance with medical bills. The information could have been as simple as whether or not they could have set up payment plans. Many of the family members would have liked assistance with obtaining equipment, how to arrange outpatient therapies, and also

assistance with skill building to assist the survivor once they were home. Only one respondent spoke of what a good job the hospital staff did at communicating everyday with a family member of the survivor. None of the respondents stated what Rosenthal and Young (1988) as the most appropriate intervention -that families receive a complete appraisal of how the traumatic brain injury has affected the survivor and likely the family members.

### **Effects on Family**

While there were commonalities among the perceived needs of families, the experience of stress and loss for families were very different. For some family members stress was not being able to find funding resources for assistive equipment or finding therapy that was not a long distance to travel. Loss could be loss of income, shattered dreams for the future, or loss of hobbies the survivor and family enjoyed.

Some of the respondents also spoke of how the survivor had neurobiological and neuropsychological changes and this was troubling to family members. According to Ergh, Rapport, Coleman, and Hanks (2002) the families seen with these changes felt the least supported are more distressed. In this research study this was not founded. The respondents did not speak of how unsupported they felt or that they seemed in more distressed than other respondents whose survives who did not speak of neurobiological or neuropsychological changes. It is interesting that the interviewed families did not see themselves like the families that Ergh, Rapport, Coleman, and Hanks (2002) had interviewed in the literature review. This may be due to what Brooks and Mc Kinlay (1983) state as a less understood and researched subject in traumatic brain injury, which is behavior and personality changes.

### **Family Role Changes**

The findings of this study highlighted that there were some significant effects on the family as a result of the traumatic brain injury. One of the respondents felt that after spending some time with the survivor their lives had dramatically changed. Another respondent realized how their independent lives had changed to one of dependency on others to help with cares and the household. These findings regarding the effects on the family and changes in roles in the family are echoed by Gan, Campbell, Gemeinhardt, and McFadden (2006) who found that survivors may need life-long support and many times families feel ill prepared for this new and long term role of the care giver.

Besides the new role of caregiver, the lack of a clear prognosis and the complicated nature of traumatic brain injuries also created stress in the lives of the survivor and their families. Respondents mostly noted that these stressors were felt in the lack of caregiver education, financial losses due to the inability to take on other work, the difficulty in navigating the medical system along with the demands of the insurance companies. Degeneffe (2001) stated that how well families cope with these stressors is dependent on education about traumatic brain injury, financial stability, and caregiver support systems. Kreutzer, Marwitz and Kepler (1992) states without good stress management skills many of the survivors and their family members have a greater risk for depression which can lead to the survivor and/or their family members using tranquilizers, sleeping pills, and alcohol to cope. The short duration of the interviews for this research was not conducive for this sort of self-disclosure of respondents. So while no one remarked on depression or the use of medication to cope with stress related to caregiving, it should not be concluded that these things did.

### **Medical / Social Work Personnel Helpfulness**

Discharge planning and other family needs not being met are very stressful to the families. This was present in both families interviewed for this research study as well as studies in the literature review. According to Serio, Kreutzer, and Gervasio (1995), when many of the family needs were not addressed right after injury, discharge planning was consequentially more stressful. Furthermore, it has been found that in many areas of the country there is not funding or professional assistance for rehabilitation or mental health services even after discharge from the inpatient rehabilitation unit. This corresponds with Blake (2008) findings that in the case of mental health services, these may be needed during the survivor's hospitalization. Proper discharge planning, funding of services for survivors of traumatic brain injury, and proper follow up may assist with a less stressful discharge and transition to home for the survivors and their family members.

### **Implications for Social Work Research and Practice**

This study is a step forward in understanding in how stress and loss affects family members of survivors of a traumatic brain injury. Further research should focus on the needs of all three groups of traumatic brain injuries (mild, moderate, severe) and whether the different degrees of injury affect the family unit. Additionally, future research should consider how the relationship of the caregiver to survivor affects the family. Further research could also include how the gender differences may affect the family system and discharge planning. This study was conducted with a somewhat rural population, and further research in these less-populated is important. In general, it may be important to study how one's culture affects the quality of life and outcome of the survivor.

With regards to practice, given the demands of many social service agencies and social workers, it may wise to inquire about an association concerning traumatic brain injury in order for better training and collaboration of social workers in the area of traumatic brain injury. It may also offer evaluation system of discharge planning. Both of these may lead to a greater support and satisfaction of survivors and their family members.

### **Strengths and Limitations**

A strength of the study was the data collection method which included face to face interviews which has the potential to increase the richness of the data and further understand the subjective experience of the respondents. Another strength was in studying a emerging issue that needs exploration and discussion in order to better address it. Unfortunately, Traumatic Brain Injury is a common tragedy, and with returning war veterans will need to have better attuned approaches to support all members. Finally, the literature did not include many examples of more rural respondents. This study may have highlighted their particular, and in some ways distinct experiences.

A limitation of the study was the small sample size. It could be that in interviewing more people, other important themes would have emerged. Another limitation of the study is that data was not compared based on the amount of time that had passed since the traumatic brain injury; respondents may have answered differently given their distance from the TBI event. Finally, this study focused on family members of the study and did not include what stress and lost of the survivor looks like. Future research which includes the survivors is recommended.

### **Conclusion**

Traumatic brain injury has a profound impact on survivors and their family members. As traumatic brain injury becomes a more recognizable condition, clinical social workers are going to see more survivors of traumatic brain injury and their family members regarding the effects of stress and loss. The need for trained clinical social workers to effectively work with the survivors and their family members will increase. It is necessary to consider current experiences, as this study does, to point the way to best practices when working with families of survivors of traumatic brain injury.

