Aggression in Traumatic Brain Injury:

Difference in Perception and Impact on Family Functioning
# Dissertation Committee

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Traumatic Brain Injury (TBI) is one of the most common neurological disorders. The Center for Disease Control reports that approximately 1.5 million Americans sustain a TBI each year, 1.1 million are treated and released from hospital emergency rooms, and 235,000 are hospitalized (Langlois, Rutland-Brown & Thomas, 2006). This costs the country upwards of $60 billion (Finkelstein, Corso & Mill, 2006). Approximately 5.3 million Americans are currently living with TBI-related disabilities, 25% of which have sustained a moderate/severe brain injury (Langlois et al., 2006). The majority of individuals who endure a TBI are typically young males between the ages of 19 and 25 and the TBI is typically a result of an automobile accident, sports-related injury, or a fall (Morton & Wehman, 1995).

TBI occurs when there is a blow or jolt to the head, disrupting the normal functioning of the brain. The injury can range from mild to severe, with each category varying in level of symptomatology (Langlois et al., 2006). A person who experiences a mild TBI will most likely remain conscious or only lose consciousness for a few minutes and experience symptoms such as headaches, confusion, and lightheadedness. A more severe injury is associated with a longer period of unconsciousness and is usually accompanied by nausea, convulsions or seizures, or the inability to awake from sleep (National Institute of Neurological Disorders and Stroke, 2002).
Injury severity may be defined in several different terms, which makes the differentiation between mild, moderate and severe injuries somewhat vague. Some authors suggest that injury severity is best defined by the score obtained from the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974). When using this method of defining injury severity, a severe TBI is defined as a GCS score ranging from 3-8, a moderate TBI is defined as GCS score ranging from 9-12, and a mild TBI is defined as a GCS score ranging from 13-15 (Teasdale & Jennett, 1974). Other methods of defining injury severity include length of Loss of Consciousness (LOC) or duration of Post Traumatic Amnesia (PTA). With these methods, severe TBI is defined as LOC greater than 1 day or PTA greater than 1 week, moderate TBI is defined as LOC greater than 30 minutes or PTA greater than 24 hours, and mild TBI is defined as LOC less than 30 minutes and PTA less than 24 hours (Kay, Newman, Cavallo, Ezrachi & Resnick, 1992; Williams, Levin & Eisenberg, 1990).

Following the immediate injury, an individual can experience post injury symptoms, also called Post Concussion Syndrome (PCS). PCS is defined as a multitude of symptoms that develop either immediately following TBI or weeks later and can last for weeks, months or years following the injury. These symptoms include physiological problems such as vertigo, dizziness, headaches, and seizures (National Institute of Neurological Disorders and Stroke, 2002), cognitive problems such as problems with memory, attention, and problem solving, and behavioral and mental health issues such as depression, irritability, aggression, anxiety and compulsive behavior (Kay et al., 1992). Although there is controversy about the nature and cause of PCS, some studies have suggested that it is very common. For example, Bazarian
and Atabaki (2001) found that 58% of the mild TBI patients in their sample met criteria for PCS one month post-injury, 43% three months post-injury, and 25% six months post-injury. Landre, Poppe, Davis, Schmaus and Hoobs (2006) examined the relationship between cognitive functioning, non-neurological factors (pain and emotional distress) and PCS. The study found that while cognitive functioning was not related to emotional distress, higher PCS scores on the Postconcussive Symptom Checklist were associated with lower (worse) scores on the SF-36 Mental Health ratings. These findings suggest that while cognitive impairment post-injury does not appear to be related to PCS, greater emotional distress is related to the presence of PCS (Landre et al., 2006).

As mentioned, TBI has been associated with cognitive problems (Binder, Rohling & Larrabee, 1997). Specifically, individuals often display deficits in the area of working memory, attention and general memory (Alexander, 1995), thus affecting their ability to concentrate and focus on stimuli in their environment. Additionally, patients often experience difficulties related to executive functioning such as problem solving, planning, and making judgments (National Institute of Neurological Disorders and Stroke, 2002), which are likely to lead to increased levels of frustration. The nature and degree of cognitive deficits are generally related to severity of the TBI. For example, Rapoport et al. (2006) investigated the effects of mild to moderate TBI on cognition and functioning in 69 older adults. These authors found that when compared to age, gender, and education matched healthy controls, the TBI group displayed poorer verbal memory, language, processing speed, and executive functioning. Moreover, the moderate TBI group accounted for the majority
of the between group difference. Another study investigated cognitive functioning in relationship to effort and injury severity. Effort was assessed by the Test of Memory Malingering, which is a tool that was specifically designed to discriminate between actual memory impaired patients and malingerers. The researchers found that, among patients who exerted good effort on the testing (defined as a passing score on the Test of Memory Malingering), as the severity of the injury increased, cognitive performance decreased (Moss, Jones, Fokias & Quinn, 2003).

Another common effect of TBI is behavioral and personality changes (Ylvisaker, Jacobs & Feeny, 2003). Individuals who have experienced an injury to the brain may develop psychiatric problems that may include anxiety, apathy, depression, anger, paranoia, confusion, frustration, agitation, insomnia, or mood swings. Max et al. (2006) found that 13% of children ages 5-14 who experienced a TBI displayed personality changes at six and 12 months after injury and 12% continued to show these changes two years after the injury. Additionally, these researchers found that the severity of the injury was predictive of personality changes; those with more severe injuries showed greater changes in personality than those with less severe injuries. In another study that examined 60 mild to very severe adult TBI patients 30 years after the injury, Koponen et al. (2002) found that 48% of the participants had an Axis I diagnosis, in contrast to a prevalence rate of 18.5% for the general population (Narrow, Rae, Robins & Regier, 2002). Of that 48%, 26% were diagnosed with major depression (vs. 4.5% in general population), 11% with alcohol abuse or dependence (vs. 5.2% in general population), 8% with panic disorder (vs. 1.4% in general population), 8% with specific phobia (vs. 4.3% in general population) and 6% with
psychotic disorders (vs. 1.0% in general population). Moreover, 23% of the participants had at least one personality disorder (vs. 9.1% in general population; Lezenwegner, Lane, Loranger & Kessler, 2007). Unfortunately, while the authors included individuals from all severity levels (15 mild, 15 moderate, 11 severe, and 19 very severe), the authors did not investigate how injury severity relates to the DSM-IV-TR diagnoses.

In addition to personality change, TBI survivors also often display behavioral problems which can include impulsivity, acting out, noncompliance, social inappropriateness, emotional outbursts, impaired self-control, and aggression (National Institute of Neurological Disorders and Stroke, 2002). Anderson, Catroppa, Haritou, Morse and Rosenfeld (2005) conducted a study of 150 children who had sustained a TBI ranging in severity from mild to severe. Children with moderate to severe TBI displayed significantly more behavioral symptoms post injury compared to pre-injury, while those with mild TBI did not. Similarly, Groom, Shaw, O’Connor, Howard and Pickens (1998) found that in their sample of 145 adult TBI survivors who endured injuries ranging from mild to severe, 20% exhibited neurobehavioral problems as measured by the Neuropsychology Behavior and Affect Profile (NBAP). The most commonly endorsed behavioral challenge was the presence of inappropriate behaviors, which were defined as “behaviors that are bizarre or inappropriate to the context in which it is occurring or to an outside event” (p. 699). In contrast to the Anderson et al. study (2005), Groom et al. (1998) found no relationship between injury severity and the presence of neurobehavioral symptoms as measured by the Full Scale NBAP. Although both studies of children (Anderson et al, 2005; Taylor et
al, 1999) and adults (Groom et al., 1998) have identified significant behavior changes following TBI, there are conflicting findings related to how injury severity relates to behavioral problems. In children, there appears to be a relationship between injury severity and behavioral problems, whereas in adults this relationship does not appear to be present. Regardless, behavioral changes are common sequelae of TBI.

Aggression

As previously mentioned, TBI is frequently accompanied and complicated by cognitive and personality changes that can produce behavioral challenges. One of these behavioral problems is aggression, which can be categorized into one of three syndromes: 1) episodic dyscontrol which is defined as brief, aggressive outbursts with no identified provocation; 2) disinhibition (frontal lobe impairment) which subsequently leads to easily provoked aggression and temper tantrums; and 3) exacerbation of pre-injury traits such as pre-morbid levels of aggression and antisociality (Miller, 1994). Although Miller’s (1994) definitions have provided a means to categorize the types of aggression in TBI survivors, there are no reports on the prevalence of each syndrome or the relationship to injury severity.

Aggression categorized as episodic dyscontrol can be defined as a behavior that is very “sudden, often unprovoked, primitive and poorly organized in nature-flailing, spitting, scratching, etc. – and usually directed at the nearest available object or person” (Miller, 1994, p. 92). An individual who displays this form of aggression post-injury often reports no or limited awareness of the actual period of violent behavior. Aggression that stems from frontal lobe damage is better described as an overreaction to a provoking situation due to the brain’s inability to control emotional
reactions and expression (Miller, 1994). In contrast to episodic dyscontrol, these acts of aggression are more often directed towards someone/something. These acts are typically not as physical or violent as seen in episodic dyscontrol, but they are more verbal and emotional due to the diminished control the individual has over their emotional reaction to various situations and events. This type of aggression is often best described as appearing similar in nature to a child throwing a tantrum.

Individuals who display this form of aggression following TBI often have limited insight regarding this behavior, as they are unable to recognize that their response is out of proportion to the instigating event, yet when it is brought to their attention they tend to have significant remorse for their actions (Miller, 1994). Finally, some individuals with TBI who display aggressive behaviors post-injury may fit into a category of individuals who had high level of aggressive behaviors pre-injury, which may only be exacerbated post-injury due to frontal lobe damage (Miller, 1994).

Aggressive behaviors are reported to occur in 11-96% of TBI patients immediately following injury (Brooke, Questad, Patterson & Bashak, 1992; Kim, Manes, Kosier, 1999; Levin & Grossman, 1978; Rao, Jellenik & Woolston, 1985). The large discrepancy is related to the variability in operational definitions of aggression as well as the use of different assessment measures. Tateno, Jorge and Robinson (2003) conducted a study that examined the correlates of aggressive behavior during the first six months post-injury. Of the 89 TBI participants, 33.7% demonstrated significant aggressive behaviors, which included verbal aggression, physical aggression against objects, and physical aggression against self or others during this early recovery period. Of the 33.7%, 56.7% had experienced a mild TBI,
23.3% a moderate TBI, and 20% a severe TBI. This study found that aggressive behaviors were significantly associated with the presence of a frontal lobe lesion, major depression, poor pre-morbid social functioning, and a history of alcohol and substance abuse. However, aggressive behaviors were not significantly associated with the severity of the injury. Baguley, Cooper and Felmingham (2006) assessed the prevalence of aggression in 228 TBI survivors which included 34 mild TBI, 38 moderate TBI, and 115 severe TBI survivors. Participants completed a battery of tests which included the Overt Aggression Scale which was utilized to assess the presence of aggression at six months, 24 months, and 60 months post-injury. Of the 228 TBI participants, 25% of the sample could be classified as aggressive at all three time point, including up to five years after injury. The most frequently endorsed type of aggression was verbal, such as screaming and yelling. Similar to the previously mentioned study conducted by Tateno et al. (2003), Baguley et al. found no relationship between injury severity and the presence of aggression. Notably, these findings further illustrate that the vast number of TBI survivors who display aggression six months post-injury will continue to display this behavior for a longtime after the injury.

The question of why aggression occurs in some, but not all, individuals who have experienced TBI is yet to be answered, although several theories have been proposed. Some believe aggression is a result of neuroanatomical alterations (Hawkins & Trobst, 2000; Kim, 2002; Mesulam, 2000) or biochemical changes (Kim, 2002; Minger et al., 2000; Stanislav, Crismon & Childs, 1998), whereas others propose that aggression is a result of psychosocial changes in survivors’ lives (Swan
& Alderman, 2004). Still others point to pre-morbid susceptibility, specifically related to personality characteristics that leave TBI survivors prone to aggression (Greve et al., 2001). Each of these explanations will be explored in further detail.

**Hypothesized Neuroanatomical Causes of Aggression in TBI**

Aggression is not a unique behavioral response specific to humans; many other animal species display similar behaviors that have been found to come from localized areas of the brain. Locations of the brain and anatomical features that have been found to control aggressive responses in mammals include the prefrontal cortex, orbitofrontal cortex, hippocampus, olfactory cortex, amygdala and hypothalamus (Cummings & Coffey, 1994; Mesulam, 2000). One specific area of interest is the prefrontal cortex, as this area is known to regulate executive and cognitive functioning as well as behaviors and impulses in humans (Hawkins & Trobst, 2000). In a study that examined the relationship between frontal lobe lesion and the presence of aggressive/violent behaviors in Vietnam veterans, Grafman et al. (1996) found that participants with frontal ventromedial lesions had significantly higher aggressive/violent scores on the Aggression/Violence Scale than did controls. Moreover, these scores were associated with verbal confrontations rather than physical assaults. It is believed that the deactivation of the orbitofrontal structures or the circuitry associated throughout this region may subsequently lead to failure of individuals to regulate their emotional state or impair their ability to control impulses (Kim, 2002). Although the previously mentioned areas of the brain have been shown to function in the production of aggressive behaviors and provide the groundwork for understanding how aggressive symptoms may arise in individuals who have
experienced a brain injury, it is important to recognize that often it is not easily discernable which area of the brain, if any, has been permanently affected in TBI. More specifically, although the above-mentioned neuroanatomical causes of aggressive acts may sufficiently explain the aggressive behaviors in some, there are likely additional factors contributing to the aggressive behaviors in others.

**Hypothesized Neurochemical Causes of Aggression in TBI**

Another approach to explaining post injury aggression focuses on change in levels of neurotransmitters, particularly those associated with the cholinergic, catecholaminergic, and serotonergic systems (Kim, 2002). It is hypothesized that the transmission of acetylcholine may be disrupted in closed head injuries, which have previously been shown to account for some of the behavioral changes in Alzheimer’s disease (Minger et al., 2000). Animal studies have suggested that catecholamines, especially dopamine and norepinephrine, may be responsible for increased aggression (Eichelman, 1988); however, a study that compared aggressive TBI patients to non-aggressive TBI patients found no significant differences in dopamine or norepinephrine levels between the two groups (Stanislav et al., 1998). Coccaro, Berman, Kavoussi and Hauger (1996) found impulsivity and aggression to be “associated with decreased serotonin metabolites in the cerebrospinal fluid (CSF) as well as blunted neuroendocrine response to serotonin agonists” in personality disordered males (cited in Kim, 2000, p. 299). Although this study was not specific to TBI survivors, it is believed to apply to that population. Therefore, while neurochemical explanations may be inconclusive at this time, there is evidence that
suggests these chemicals may play some role in the production of aggressive behaviors.

**Hypothesized Psychological Impairment**

Some clinicians and researchers believe that aggression may not directly result from the anatomical or chemical changes in the brains of individuals who have experienced a TBI, but rather from their current level of cognitive functioning. Brain injured patients often display deficits in executive functioning and impulse control in neuropsychological testing. Some studies have found that individuals with more cognitive impairments are more likely to present with aggressive behaviors than individuals with fewer cognitive impairments (Barratt, Stanford, Kent & Felthouse, 1997; Foster, Hillbrand & Silverstein, 1993). In a study that examined the prevalence of TBI in a group of partner-abusive men with previous criminal convictions for violence, Marsh and Martinovich (2006) found that 58% of their sample reported a TBI. Of that 58%, 32% were classified as mild, 18% classified as moderate, and 50% classified as severe TBI. Moreover, the participants who reported to have endured a TBI scored significantly lower on a measure of current IQ and significantly lower on two of the three measures of executive functioning than those participants who did not report a previous TBI. These results further support the hypothesis that aggression may be directly linked to impaired cognitive and executive functioning.

**Hypothesized Psychosocial and Pre-morbid causes of Aggression in TBI**

In addition to impairment of executive and cognitive functioning, psychosocial variables may also play a role in post-injury aggression. Some research suggests that aggression and other emotional and behavioral changes following a
brain injury may be a result of psychosocial variables such as level of distress related to perceived demands and/or level of pre-morbid functioning. Swan and Alderman (2004) presented the case studies of two TBI patients during rehabilitation in which aggression, as measured by the Overt Aggression Scale-MNR, was compared to the number of expectations placed on the individual, as measured by the Neurobehavioral Expectations Scale (NES). The NES measures expectations and demands typically placed on TBI patients during rehabilitation and included such things as attending and participating in rehabilitation sessions and initiating and completing daily hygiene routines. They found that as the expectations and demands of the individual increased, the aggressive acts also increased. This suggests that the more these two individuals believed was expected of them, the more aggressive they became. Although these findings are compelling, it is important to be cautious in generalizing these results based on these two case studies.

Other researchers suggest that personality and pre-morbid characteristics may better predict the likelihood of aggression post-TBI. Greve et al. (2001) compared pre-morbid characteristics of aggressive brain injured patients to non-aggressive brain injured patients. Individuals were classified as either aggressive or non-aggressive based on information provided by the participant and the staff as well as a review of previous behavioral records. Each participant completed the Lifetime History of Aggression Questionnaire, the Eysenck Personality Questionnaire, the Barratt Impulsiveness Scale-11, and the Buss-Perry Aggression Questionnaire. Results suggested that aggressive individuals had a higher incidence of pre-morbid aggression and impulsivity when compared to the non-aggressive group. Thus, Greve et al.
(2001) concluded that the brain injury did not cause the aggression and impulsivity, but rather the injury further disinhibited the individual (due to changes in executive functioning); this change increases aggressive behaviors but does not create them. Greve et al. also contended that the reason aggression is very common following TBI is because 58% of the TBI population is reported to be impulsive and aggressive pre-injury. Therefore, perhaps the best predictor of aggression following TBI is pre-morbid history of impulsivity and aggressive coping styles, which increases the likelihood of injury.

Other research has suggested that it is other psychosocial variables, such as the pre-morbid or post-morbid level of distress or presence of mental illness that may predict aggressive behaviors. Baguley et al. (2006) conducted a study that examined the aggressive behaviors of individuals with mild, moderate and severe TBI at 6, 24, and 60 months post-injury, using both the report of the injured individual and a family member. One hundred and nine patients at 6 months, 133 patients at 24 months, and 67 patients at 60 months as well as their caregivers completed multiple measures including the Overt Aggression Scale, the Beck Depression Inventory, and the Trauma Complaints List. Spearman's rank order correlation showed that post-morbid depression, concurrent somatic complaints such as headaches, dizziness and nausea, and younger age at injury were consistently associated with aggressive behaviors.

Another study found a similar relationship between depression and aggressive behavior. Tateno et al. (2003) investigated whether a history of substance abuse or mood disorder pre-injury or a diagnosis of depression post-injury would predict post-
injury aggressive behavior. The researchers found that aggressive TBI patients had a significantly higher frequency of pre-morbid substance abuse and mood disorder and a higher frequency of diagnosis of depression following the brain injury.

A final proposed psychosocial explanation of aggression following brain injury is that aggression is a product of episodic dyscontrol syndrome (EDS). EDS is defined as an unpredictable and uncharacteristic, sudden outburst of rage, which can result in severe physical and verbal aggression and destructiveness (Eames & Wood, 2003). These episodes are usually brief and are often quickly followed by a sense of remorse and regret and may at times be followed by complaints of headache, fatigue, and drowsiness. EDS can cause significant distress for family members as the episodes are unpredictable and are often an extreme deviation from the typical personality of the injured person (Wood & Yurdakul, 1997).

Eames and Wood (2003) presented three case studies in which EDS appeared following TBI. In one case, a man who had endured a TBI as a result of a motor vehicle accident at age 36 exhibited frequent outbursts of extreme verbal and destructive aggression for two years following the injury. These outbursts subsequently lead to his 13-year-old daughter refusing to be alone in his presence out of fear of being hurt. In another case, a woman who endured a TBI at the age of eight showed signs of frequent uncontrollable outbursts of aggression and irritability for nine years post injury. These emotional outbursts lead to family problems and a subsequent separation of a long-standing relationship with her boyfriend. These studies suggest that EDS may be the cause of aggressive behaviors in some cases, but the cause of EDS has not been described. Regardless of what causes aggressive
behaviors, it is apparent that the agitated acts not only affect the TBI survivors but also the people surrounding them, especially significant others and family members.

Previous research has suggested that the prevalence of aggressive behaviors in TBI survivors is quite high, with reports ranging from 11-96% (Brooke, Questad, Patterson, 1992; Kim, Manes, Kosier, 1999; Levin & Grossman, 1978; Rao, Jellenik & Woolston, 1985) depending on the operational definition of aggression. Moreover, it appears that these challenging behaviors remain up to 5 years post-injury in 25% of the population (Baguley et al., 2006). What is lacking in the research is a clear definition of what constitutes aggression and the correspondence in ratings of post-injury aggression between the individual with TBI and the caregiver/family member.

**Self-Awareness**

Previous research suggests there is often a marked discrepancy in the reports between the TBI survivor and his/her family members regarding behavioral changes post-injury (Fordyce & Roueche, 1986; Marsh & Kersel, 2006; Prigatano, 1991; Teasdale et al., 1997). It has been reported that up to 45% of survivors of moderate to severe TBI demonstrate self-awareness deficits (Flashman & McAlister, 2002). A common way of assessing self-awareness is via discrepancy ratings between TBI survivors and their caregivers (Prigatano, 1991; Teasdale et al., 1997). Fleming and Strong (1999) suggested that self-awareness of deficits often improves during the first six months to one-year post-injury, but individuals whose deficits last beyond that period rarely improve (Newman, Garmone, Beatty & Ziccardi, 2000; Ranseen, Bohaska & Schmitt, 1990). In a study of 47 TBI survivors and their major caregivers, 80% of the behaviorally disturbed individuals with TBI reported a significant
overestimation in their social functioning when compared to their caregivers’ ratings, whereas only 45% of the non-behavioral group produced this discrepancy in ratings (Bach & David, 2006). Moreover, Landham, Weissenburger and Schwab (2000) found no relationship between concordance ratings and injury severity, suggesting that self-awareness is not related to the severity level of the injury.