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## Appendix A

### CONSENT FORM

Please read this form and ask any questions you may have before agreeing to participate in the study.

Please keep a copy of this form for your records.

<b>Project Name</b>	Stress and loss in families of survivors of traumatic brain injury	<b>IRB Tracking Number</b>	284746-1
General Information Statement about the study:			
This study shows what ambiguous loss looks like in families who have a survivor of a traumatic brain injury			
You are invited to participate in this research.			
You were selected as a possible participant for this study because:			
you have a family member who is a survivor of a traumatic brain injury			
Study is being conducted by:			
		Tracy Ketzbeck	
Research Advisor (if applicable):			
		Jessica Toft	

Department Affiliation:	Social Work
<b>Background Information</b>	
The purpose of the study is:	
<b>This study will examine what stress and loss looks like in families such as yours who have a survivor of a traumatic brain injury. Furthermore, this study will explore what supports you believe were helpful while learning to live with the injury, as well as supports you believe would be beneficial during all phases of learning to live with the injury.</b>	
<b>Procedures</b>	
If you agree to be in the study, you will be asked to do the following: State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.	
<b>If you agree to be in the study, we will determine a time and location to meet in a private place for an audio taped interview. The interview consists of 12 questions which ask about your initial experiences after learning about the traumatic brain injury and what types of support system do you have since the injury. The interview will take about 60 minutes.</b>	
<b>Risks and Benefits of being in the study</b>	
The risks involved for participating in the study are:	
<b>You, the participant, may experience some uncomfortable emotions after speaking about your family member's traumatic brain injury. The research will be giving you a handout containing mental health resources after the audio taped interview is concluded.</b>	
The direct benefits you will receive from participating in the study are:	
<b>The participants will be given a \$30 Target gift card for their participation in the audio taped interview.</b>	
<b>Compensation</b>	
Details of compensation (if and when disbursement will occur and conditions of compensation) include:	
Note: In the event that this research activity results in an injury, treatment will be available, including first aid, emergency treatment and follow-up care as needed. Payment for any such treatment must be provided by you or your third party payer if any (such as health insurance, Medicare, etc.).	
<b>The participants will receive a \$30 Target gift card.</b>	

<b>Confidentiality</b>			
The records of this study will be kept confidential. In any sort of report published, information will not be provided that will make it possible to identify you in any way. The types of records, who will have access to records and when they will be destroyed as a result of this study include:			
<b>All audio records will be in a locked filing cabinet. The audio tapes will be transcribed by the researcher and printed transcriptions will be kept in a locked in a file cabinet. The audio tapes and transcripts will be destroyed on June 1, 2012.</b>			
<b>Voluntary Nature of the Study</b>			
Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until the date/time specified in the study. You are also free to skip any questions that may be asked unless there is an exception(s) to this rule listed below with its rationale for the exception(s).			
<b>You are free to withdraw from this research project up to 7 days after your interview.</b> After that time the data will be included in the study.			
Should you decide to withdraw, data collected about you		<b>The data will be destroyed via erasing the tapes and shredding the printed transcription.</b>	
<b>Contacts and Questions</b>			
You may contact any of the resources listed below with questions or concerns about the study.			
Researcher name	Tracy Ketzeback		
Researcher email	<a href="mailto:ketz5265@stthomas.edu">ketz5265@stthomas.edu</a>		
Researcher phone			
Research Advisor name	Jessica Toft		
Research Advisor email	<a href="mailto:jetoft@stthomas.edu">jetoft@stthomas.edu</a>		
Research Advisor phone	651-962-5803		
UST IRB Office	651.962.5341		
<b>Statement of Consent</b>			
<b>I have read the above information. My questions have been answered to my satisfaction and I am at least 18 years old. I consent to participate in an approximately one hour long audio taped interview. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent to participate in the study.</b>			
Signature of Study Participant Electronic signature		Date	

Print Name of Study Participant			
Signature of Parent or Guardian (if applicable) Electronic Signature		Date	
Print Name of Parent or Guardian (if applicable)			
Signature of Researcher Electronic signature*		Date	
Print Name of Researcher			

\*Electronic signatures certify that::

The signatory agrees that he or she is aware of the polities on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.



## **Appendix B**

### **Questions for family members**

1. How is the survivor related to you?
2. How was the survivor injured?
3. How long ago was your family member's traumatic brain injury?
4. How severe was the brain injury?
5. How were you informed of the traumatic brain injury? What was that like for you?
6. Did you get a clear understanding of how the injury may affect you and your family long term? If yes, what was that like?
7. Are you or were you the caregiver to your family member with a traumatic brain injury? If yes, were you able to assist with care prior to your family member being discharged from a care facility?
8. Did you feel prepared to care for your family member? If yes, what type of education/support did you receive and did that support continue upon discharge? If you

received any what was the most effective assistance you received? If no, are there any supports you wish you would have had after discharge from a care facility?

9. Have you experienced any stress since your family member experienced the traumatic brain injury? Can you tell me about stress?
10. Have you experienced any losses of future wishes for your family member who is the survivor? Any for yourself?
11. What do you think others expect of you in relation to your family member who is the survivor of the traumatic brain injury?
12. Did you have contact with a social worker during any part of your family member's hospitalization or discharge planning? What was that like for you?
13. Do you have any recommendation for anyone in the helping professions who work with families of survivors of Traumatic Brain Injury?