One study examined the correspondence rates on the Head Injury Behavior Rating Scale (HIBS) between 62 adults who had experienced a severe TBI and their primary caregivers at one year post-injury. The total number of behavioral problems and the frequency of these problems were investigated. Caregivers reported significantly more behavioral problems \( (M = 9.84) \) compared to the survivors’ self-rating \( (M = 6.18) \), and greater frequency of seven of the behaviors (overly sensitive, impulsivity, lacks motivation, childish, poor insight, lack of initiative, and irresponsibility) when compared to the self-ratings (Marsh & Kersel, 2006).

Evans, Shere, Nick, Nakase-Richardson and Yablon (2005) examined the relationship between impaired self-awareness (ISA) and depression following TBI. ISA was defined as the patient’s lack of awareness or appreciation of the severity of his or her deficits and the impact these deficits have on their work or daily living abilities. ISA was measured by computing the discrepancy between ratings from the TBI survivor and a clinician on the Awareness Questionnaire that includes cognitive, behavioral and motor subscales. Of the 96 TBI participants, 85% rated themselves as more competent in all domains than their clinicians, and 34% rated themselves more than 20 points greater than did their clinicians.
Malec, Machulda and Moessner (1997) examined the relationship of perceptions of TBI survivors, their significant others, and staff personnel on the Mayo-Portland Adaptability Inventory (MPAI). Additionally, TBI survivors were classified as either depressed or nondepressed depending on their scores on the MPAI-indicator of depression. The researchers found that staff and TBI survivor’s scores on the MPAI were moderately correlated only for those TBI survivor’s identified as depressed by the MPAI-indicator of depression. Moreover, TBI survivors who illustrated impaired self-awareness were infrequently depressed. These results suggest that lack of awareness of deficits serves as a protective factor against the development and presence of depression in the TBI survivor.

**Depression**

Psychopathology following brain injury, specifically depression, appears to affect the TBI survivor and the caregiver/family member. Hibbard, Uysal, Kepler, Bogdany and Silver (1998) assessed 100 adult patients who had endured a brain injury on average 8 years previously. 61% of this sample met criteria for a diagnosis of major depressive disorder. In a larger study where 722 TBI patients were assessed an average of 2.5 years post injury, 42% were diagnosed with major depression (Kreutzer, Seel & Gourley, 2001).

Previous research suggests that depression may be associated with the aggressive behaviors following injury (Baguley, Cooper & Felmingham, 2006; Tateno, Jorge & Robinson, 2003). Baguley et al. (2006) found that at 6 months post-injury, the most significant predictor of aggression was depression as it accounted for 19.5% of the variance. In another study that looked at aggressive behaviors in 89
patients with TBI compared to 26 non-TBI patients, aggressive behavior was significantly associated with the presence of major depression (Tateno et al., 2003).

In addition to the TBI survivors, depression is also common in the caregivers/family members. Post-injury, the caregiver/family member is likely to experience psychological problems that include stress, depression, anxiety and a sense of burden (Brooks, 1991). Marsh, Kersel, Havil and Sleigh (1998) assessed 69 caregivers of individuals who had endured a severe TBI six months previously. One-third of these caregivers displayed clinically significant levels of depression, anxiety and impairment in social functioning. In a continuation of this study, at one-year post injury, the prevalence of depression and anxiety remained the same (Marsh et al., 2002). In another study, 23% of caregivers/family members of TBI survivors were experiencing clinically significant levels of depression up to three years post-injury (Harris, Godfrey, Partridge and Knight, 2001).

Family Functioning

Given the frequency of behavioral changes following TBI, it is not surprising that several studies have found significant negative changes in family functioning following TBI. Previous studies have found that one-third to one-half of families of brain injured people report unhealthy or poorer family functioning following the injury (Kreutzer, Gervasio & Camplair, 1994a; Marsh, Kersel, Havill & Sleigh, 2002; Testa, Malec, Moessner & Brown, 2006), although the reasons for these changes remain unclear. Notably, several researchers have reported that the overall severity of the injury does not appear to be significantly related to family functioning (Anderson, Catroppa, Haritou, Morse & Rosenfeld, 2005; Gan & Schuller, 2002; Groom, Shaw,
O’Conner, Howard & Pickens 1998; Sawchyn, Mateer & Braxton, 2005), but specific neurobehavioral changes in the TBI survivor have been identified as significant predictors and correlates of family functioning (Anderson et al, 2005; Anderson, Paramount & Monk, 2002; Groom et al, 1998; Kreutzer, Gervasio & Camplair, 1994b; Testa et al., 2006). More specifically, some of the neurobehavioral changes such as greater anger problems (Ponsford, Oliver, Ponsford & Nelms, 2003) and poor impulse control (Wells, Dywan & Dumas, 2005) are associated with declines in family functioning. Another area that has been found to be correlated with poorer family functioning following TBI is the discrepancy between perceptions of behavioral changes as reported by the caregiver and the injured individual (Livingston & Brooks, 1988).

Testa et al. (2006) examined family functioning in 47 mild and 75 moderate/severe TBI patients. They found that distressed family functioning was strongly correlated with increased rates of neurobehavioral symptoms including depression, somatic complaints, memory problems, communication difficulties, aggression, and motor issues. They also found that the best predictors of family functioning at one year post-injury were the level of family functioning at discharge and the presence of depression and memory/attentional deficits in the brain injured person at follow-up. Similarly, in a study that explored the relationship between neurobehavioral symptoms, family functioning and caregiver distress, the authors found all subscales of the Neuropsychological Behavior and Affect Profile (NBAP) to be moderately high and statistically related to the Family Assessment Device-General Functioning Subscale (FAD-GF) ranging from $r=.29$ (Mania subscale) to $r=.54$ (Full...
TBI AND AGGRESSION

Scale NBAP). The best predictors for the elevated FAD-GF were the TBI survivor’s depression and inappropriateness, which is defined as “behavior that is bizarre or inappropriate to the context in which it is occurring or to an outside event” identified in the injured person (Groom et al., 1998, p.699).

Thompsen (1997) utilized testing and interviews and found that the adjustment of relatives was not related to the degree of the injury, but rather it was more greatly influenced by personality changes in the TBI survivor. Similar results were found in a longitudinal study conducted by Brooks and McKinley (1983), who assessed individuals and their family members at 3, 6, and 12 months and 5 and 7 years post-injury. Brooks and McKinley also found no relationship between level of burden reported by the caregiver and severity of the injury. Similar to the Thompsen study, Brooks and McKinley also found a significant relationship between personality changes and level of burden. The most compelling part of this study was that at 5 years post-injury, the level of subjective burden in the caregivers had significantly increased from the first year, and this level remained constant even at 7-years post-injury (Brooks & McKinley, 1983).

Gan and Schuller (2002), in accord with the previous studies, also found no relationship between injury severity and level of family distress as measured by the Family Assessment Measure –III (FAM-III); however, all family members of individuals who had suffered a TBI scored in the elevated ranges on all subscales of the FAM-III. This study found that not only does the primary caregiver experience stress, but so do other family members, such as siblings and children. Additionally and more importantly, there were no differences in the level of unhealthy family
functioning found over the various time courses (2, 2-5 or +5 years post injury), suggesting that this is a long-term consequence of the injury and something that requires attention when treating patients and families of brain injuries. Moreover, the researchers found that the TBI survivors did not report a significant difference in family functioning compared to the general population on which the FAM-III was normed (overall the TBI sample reported healthy family functioning). However, the caregivers/family members of this study did report significant levels of unhealthy family functioning compared to the normative group. The authors believed that the TBI survivor’s lack of self awareness accounted for the differences in perceptions of family functioning, meaning that the caregivers were a more reliable rater of the health of the family system. The authors also hypothesized that the TBI survivor’s inability to recognize the poor level of family functioning prevents him/her from changing any behaviors which may be exacerbating family distress.

**Qualitative Research**

The majority of the previously reviewed studies relied primarily on quantitative methods, but previous research has also utilized qualitative methodologies as a means to gain information related to post-injury experiences. This research approach allows investigators the opportunity to obtain the unique post-injury experiences of the TBI survivor and the caregiver/family member. Some studies have used focus groups as a means of obtaining this type of information (Wallace, Evans, Arnold & Hux, 2007) whereas others have used interviews (Gagnon, Swaine, Champagne & Lefebvre, 2008; Nichols, 2007; Turner et al., 2007) Qualitative studies thus far have investigated such topics as the rehabilitation
experiences of the TBI survivor (Wallace et al., 2007), the service needs for adolescent TBI survivors as reported by the adolescent and his/her parent (Gagnon et al., 2008), the TBI survivor’s awareness of deficits (O’Callaghan, Powell & Oyebode, 2006; Yeates, Henwood, Gracey & Evans, 2007), the TBI survivor’s perception of social interactions and psychosocial adjustment (Nichols, 2007; Shotton, Simpson & Smith, 2007), and the transition experience of the TBI survivor and his/her caregiver/family member (Turner et al., 2007). Other studies have investigated the topic of TBI more broadly and have attempted to describe the general life experience of TBI survivors (Brown, Lyons & Rose, 2006; Chamberlain, 2006; Westcott, 2007) or the caregivers/family members (Jumisko, Lexell & Soderber, 2007; Wongvatunyu & Porter, 2005).

Jumisko et al. (2007) interviewed 8 family members of TBI survivors to gain a better understanding of their experience of living with an individual following moderate or severe TBI. Participants were asked to reflect on three themes, which included life before and after the injury, meeting other people, and caring for the TBI survivor. Text was analyzed using the phenomenological hermeneutic interpretation inspired by Ricoeur (1976). The authors suggested that the caregiver/family member believed that his/her experience post-injury was defined as a “fight not to lose one’s foothold” (p. 362). Caregivers/family members commonly reported that they had to learn who the TBI survivor was, as he/she was a different person following the injury. Moreover, caregivers/family members reported that they had to take on additional responsibilities and needed to be available to the TBI survivor at all times, which changed the relationship between the two individuals.
Similarly, Wongvatunyu and Porter (2005) sought to describe the mother’s experience in assisting her young adult child who had survived a moderate or severe TBI. Seven mothers were interviewed three separate times over a two-month period and asked to comment on their perceptions, actions and intentions pertaining to their experiences of helping their child who survived a TBI. Using a phenomenological method, five phenomena related to the mothers’ experiences were identified: “reconnecting my child’s brain, considering my child’s safety, making our lives as normal as possible, and dealing with our biggest problem and advocating for my child” (p. 48). These themes demonstrate the life change experienced not only by the TBI survivor but also by the family member.

While previous research has sought to describe the TBI survivor’s (Brown, et al., 2006; Chamberlain, 2006; Westcott, 2007) and the caregiver/family member’s (Jumisko et al., 2007; Wongvatunyu & Porter, 2005) experience post-injury, no qualitative studies have investigated the presence and experience of dealing with aggressive behaviors in the TBI survivor post-injury. Additionally, no studies have sought to describe how these behavioral changes impact family functioning by means of semi-structured interviews and quantitative methods.

Summary

As the previous research has found, the variables of aggression, differences in perception of neurobehavioral change between the TBI survivor and the caregiver, and the impact both of these have on family functioning seem to play a large role in the lives of all members of the family unit following a traumatic brain injury. Aggression appears to have a significant impact on the caregiver and the ability of the
family to function in a healthy manner. Additionally, the lack of awareness of this
development in the injured individual appears to be related to the level of
family functioning and distress experienced in the home environment. Finally, the
research suggests that family functioning decreases significantly following the injury.
However, what the previous research has failed to investigate is the specific
relationship between the presence and type of aggression, the awareness of this
behavioral change, and the impact these variables have on family functioning.
Chapter II

Rationale and Hypotheses

TBI can produce longstanding changes in the survivor's functioning, and can create challenges for family members as they attempt to adjust to the changes in their loved one's functioning. Previous research has explored many different aspects of the adjustment process, but studies have generally obtained information from only one source, either the survivor or the caregiver. Previous research has explored the post-injury experience of parents (Prigatano & Gray, 2007; Wongvatunyu & Porter, 2005), caregivers/family members (Curry, 2006; Grubbs, 2003; Delehanty & Kieren, 1998; Jumisko et al., 2007), children (Butera-Prinzi & Perlesz, 2004), and the TBI survivor (Brown et al., 2006; Chamberlain, 2006; Dixon, Thornton & Young, 2007; Nicholas, 2007; O'Callaghan et al., 2006; Oppermann, 2004; Shotton et al., 2007; Westcott, 2007). Of the studies that have investigated the experience of both the TBI survivor and the caregiver/family member (Conneeley, 2003; Gagnon et al., 2008; Rotondi, 2007; Turner et al., 2007; Yeates et al., 2007), the correspondence between reported experiences following the injury and the impact it had on the family relationship was not explored.

The current project was designed to provide additional information of the post-injury adjustment of TBI survivors through both qualitative and quantitative
data. One aim of the current study is to examine the correspondence between the perceptions of both the TBI survivor and the caregiver/family member. Areas of post-injury functioning that are of particular interest include the TBI survivor's aggressive tendencies, behavioral, affective/emotional and physical changes, and family functioning. Therefore, the following research objectives are proposed:

Objective 1: To describe the injury and post-injury experiences of both the TBI survivor and the caregiver/family member. Specific focus areas will include the TBI survivor's aggressive tendencies, behavioral, affective/emotional and physical changes, and overall family interactions and functioning.

The research and clinical literature suggests that individuals who have endured a brain injury often lack self-awareness of behavioral changes within themselves (Garmoe, Newman & O'Connell, 2005; Hart, Whyte, Kim & Vaccaro, 2005; Marsh & Kersel, 2006; Prigatano Borgaro, Baker & Wethe, 2005; Sherer et al., 1998). While previous research has investigated impaired self-awareness, there is paucity of research investigating its impact on the family.

Objective 2: To examine the presence or absence of similar themes in the TBI survivor's and the caregiver/family member's descriptions of changes in functioning post-injury, specifically related to aggression, overall behavioral/affective change, and family functioning.

In addition to information that will be analyzed qualitatively, the respondents will provide Likert scale ratings of functioning. These will be analyzed quantitatively, and the following null hypotheses will be tested:
Ho1: There are no statistically significant differences in ratings of the TBI survivor compared with the caregiver/family member on Likert-scales of aggression, behavioral, affective/emotional, and physical changes in the TBI survivor.

Ho2: There is no statistically significant difference in ratings of family functioning between the TBI survivor and the caregiver/family member.

As previously illustrated, aggression is a common phenomenon following brain injury (Baguley et al., 2006; Levin & Grossman, 1978; Rao et al., 1985; Silver & Yudofsky, 1994; Tateno et al., 2003), and an area that has been overlooked with regard to family functioning following TBI. Previous research has also shown that, in a broad sense, neurobehavioral changes significantly impact the level of family functioning (Anderson et al, 2005; Anderson, Paramount & Monk, 2002; Groom et al, 1998; Kreutzer et al. 1994a; Testa et al., 2006). However, there has been a lack of research assessing the impact aggression (verbal and/or physical) specifically has on family interactions. The current study will investigate the relationship between the presence and/or absence of aggression and the classification of family functioning (healthy vs. unhealthy) if a sufficient number of participants fall into each grouping, based on scores on the FAD. The following null hypotheses will be tested.

Ho3: There is no statistically significant difference in amount of self-reported aggression by TBI survivors whose FAD scores indicate healthy functioning compared with those TBI survivors whose FAD scores indicate unhealthy family functioning.

Ho4: There is no statistically significant difference in amount of aggression in the TBI survivors reported by the caregivers/family members whose FAD scores
indicate healthy functioning compared with those caregivers/family members whose FAD scores indicate unhealthy family functioning.

Ho5: There is no statistically significant difference in amount of self-reported aggression by TBI survivors whose FAD scores indicate healthy functioning compared to the amount of aggression by the TBI survivor as reported by the caregivers/family members whose FAD scores indicate healthy functioning.

Ho6: There is no statistically significant difference in amount of self-reported aggression by TBI survivors whose FAD scores indicate unhealthy functioning compared to the amount of aggression by the TBI survivor as reported by the caregivers/family members whose FAD scores indicate unhealthy functioning.

Data generated by the measure of depression will not be subject to formal hypotheses but will be analyzed in an exploratory way.
Chapter III

Method

Participants

The participants will be recruited from various support groups facilitated by the Brain Injury Association of Ohio throughout the greater Cincinnati area, and from InReturn, a local manufacturing facility that employs brain injury survivors. Both participants and their caregivers/family members will be invited to take part in the study. To be included, all participants must be at least 18 years of age, speak English fluently, and have sustained a head injury (either open or closed head injuries) at least 6 months prior to the study. A minimum of 30 dyads will participate. Preference will be given to participants who indicate a spouse/significant other or parent relationship to the TBI survivor.

Power Issues

Previous TBI research has utilized varying sample sizes, ranging from single case studies (Butera-Prinzi & Perlesz, 2004; Eames & Wood, 2003) to samples as large as 228 participants (Baguley et al., 2006). Much of the variability in sample sizes depends on the methodology and focus of the study. Quantitative studies that obtain reports from both the TBI survivor as well as the caregiver/family member tend to utilize smaller sample sizes ranging from 34 pairs (Cavallo, Kay & Ezrachi,
1992) to 63 pairs (Testa et al., 2006). Previous qualitative studies which incorporate semi-structured interviews with both the TBI survivor and the caregiver/family member report even smaller sample sizes ranging from only 3 pairs (Yeates et al., 2007) to 15 pairs (Gagnon et al., 2008).

According to Cohen (1992), in order to detect a medium-sized difference between two independent sample means for a power of .80 at α=.05, a sample size of 64 is needed in each group. In order to detect a large-sized difference for the same analysis requires 26 participants in each group. Due to a limited number of possible participants, it is unlikely that sample size necessary to generate a medium effect size will be obtained. This will be one of the limitations of this study.

Measures

Aggression. Anger and aggression of the TBI survivor will be measured using the original version of the Aggression Questionnaire (AQ; Buss & Perry, 1992, see Appendix A), to be completed by the head injured individual, and the Partner Aggression Questionnaire (AQ-P; O'Conner, Archer & Wu, 2001, see Appendix B), to be completed by the caregiver/family member. The AQ/AQ-P is an instrument that is an updated version of the Buss-Durkee Hostility Inventory (Buss & Durkee, 1957) and is composed of 29 items that make up four scales: Physical Aggression (PHY), Verbal Aggression (VER), Anger (ANG), and Hostility (HOS). A total AQ/ AQ-P score can also be calculated to measure overall level of anger and aggression as reported by the respondent. Each item is rated on a five point scale ranging from “Not at all like me” to “Completely like me” on the AQ, and ranging from “Never or hardly ever applies to him/her” to “Very often applies to him/her” on the AQ-P. The
questionnaire is written at a third-grade reading level, and has age and sex-stratified norms ranging from 9 years to 88 years. This measure is reported to have good internal consistency reliability, ranging from .76 to .94, and test-retest reliability of the sub-scales ranging from .76 to .94. Previous research has utilized the original version of the AQ in addition to the AQ-P to provide assessment of differences in perceptions of the presence and characteristics of aggression following traumatic brain injury (Dyer, Bell, McCann & Rauch, 2006). Questions on the AQ are identical to the questions on the AQ-P, which allows for direct comparison of the four subscales and total aggression score.

**Family Functioning.** Family functioning will be measured by the Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983), a self-report measure composed of 60 questions rated on a 4-point likert-type scale ranging from “strongly agree” to “strongly disagree” (see Appendix C). The FAD is designed to measure family functioning based on the McMaster Model of Family Functioning (Epstein et al., 1983). It is composed of seven scales, six of which measure the dimensions of the McMaster Model: Affective Involvement, Affective Responsiveness, Behavior Control, Communication, Problem Solving and Roles. The seventh scale is defined as the General Functioning scale. Means scores are computed for each scale and range from 1 defined as “very healthy” to 4 defined as “very unhealthy”.

This measure is reported to have good internal consistency, ranging from .72 (both Behavior Control and Roles) to .92 (General Functioning scale) and good test-retest reliability over one week, ranging from .66 (Problem Solving) to .76 (Affective Responsiveness; Kabacoff, Miller, Epstein, Bishop & Keitner, 1985). This is a
commonly used assessment measure of family functioning following traumatic brain injury (Anderson, 2002; Groom et al., 1998; Kreutzer et al., 1994; Kolakowsky-Hayner & Kishore, 1999; Nabors et al., 2002; Ponsford et al., 2003; Sanders, Caroselli, High Becher, Neese & Scheibel, 2002). A cut-off mean score greater than 2 on the FAD-GF will be utilized to differentiate unhealthy from healthy families, a technique suggested by the authors of the FAD (Miller, Epstein, Bishop & Keitner, 1985).

**Qualitative Information.** The Head Injury Family Interview (HI-FI; Kay, Cavallo, Ezrachi & Vavagiakis, 1995) will be used to obtain detailed information about the TBI and its sequelae. The HI-FI is a semi-structured interview used to gain information related to several areas of concern and interest in TBI research. It was developed by Kay et al. (1995) as a way to document the details of the injury and the perceptions of both the TBI survivor and a caregiver/family member related to affective, behavioral, cognitive and physical impairment specific to TBI.

Sections that will be used in this study include the Demographic and Pre-injury Form, sections of the Interview for the Person with the Head Injury (PHI), sections of the Significant Other Interview (SO), and the Impact on the Family Interview (see Appendix D). The Demographic and Pre-injury Form records basic information about the TBI survivor such as age, sex, ethnicity, education, marital and employment status, and specifics of the accident and brain injury. Additionally, this section of the interview includes questions related to pre-accident history, which include such topics as alcohol use, psychiatric history, neurological history, learning problems, pre-existing disabilities, social functioning, and leisure activities. Sections
of the Interview for the Person with the Head Injury that will be administered include: Problems and Changes, Household Responsibilities and the Problem Checklist (PCL). Sections of the Significant Other Interview that will be administered include: Problems and Changes, Problem Checklist (PCL) and Activities of Daily Living. The final portion of the HI-FI, the Impact of the Family Interview, will be used in its entirety and includes a General Section, and a specific section related to the relationship to the other member in the dyad. The interview contains specific sections for spouses, parents, adult siblings, siblings living at home, adult children and children at home (Kay et al., 1995).

The PCL, which is part of the Significant Other Interview and the Interview with the Person with the Head Injury, is a 43-item checklist of symptoms frequently reported following a head injury. First, questions are asked in a yes/no response format in which the caregiver and the TBI survivor assess the presence or absence of different symptoms. If an item is endorsed (Yes), then a follow-up question regarding the severity of the problem is posed in which the respondent is asked to rate the difficulty of the symptom on a 1-7 scale (1 “no problem” through 7 “severe problem”). On the Significant Other version of the PCL, the responded is then asked whether this is a change from pre-injury functioning (Yes/No), and the amount of a strain or burden this specific problem has caused is rated on a 7-point Likert scale. Factor analysis of the PCL yielded three-factors: Affective/Behavioral; Cognitive, and; Physical/Dependency. The PCL has been shown to be both a reliable and valid measure, with good internal consistency of the items in each factor for both the PHI and SO versions. Cronbach’s alphas range from .87 to .92 in the Affective/Behavioral
factor, .77 to .88 in the Cognitive factor, and .65 to .80 in the Physical/Dependency factor (Kay et al., 1995). The HI-FI has been used in previous TBI research (Cavallo et al., 1992; Nabors et al., 2002).

**Injury Severity.** Injury severity will be determined by review of injury history provided by the caregiver/family member during the HI-FI. Individuals will be classified as suffering a mild, moderate or severe TBI depending on their length of coma (LOC), and/or duration of post traumatic amnesia (PTA). Mild brain injury will be defined as LOC less than 30 minutes or PTA less than 24 hours. Moderate brain injury will be defined as LOC greater than 30 minutes or PTA greater than 24 hours. Severe brain injury will be defined as LOC greater than 1 day or PTA greater than 1 week. These rating definitions have been used in previous traumatic brain injury research (Gan, Campbell, Gemeinhardt & McFadden, 2006; Kolb & Whishaw, 2003).

**Current Level of Disability.** The individual’s current level of disability will be measured by the Disability Rating Scale (DRS; Rappaport, Hall, Hopkins, Belleza & Cope, 1982). The DRS is a functional assessment measure comprised of 8 items divided into 4 categories: Arousal and awareness; Cognitive ability to handle self-care functions; Physical dependence upon others, and; Psychosocial adaptability for work, housework or school (see Appendix E). Scores obtained from this measure range from 0 (no disability) to 29 (Extreme Vegetative State) The DRS has been used previously in TBI research to measure the level of disability at the time of participation in the study (McCauley, Hannay & Swank, 2001; Rappaport, 2006; Sanders et al., 2002).
Depression. The presence/absence of depression in the TBI survivor and the
caregiver/family member will be assessed by the Beck Depression Inventory- II
(BDI-II; Beck & Steer, 1988). The BDI-II is a self-report measure comprised of 21
items that evaluate key symptoms of depression including sadness, pessimism, self-
dissatisfaction, guilt, punishment, self-dislike, self-accusation, suicidal ideas, crying,
irritability, social withdrawal, indecisiveness, body image change, work difficulty,
insomnia, fatigue, loss of appetite, weight loss, somatic preoccupation, and loss of
libido (see Appendix F). Each item is measured on a 0 (not present) to 3 (severe)
scale. Scores on each item are added together to provide a total score ranging from 0
to 63. Cut scores are provided for categorizing the severity of depression based on the
total score. The higher the score, the more severe and likely depression is present.
The BDI-II has been shown to a reliable measure, with coefficient alphas of .92
(outpatient sample) and .93 (nonclinical sample) and test-retest reliability coefficient
of .93. The concurrent validity of the BDI-II is also solid with a moderately high
correlation with the Hamilton Psychiatric Rating Scale for Depression- Revised.

Procedure

After obtaining approval from Xavier University’s IRB and permission from
the organizations that sponsor the support groups, participants will be recruited
through support groups conducted by the Brain Injury Association of Ohio, and from
InReturn. The primary investigator will make an announcement about the study and
distribute her contact information to individuals who indicate that they meet inclusion
criteria. Individuals interested in participating will contact the PI and they will reach a
mutually agreed upon time to meet. Informed consent will be obtained from both
members of the dyad (see Appendix G). The TBI survivor and the caregiver/family member will be interviewed separately by the primary investigator using the Head Injury Family Interview.

While one member of the dyad is being interviewed, the other member will complete the AQ/AQ-P, FAD and BDI-II. Across pairs there will be a counterbalance in the order of administration of measures and the interview. For example, in pair 1 the TBI survivor will be interviewed first while the caregiver/family member completes the AQ-P, FAD, and BDI-II. In the second pair, the caregiver/family member will be interviewed first while the TBI survivor completes the AQ, FAD, and BDI-II. This alternation will continue throughout the pairs. Additionally, the packets will be counter-balanced, alternating the order of the AQ/AQ-P, FAD, and BDI-II. While this is the hope, it is possible that due to various circumstances, this may not always occur as dyads may not be able to be interviewed on the same day or at the same time. Therefore, counter-balancing will occur as often as possible.

All interviews will be audio-taped using standard cassette recording equipment. When interviews are completed, the audio tapes will be transcribed either by the researcher or the research assistant(s), removing any identifying information. All information will be kept confidential. Information obtained from the structured interview will provide the data necessary to determine the level of injury severity and gain a general understanding of the TBI individual’s functioning before and after the accident. The open-ended questions of the interview will provide both the caregiver and the TBI survivor the opportunity to share pre-injury information related to personality and functioning, and their unique experiences related to the injury as well.

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as following the injury. During the interviews, the researcher will complete the DRS in order to assess the individual’s current level of disability. If any individual has difficulty completing the AQ/AQ-P, FAD, or BDI-II measures on their own, the researcher/research assistant will be present to assist in reading and explaining how the measures are to be completed.
Chapter IV

Proposed Data Analyses

Description of Sample

Information obtained from the Demographic and Pre-injury form of the HI-FI will be analyzed by frequency analyses, which will be reported as percentages. This will include demographic data for the TBI survivors and caregivers/family members (i.e., gender, ethnicity, marital status, and employment statuses), injury information (i.e., etiology of injury, time since injury, CT or MRI abnormalities, brain surgery, and other accident related injuries), and pre-morbid histories of the TBI survivors (i.e., drug/alcohol use, psychiatric history, neurological history, previous learning problems, and pre-existing disabilities). Means and standard deviations will be computed on the Disability Rating Scale, Injury Severity, and FAD-GF to provide a description of the sample with regards to level of injury severity, current disability level, and overall family interactions and functioning. Means and standard deviations will be reported for AQ/AQ-P and PCL to provide a description of the TBI sample with regards to aggressive tendencies, and behavioral, affective/emotional, and physical changes post-injury.
Description of Injury and Post-injury Experiences

Objective 1 of the study is to describe the injury and post-injury experiences of both the TBI survivor and the caregiver/family member, with specific emphasis on their perceptions of aggressive tendencies, behavioral, affective/emotional and physical changes, and overall family interactions and functioning. To meet these objectives, the qualitative information obtained from the HI-FI will be analyzed for the emergence of reoccurring themes using Auerbach and Silverstein's (1999) grounded theory method, which will be described in further detail below. Themes will be supported with direct quotations from participants.

Objective 2 of the study is to investigate the similarity or differences in the themes reported by the TBI survivor and the caregiver/family member. This feature of the qualitative analysis will focus specifically on aggressive tendencies, behavioral, affective/emotional and physical changes in the TBI survivor, and overall family interactions and functioning post-injury. To meet these objectives, the qualitative information obtained from the HI-FI will be analyzed for the emergence of reoccurring or divergent themes between the TBI survivors and the caregivers/family members. Themes will identified using the grounded theory method (Auerbach & Silverstein, 1999) and will be supported with direct quotations from participants.

Qualitative Analyses

Information obtained from the HI-FI related to the experience of the TBI survivor and the caregiver/family member post-injury will be analyzed qualitatively using a methodology suggested by Auerbach and Silverstein (1999). Given the structure of the HI-FI, many questions are first presented in a yes/no fashion as to
identify the presence or absence of various experiences or symptoms. If endorsed, these items are then followed up with open-ended questions, which allows for further elaboration and exploration. The semi-structured format provides a means to categorize information and easily identify relevant text, which is the first step suggested by Auerbach and Silverstein (1999). Once the relevant text is identified (answers to the follow-up questions), a thematic analysis will be conducted by the researcher in order to identify themes. Auerbach and Silverstein (1999) define a theme as an idea that is expressed by more than one participant. In this study, the researcher will identify repeating ideas within each content area (aggressive tendencies, behavioral, affective/emotional and physical changes, and family interactions and functioning) as reported by the TBI survivor compared to the caregiver/family member. The primary researcher will then use these themes to construct a theoretical narrative in hopes of organizing the participant’s experience into a coherent story by utilizing as many of his/her specific words as possible, while also including the researcher’s theoretical framework for the study. As previously mentioned, themes will be supported by direct quotations of the participants.

Quantitative Analyses

Hypothesis 1 will compare possible differences in the ratings of aggressive tendencies, as measured by the AQ/AQ-P from the TBI survivors and the caregivers/family members. In order to test this hypothesis, paired sample t-tests will be conducted on the scores generated by the TBI survivor on the AQ and their caregiver/family member on the AQ-P.
Hypothesis 2 will compare possible differences in the ratings of family functioning as measured by the FAD-GF from the TBI survivors and the caregivers/family members. In order to test this hypothesis, paired samples t-tests will be conducted on the scores generated by the TBI survivors versus their caregiver/family member on the FAD-GF.

Hypotheses 3, 4, 5 & 6 will only be tested if the scores of the FAD-GF result in healthy/unhealthy sortings of a minimum of 15 participants in each group. The number of participants required in each group is the minimum number suggested by Heiman (1998) when conducting paired samples t-test.

Hypothesis 3 will compare possible differences in the ratings of aggression as measured by the AQ from TBI survivors reporting healthy family functioning (FAD-GF score of ≤ 2) and TBI survivors reporting unhealthy family functioning (FAD-GF scores > than 2). In order to test this hypothesis, an independent samples t-test will be conducted on the scores generated by the TBI survivors reporting healthy family functioning versus TBI survivors reporting unhealthy family functioning on the AQ.

Hypothesis 4 will compare possible differences in the rating of aggression as measured by the AQ-P from caregivers/family members reporting healthy family functioning (FAD-GF score of ≤ 2) and caregivers/family members reporting unhealthy family functioning (FAD-GF scores > than 2). In order to test this hypothesis, an independent samples t-test will be conducted on the scores generated by the caregivers/family members reporting healthy family functioning versus caregivers/family members reporting unhealthy family functioning on the AQ-P.
Hypothesis 5 will compare possible differences in the ratings of aggression as measured by the AQ/AQ-P from TBI survivors reporting healthy family functioning (FAD-GF score of \( \leq 2 \)) and caregivers/family members reporting healthy family functioning (FAD-GF score of \( \leq 2 \)). In order to test this hypothesis, an independent samples t-test will be conducted on the scores generated by the TBI survivors reporting healthy family functioning versus caregivers/family members reporting healthy family functioning on the AQ/AQ-P.

Hypothesis 6 will compare possible differences in the ratings of aggression as measured by the AQ/AQ-P from TBI survivors reporting unhealthy family functioning (FAD-GF scores \( > 2 \)) and caregivers/family members reporting unhealthy family functioning (FAD-GF scores \( > 2 \)). In order to test this hypothesis, an independent samples t-test will be conducted on the scores generated by the TBI survivors reporting unhealthy family functioning versus caregivers/family members reporting unhealthy family functioning on the AQ/AQ-P.
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Appendix A

Appendix B

Appendix C

Instrument Used

The Family Assessment Device (FAD) is protected by copyright so it is not reproduced in this document. This measure is available through Brown University Family Research Program. Contact Christine E. Ryan, Ph.D. at Christine_Ryan@Brown.edu to obtain further information.
Appendix D

Instrument Used

The N.Y.U. Head Injury Family Interview was developed under funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (Grant No. H133B0028) to New York University Medical Center. Use, modification, or translation of the HI-FI requires permission of the authors: Thomas Kay, Marie M. Cavallo, and Ora Ezrachi; therefore, it is not reproduced in this document. Please contact Dr. Ezrachi (Ora.Ezrachi@nyumc.org) for further information about the HI-FI.
Appendix E

The Disability Rating Scale (DRS) is available in the public domain. See Rappaport, M., Hall, K.M., Hopkins, K., Belleza, T., & Cope, N.D. (1982). Disability rating scale for severe head trauma: Coma to community. *Archives of physical medicine and rehabilitation, 63*(3), 118-123.
Appendix F

Instrument Used

The Beck Depression Inventory- II (BDI-II) is protected by copyright so it is not reproduced in this document. This measure is available through Pearson Assessments at www.pearsonassessments.com.
Appendix G

Draft Informed Consent

Study Title: The experience of a Traumatic Brain Injury: TBI survivors' and caregiver/family members' perspectives.

Investigator: Lesly Hendershot, M.A. (513) 543-7050

Contact Information: Kathleen Hart, Ph.D. (513) 745-3278

You are being asked to participate in a study conducted through Xavier University. The University requires that you give your signed agreement to participate in the study. The investigator will explain in detail the purpose of the study, the procedures to be used, and the potential benefits and risks of participation. You may ask any questions you have about the study. You have the right to refuse participation in the study. You also have the right to withdraw from the study at any time without explanation or penalty.

A basic explanation of the study is written below. Please read this explanation and discuss any questions that you may have. If you decide to participate in the project, please sign the form below in the presence of the person who explained the study to you. You will be given a copy of this form to keep.

For this study, we are interested in the TBI survivors’ and their caregivers/family members’ experiences following the injury. Some basic demographic information will be collected (e.g. your age, marital status, race/ethnicity, etc.) as well as information related to the injury. You will be asked to share your experience related to the TBI (how it happened, what has changed, and what has stayed the same) through an interview, which will last approximately an hour. You should be able to freely and easily answer the questions asked, but may choose to not answer questions you are uncomfortable answering. This interview will be conducted in a separate room to ensure privacy. The interview will be audio taped so that we can devote full attention to the conversation.

In addition to the interview, you will also be asked to complete two questionnaires. One questionnaire will ask questions about the family and the other will ask questions about behaviors in the TBI survivor. Through the interview and questionnaires we hope to better understand your experiences.

There are minimal risks of participating in this study. Some people may get upset when discussing personal issues related to their lives. If this occurs you are free to refuse to answer any questions or discontinue participation in the study. The potential benefits of participation include the opportunity to help others understand your TBI experience.
All information gathered will be kept confidential. Your name will not be associated in any way with the study. Any identifying information will not be included in the data analysis. Audio recordings of the interviews will be stored separately from consent and demographic information forms. These recordings will be kept in a locked cabinet, accessible only to the interviewer. Tapes may be used for educational or professional purposes, but at no time will they be matched with any identifying information. Upon completion of the study, all materials will be destroyed in its entirety. As indicated above, you have the right to refuse participation or withdraw from the study at any point without penalty or explanation.

I understand that it is not possible to identify all potential risks in a research procedure; however, I believe that reasonable safeguards have been taken to minimize both the known and potential unknown risks.

__________________________________________  _____________
Signature                                      Date

__________________________________________  _____________
Family Member Signature                       Date

__________________________________________  _____________
Witness Signature                             Date
Chapter V

Dissertation

Abstract

The objectives of this study were to describe the post injury experience as reported by TBI survivors and family members, with specific focus on aggressive behaviors and family functioning. Participants were 27 TBI survivors and 21 caregiver/family members with a mean time since injury (TSI) of 13.59 years (SD=9.38). Both members of the dyad completed measures of aggression and family functioning and were interviewed separately using a semi-structured interview to gain qualitative information related to post-injury changes. Results showed no significant difference between the reports provided by the TBI survivors and the caregiver/family members. However, TBI survivors who reported an unhealthy level of family functioning endorsed a significantly higher level of aggression than TBI survivors who reported healthy family functioning. Themes that emerged related to long-term changes in the TBI survivor post-injury included the presence of anger/irritability, memory problems, and depression and increased emotionality.
Aggression in Traumatic Brain Injury: 
Difference in Perception and Impact on Family Functioning

Traumatic Brain Injury (TBI) is one of the most common neurological disorders. The Center for Disease Control reports that approximately 1.5 million Americans sustain a TBI each year. Of these, 1.1 million are treated and released from hospital emergency rooms, and 235,000 are hospitalized (Langlois, Rutland-Brown & Thomas, 2006). Approximately 5.3 million Americans are currently living with TBI-related disabilities, 25% of whom have sustained a moderate/severe brain injury (Langlois et al., 2006). The majority of individuals who endure a TBI are typically young males between the ages of 19 and 25 and the TBI is typically a result of an automobile accident, sports-related injury, or a fall (Morton & Wehman, 1995).

TBI occurs when there is a blow or jolt to the head, disrupting the normal functioning of the brain. The injury can range from mild to severe, with each category varying in level of symptomatology (Langlois et al., 2006). Injury severity may be defined by the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) obtained immediately following the injury, the length of Loss of Consciousness (LOC) and/or the duration of Post Traumatic Amnesia (PTA). A widely used method of defining injury severity in the research is by using the LOC and/or PTA (Kay, Newman, Cavallo, Ezrachi & Resnick, 1992; Williams, Levin & Eisenberg, 1990).

Following the immediate injury, an individual can experience post injury symptoms, also called Post Concussion Syndrome (PCS). PCS is defined as a multitude of symptoms that develop either immediately following TBI or weeks later.
and can last for weeks, months or years following the injury. These symptoms include physiological problems such as vertigo, dizziness, headaches, and seizures (National Institute of Neurological Disorders and Stroke, 2002), cognitive difficulties such as problems with memory, attention, and problem solving, and behavioral and mental health issues such as depression, irritability, aggression, anxiety and compulsive behavior (Kay et al., 1992). Although there is controversy about the nature and cause of PCS, some studies have suggested that it is very common. For example, Bazarian and Atabaki (2001) found that 58% of the mild TBI patients in their sample met criteria for PCS one month post-injury, 43% three months post-injury, and 25% six months post-injury.

**Aggression**

TBI can be accompanied and complicated by cognitive and personality changes that result in emotional and behavioral challenges, including emotional disinhibition and aggression. Previous research has suggested that the prevalence of aggressive behaviors in TBI survivors may be quite high, with reports ranging from 11-96% (Brooke, Questad, Patterson, 1992; Kim, Manes, Kosier, 1999; Levin & Grossman, 1978; Rao, Jellenik & Woolston, 1985) depending on the operational definition of aggression. Moreover, it appears that these challenging behaviors remain up to 5 years post-injury in 25% of TBI survivors (Baguley et al., 2006). However, research in this area is complicated by lack of a clear definition of what constitutes aggression and significant differences in ratings of post-injury aggression by the individual with TBI and others, such as caregivers or family members.
Tateno, Jorge and Robinson (2003) conducted a study that examined the correlates of aggressive behavior during the first six months post-injury. Of the 89 TBI participants, 33.7% demonstrated significant aggressive behaviors, which included verbal aggression, physical aggression against objects, and physical aggression against self or others during this early recovery period. They found that aggressive behaviors were significantly associated with the presence of a frontal lobe lesion, major depression, poor pre-morbid social functioning, and a history of alcohol and substance abuse, but the aggression was not significantly associated with the severity of the injury. Baguley et al. (2006) assessed the prevalence of aggression in TBI survivors. Participants completed a battery of tests that included the Overt Aggression Scale that was utilized to assess the presence of aggression at six months, two years, and five years post-injury. Of the 228 TBI participants, 25% of the sample could be classified as aggressive at all three time points, including five years after injury. Verbal aggression, such as screaming and yelling, was the most frequently endorsed type of aggression. Like Tateno et al. (2003), Baguley et al. found no relationship between injury severity and the presence of aggression. Together, the findings of these studies suggest that the majority of TBI survivors who display aggression six months post-injury will continue to display this behavior for a long time after the injury.

Self-Awareness

Many previous studies have found that the reports of caregivers and family members differ significantly from the self-report of the TBI survivor, particularly with regard to behavioral changes post-injury (Fordyce & Roueche, 1986; Hart,
Whyte, Kim & Vaccaro, 2005; Marsh & Kersel, 2006; Prigatano, 1991). It has been reported that up to 45% of survivors of moderate to severe TBI demonstrate self-awareness deficits (Flashman & McAlister, 2002). A common way of assessing self-awareness is via discrepancy ratings between TBI survivors and their caregivers (Prigatano, 1991; Hart et al, 2005). Fleming and Strong (1999) suggested that self-awareness of deficits often improves during the first six months to one-year post-injury, but individuals whose deficits last beyond that period rarely improve (Newman, Garmone, Beatty & Ziccardi, 2000; Ranseen, Bohaska & Schmitt, 1990). In a study of 47 TBI survivors and their caregivers, 80% of the behaviorally disturbed individuals reported a significant overestimation of their social functioning when compared to their caregivers’ ratings, whereas only 45% of the non-behaviorally disturbed group produced this discrepancy in ratings (Bach & David, 2006).

Marsh and Kersel (2006) examined the correspondence rates of 62 adults who had experienced a severe TBI and their primary caregivers at one year post-injury on the Head Injury Behavior Rating Scale (HIBS). The total number of behavioral problems and the frequency of these problems were investigated. Caregivers reported significantly more behavioral problems ($M = 9.84$) compared to the survivors’ self-rating ($M = 6.18$), and caregivers reported a significantly higher frequency of seven of the behaviors (overly sensitive, impulsivity, lacks motivation, childish, poor insight, lack of initiative, and irresponsibility) when compared to the self-ratings.

**Family Functioning**

Given the frequency of behavioral changes following TBI, it is not surprising that several studies have found significant negative changes in family functioning.
following TBI. The reasons for these changes remain unclear. Previous studies have found that one-third to one-half of families of brain injured people report unhealthy or poorer family functioning following the injury (Kreutzer, Gervasio & Camplair, 1994a; Marsh, Kersel, Havill & Sleigh, 2002; Testa, Malec, Moessner & Brown, 2006). Several studies have found that the overall severity of the injury does not appear to be significantly related to family functioning (Anderson, Catroppa, Haritou, Morse & Rosenfeld, 2005; Gan & Schuller, 2002; Groom, Shaw, O’Conner, Howard & Pickens 1998; Sawchyn, Mateer & Braxton, 2005), but specific neurobehavioral changes in the TBI survivor have been identified as significant predictors and correlates of family functioning (Anderson et al, 2005; Anderson, Paramount & Monk, 2002; Groom et al, 1998; Kreutzer, Gervasio & Camplair, 1994b; Testa et al., 2006). More specifically, greater anger problems (Ponsford, Oliver, Ponsford & Nelms, 2003) and poor impulse control (Wells, Dywan & Dumas, 2005) are associated with declines in family functioning. Another area that has been found to be correlated with poorer family functioning following TBI is the difference in opinions of behavioral changes as reported by the caregiver and the injured individual (Livingston & Brooks, 1988).

The current study was designed to provide additional information about the long-term post-injury adjustment of TBI survivors based on both qualitative and quantitative information. Based on information gathered in semi-structured interviews, the first objective was to describe the injury and post-injury experiences of both the TBI survivor and the caregiver/family member and to examine the presence of absence of similar themes in their descriptions of their experiences.
Specific focus areas included the TBI survivor’s aggressive tendencies, behavioral, affective/emotional and physical changes, and overall family interactions and functioning.

In addition to the qualitative aspects of this study, quantitative data were also collected. TBI survivors and caregivers/family members separately completed the Aggressive Questionnaire/Partner Aggressive Questionnaire and the Family Assessment Device (FAD). We hypothesized that caregiver/family members would report significantly higher levels of aggression and poorer family functioning than the TBI survivors and that those caregivers who reported unhealthy family functioning on the FAD would report higher levels of aggression in the TBI survivor.

Method

Participants

Participants were 27 community dwelling TBI survivors and 21 caregiver/family members recruited from the Brain Injury Association of Ohio Cincinnati support groups between February and December 2009. Table 1 provides information about the demographic characteristics of the sample. As can be seen, most of sample were men (59%), and nearly half of the TBIs were sustained in motor vehicle accidents (48%). The mean age at time of injury was 32.80 years (SD=13.27), and the average time since injury was 13.59 years (SD=9.38). The majority of the sample was composed of severely injured persons (77.8%) as determined by the length of coma (LOC) and/or duration of post traumatic amnesia (PTA). Based on information obtained from the Disability Rating Scale, current level of disability ranged from 0 to 10.0 (mean=3.63, SD=2.57), with 29.6% falling in the partially disabled category. Interestingly, while 85% of the sample reported to have been
working either full or part-time prior to the injury, only 37% reported to be working post injury and 56% reported to be unemployed due to their disability. Additionally, 7% of the TBI survivors indicated a change in marital status post injury. Select pre-accident characteristics are also presented in Table 1. Notably, 30% of the sample reported moderate to heavy alcohol use, 22% reported moderate to heavy drug use, and 11% reported a significant psychiatric history prior to the accident.

Caregiver/family member demographic characteristics are presented in Table 2. Due to the inability of 6 TBI survivors to identify a caregiver/family member willing to participate, the caregiver/family member sample was smaller (n=21). In contrast to the TBI survivors, the majority (63%) of caregiver/family members were women with more than half (62%) of the sample being either a parent or spouse to the TBI survivor. The majority (85%) endorsed that they knew the TBI survivor “very well.”

Measures

Aggression Questionnaire and Partner Aggression Questionnaire (AQ/AQ-P). To assess the overall level of the TBI survivor’s anger and aggression, the TBI survivor and the caregiver completed similar instruments, the AQ (Buss & Perry, 1992, see Appendix A), an updated version of the Buss-Durkee Hostility Inventory (Buss & Durkee, 1957) and the AQ-P (O’Conner, Archer & Wu, 2001, see Appendix B). The 29 items on the measures are identical which allows for direct comparison of the total aggression score. Each item is rated on a five point scale ranging from “Not at all like me” to “Completely like me” on the AQ, and ranging from “Never or hardly ever applies to him/her” to “Very often applies to him/her” on
the AQ-P. The total score which can range from 29 to 145, was used in this study. This measure is reported to have good internal consistency reliability, ranging from .76 to .94, and test-retest reliability of the sub-scales ranging from .76 to .94 (Buss & Perry, 1992). Previous research has utilized the AQ and the AQ-P to provide assessment of differences in perceptions of the presence and characteristics of aggression following traumatic brain injury (Dyer, Bell, McCann & Rauch, 2006).

**Family Assessment Device (FAD).** The FAD (Epstein, Baldwin & Bishop, 1983) is a self-report measure composed of 60 questions rated on a 4-point likert-type scale ranging from “strongly agree” to “strongly disagree” (see Appendix C). The FAD is designed to measure family functioning based on the McMaster Model of Family Functioning (Epstein et al., 1983) and has been used frequently in TBI research (Anderson, 2002; Groom et al., 1998; Kreutzer et al., 1994; Kolakowsky-Hayner & Kishore, 1999; Nabors et al., 2002; Ponsford et al., 2003; Sanders et al., 2002). This measure is reported to have good internal consistency, ranging from .72 (both Behavior Control and Roles scales) to .92 (General Functioning scale) and good test-retest reliability over one week, ranging from .66 (Problem Solving) to .76 (Affective Responsiveness; Kabacoff, Miller, Epstein, Bishop & Keitner, 1985). The 12-item General Functioning scale (FAD-GF) which measures overall functioning of the family was used in this study. A cut-off mean score greater than 2 on the FAD-GF was utilized to differentiate unhealthy from healthy families, a technique suggested by the authors of the FAD (Miller, Epstein, Bishop & Keitner, 1985).

**Head Injury Family Interview (HI-FI).** The Head Injury Family Interview (HI-FI; Kay, Cavallo, Ezrachi & Vavagiakis, 1995) was used to obtain detailed
information about the experiences of the TBI survivor and caregiver/family member. The HI-FI is a semi-structured interview that gathers information related to several areas of concern and interest in TBI research. It was developed by Kay et al. (1995) as a way to document the details of the injury and the perceptions of both the TBI survivor and a caregiver/family member related to affective, behavioral, cognitive and physical impairment specific to TBI. Sections that were used in this study include the Demographic and Pre-injury Form, sections of the Interview for the Person with the Head Injury (PHI), sections of the Significant Other Interview (SO), and the Impact on the Family Interview (see Appendix D). The HI-FI is composed of yes/no questions and open-ended questions, thus both quantitative and qualitative data related to pre-injury characteristics and post injury sequelae were obtained. The HI-FI has been used in previous TBI research (Cavallo et al., 1992; Nabors et al., 2002).

**Injury Severity.** Injury severity was determined by review of injury history provided by the caregiver/family member during the HI-FI. Individuals were classified as suffering a mild, moderate or severe TBI depending on their length of coma (LOC), and/or duration of post traumatic amnesia (PTA). Mild brain injury was defined as LOC less than 30 minutes or PTA less than 24 hours. Moderate brain injury was defined as LOC greater than 30 minutes or PTA greater than 24 hours. Severe brain injury was defined as LOC greater than 1 day or PTA greater than 1 week. These rating definitions have been used in previous traumatic brain injury research (Gan, Campbell, Gemeinhardt & McFadden, 2006; Kolb & Whishaw, 2003).

**Disability Rating Scale (DRS).** The individual’s current level of disability was measured by the Disability Rating Scale (DRS; Rappaport, Hall, Hopkins,
Belleza & Cope, 1982; see Appendix E). The DRS is a functional assessment measure comprised of 8 items divided into 4 categories: Arousal and awareness; Cognitive ability to handle self-care functions; Physical dependence upon others; and Psychosocial adaptability for work, housework or school. Scores obtained from this measure range from 0 (no disability) to 29 (Extreme Vegetative State) The DRS has been used previously in TBI research to measure the level of disability at the time of participation in the study (McCauley, Hannay & Swank, 2001; Rappaport, 2006; Sanders et al., 2002).

Procedure

The study was approved by Xavier University’s Institutional Review Board (Appendix F). Participants were recruited through support groups conducted by the Brain Injury Association of Ohio. The primary investigator or a graduate student assistant attended regular meetings between February and December 2009 and made an announcement about the study and distributed her contact information to individuals who indicated that they meet inclusion criteria (were at least 18 years of age, English speaking, and sustained a open or closed head injury at least 6 months prior to study). Individuals interested in participating contacted the PI and a mutually agreed upon time to meet was determined. Informed consent was obtained from both members of the dyad (see Appendix G). The TBI survivor and the caregiver/family member were interviewed separately by the primary investigator and/or the secondary investigator using the Head Injury Family Interview.

While one member of the dyad was being interviewed, the other member completed the AQ/AQ-P, FAD and BDI-II. Across pairs there was a counter-balance
in the order of administration of measures and the interview. For example, in pair 1 the TBI survivor was interviewed first while the caregiver/family member completed the AQ-P, FAD, and BDI-II. In the second pair, the caregiver/family member was interviewed first while the TBI survivor completes the AQ, FAD, and BDI-II. This alternation continued throughout the pairs when both individuals of the dyad were interviewed on the same date (n=16). Additionally, the packets were counterbalanced, alternating the order of the AQ/AQ-P, FAD, and BDI-II.

All interviews were audiotaped and transcribed by the researcher or a research assistant, removing any identifying information. All information was kept confidential. Information obtained from the structured interview provided the data necessary to determine the level of injury severity and gain a general understanding of the TBI individual’s functioning before and after the accident. During the interviews, the researcher completed the DRS in order to assess the individual’s current level of disability. If the TBI survivor (n = 3) was unable to complete the AQ/AQ-P, FAD, or BDI-II measures independently, the researcher/research assistant assisted in reading and clarifying how the measures were to be completed.

Results

Quantitative Research

A primary aim of the study was to examine possible differences in reports of aggression and family functioning between TBI survivors and caregiver/family members. Total scores of the AQ/AQ-P and the FAD-GF were compared using paired-samples t-test. Table 3 provides the means, standard deviations and t-test results of these analyses. As can be seen, there were no statistically significant
differences in scores on the AQ/AQ-P or FAD-GF. Notably, however, 11% of the TBI survivors self-reported and 14% of the caregiver/family members reported a higher AQ/AQ-P total score than the general population mean reported by Buss & Perry (1992).

Next, we divided the dyads into groups based on agreement or disagreement of reports of family functioning (Healthy vs. Unhealthy) based on the FAD-GF scores, using criteria described by Miller et al. (1985). Agreement between the categorization of FAD-GF scores derived from TBI survivors and caregivers was low. Of the 21 dyads, 11 dyads (52%) produced FAD-GF scores by both respondents that were in the same category; 6 dyads (29%) produced scores that were both in the Healthy category and 5 dyads (24%) both reported an Unhealthy level of family functioning. The dyads that reported an Unhealthy level of family functioning appeared to report a higher level of aggression as reported by both the TBI survivors ($M=72.0$ $SD=29.17$) and the caregiver/family members ($M=84.40$ $SD=20.82$) compared to the dyads that reported a Healthy level of family functioning. However, due to the small sample size in each of these groups, statistical comparison of AQ/AQ-P scores was not computed. A summary of these results is presented in Table 4.

The AQ and AQ-P scores for TBI survivors and caregiver/family member individually reporting Healthy versus Unhealthy family functioning are presented in Table 5, along with the t-test results comparing them. When divided based on the TBI survivors’ FAD-GF scores, there was a significant difference in AQ scores. The magnitude of the differences in the means was very large (eta squared = .17). This
finding indicates that the TBI survivors who classified their family as functioning in the Unhealthy range self-reported a significantly higher amount of aggression compared to those TBI survivors who classified their family as functioning in the Healthy range. Notably, the majority of the caregiver/family member sample (67%) reported a Healthy level of family functioning as assessed by the FAD-GF. Since there was not an equal distribution of caregiver/family members reporting Healthy (n=14) and Unhealthy family functioning (n=7), a statistical comparison of AQ-P scores was not computed.

Because time since injury (TSI) was found in a previous study (Erg, Rapport, Coleman & Hanks, 2002) to be related to family functioning, we compared the FAD-GF and AQ/AQ-P scores of those whose injury occurred 10 or fewer years ago (n =12) with the scores of those whose injury occurred 11 or more years ago (n = 15). The means, standard deviations, and t-test results for these analyses are presented in Table 6 for both caregiver/family members’ and TBI survivors’ scores. It should be noted that the sample size for the caregiver/family member ratings (n=21) is less than the TBI ratings (n=27), as single TBI participants were included in addition to the dyad participants. As can be seen, caregiver/family members’ ratings of family functioning did not differ by TSI, but TBI survivors with TSI less than 11 years reported significantly poorer family functioning compared to TBI survivors with TSI greater than 11 years (eta=0.11). Total scores of the AQ and AQ-P were not significantly different by TSI, using either TBI survivor or caregiver/family member scores. Additionally, Pearson product moment correlation also yielded no significant relationship between TSI and family functioning.
Qualitative Findings

The other primary objective of this study was to describe the injury and post-injury experiences of both the TBI survivor and the caregiver/family member using qualitative methods. This portion of the study specifically focused on changes in the TBI survivor post injury; ability to cope with post-injury changes; and overall family interactions and functioning. In addition to the open-ended questions of the HI-FI, TBI survivors and caregiver/family members answered closed-ended (yes/no; ratings) questions. If the closed-ended questions indicated the presence of a problem, the individual was asked to elaborate, from which the direct quotations were obtained.

Tables 7, 8 and 9 provide a summary of participants’ responses to many of the close-ended questions. Both the TBI survivors and the caregiver/family members were first asked if there were any significant changes in the TBI survivor since the injury. Nearly all of the participants (95%) positively answered this question indicating some significant change in the TBI survivor post injury. Individuals were then asked to identify if there were changes in specific areas including physical problems, changes in behavior, differences in thinking, and differences in social interactions. Nearly half of the sample (52% of TBI survivors and caregivers/family members) endorsed changes in all of the areas. The most consistently cited problem was changes in thinking.

Caregiver/family members also answered questions specifically related to the impact the injury has had on the family. 81% of the caregiver/family members reported that the TBI survivor was more dependent on the family, and 57% of the
sample reported a necessary change in living arrangement for the TBI survivor post injury.

Themes that emerged from the open-ended questions answered by both the TBI survivors and caregiver/family members are presented in Table 10. As previously mentioned, 85% of the TBI survivors and 86% caregiver/family members reported a behavioral change in the TBI survivor post injury. When asked to elaborate, nearly one half of the caregiver/family members (48%) and one third of the TBI sample (33%) identified problems with anger/irritability in the TBI survivor. For example, one TBI survivor stated, “the biggest issue that I deal with on a regular basis is the underlying cauldron of anger. …when I first got out of the hospital my idea then was a pair of gloves and a bat would take care of everything.”

Of the TBI survivors and caregiver/family members who endorsed a change in thinking, nearly half of the TBI survivors (44%) and caregiver/family members (48%) included memory problems in the elaboration of these changes. For example, one caregiver stated, “The memory of a lot of things are just not there.” A TBI survivor stated, “I can’t remember peoples names. I have trouble remembering all kinds of things. I have to think of special ways to remember.” Other direct quotes to support this theme are presented in Table 11.

Depression emerged as another theme in the interviews when participants were asked to elaborate on what the overall biggest change was post injury. Nearly 14% of both samples reported difficulties with depression and increased emotionality. A TBI survivor stated, “I just can’t shake the depression and I did not have that prior
(sic)...I’m just not a happy person.” Additional quotes to support this theme are presented in Table 12.

Not all post-injury changes described by TBI survivors or family members were negative. Interestingly, when discussing changes in social interactions, 26% of the TBI survivors and 29% of the caregiver/family members indicated that the TBI survivor was more sociable and talkative since their injury, which highlights a potential strength that emerged as a result of the injury. For example, one caregiver stated, “She is much more social.” Other direct quotes to support this theme are presented in Table 13. Direct quotes that do not support the previously identified themes are presented in Appendix K.

Discussion

Although previous studies have assessed the prevalence of aggression in the TBI population post injury, few studies have examined specifically how aggression may impact family functioning. Moreover, previous studies have failed to investigate the specific relationship between aggression, awareness of this behavioral change, and the impact this has on family functioning. Finally, very few studies have examined the long-term impact of TBI on the family system or have provided a qualitative assessment of the post-injury changes as reported by the TBI survivor and the caregiver/family member many years after the injury has occurred. One goal of the present study was to investigate possible discrepancies in reports of aggression and family functioning between the TBI survivors and the caregiver/family members. Another goal of the study was to determine if reports of aggression differed based on the level of family functioning reported (Healthy verses Unhealthy). The final goal of
the study was to describe the post injury experience, focusing on aggressive behaviors and family functioning as reported by the TBI survivor and the caregiver/family member, specifically investigating similarities and differences in these reports.

Although the present sample size was relatively small and similar to previous TBI samples with regards to gender (59% male) and etiology of injury (48% motor vehicle accident), this group of participants is different from many previously studied samples with regards to the length of time since injury. Previous studies that have investigated the prevalence and impact of aggression in the TBI population have reported mean TSIs ranging from 23 days (Tateno et al, 2003) to 5 years (Baguley et al, 2006). Studies that have previously investigated family functioning post TBI have reported mean TSIs ranging from 57.5 days (Carnes & Quinn, 2005) to 12 years (Katz, Kravetz & Grynbaum, 2005). The present samples mean TSI of 13.59 years (SD=9.38) is much greater than most previous studies' samples. Therefore, the findings from this study are unique in that it captures the long-term adjustment and changes of TBI survivors and caregiver/family members. Themes that emerged related to these long-term changes included the presence of anger/irritability, memory problems, depression, and increased emotionality. More specifically, even more than a decade post-injury, 11% of the TBI survivors and 14% of caregiver/family members in this sample report higher levels of aggression in the TBI survivor as compared to the general population. Additionally, 20% of the sample reported an Unhealthy level of family functioning 11 or more years post injury; however, this percentage is relatively similar to the general population mean of 22% (Miller, Epstein, Bishop & Keitner, 1985).
In the current study, differences in reports of aggressive behaviors or type of family functioning between the TBI survivors and the caregiver/family members were not significant. Therefore, it appears that this sample of TBI survivors shared a similar understanding with the caregiver/family members with regards to how the family is functioning and behavioral changes within themselves. Draper, Ponsford & Schonberger (2007) reported a similar agreement within their sample, they found no differences in reports of behavioral changes between the TBI survivors and the caregiver/family members. Similar to the present study, their sample was assessed many years post-injury (mean TSI=10.56 years). Previous studies that have reported discrepancy in ratings of behavioral changes between TBI survivors and caregiver/family members generally assessed for these differences within one year of the injury (Bach & David, 2006; Marsh & Kersel, 2006). This suggests that given enough time and opportunity for feedback, the TBI survivors’ self-awareness may increase, allowing for similar understanding of the post-injury changes.

The only significant difference in the current study was in self-reported level of aggression of TBI survivors reporting a Healthy level of family functioning compared to those TBI survivors reporting an Unhealthy level of family functioning. The TBI survivors who rated their family as functioning as unhealthy reported significantly higher amounts of aggression than those who described their family as healthy. Previous research has identified a similar association between aggression and family functioning at one-year post injury (Testa et al., 2006). The current finding suggests that the association between these two variables remains many years after the injury.
Concerning the overall assessment of aggression in the TBI sample, only 11% of the TBI survivors self-reported and 14% of the caregiver/family members reported levels of aggressive behavior that are higher than the general population. Previous research has estimated aggressive behaviors to be present in 11-96% of TBI survivors immediately following injury (Brooke et al., 1992; Kim et al., 1999; Levin & Grossman, 1978; Rao, Jellenik & Woolston, 1985). Studies that have examined the presence of aggressive behaviors six months and five years post injury report prevalence rates of 33.7% (Baguley et al., 2006) and 25% respectively (Tateno et al., 2003). These two previous studies significantly differed from the current study with regard to length of time since injury and distribution of men and women. Again, the greater TSI and more equal representation of men and women may contribute to the lower levels of aggressive behaviors in the TBI survivors.

Although FAD-GF scores of TBI survivors did not significantly differ from that of their caregiver/family member, the categorization of their scores into Healthy or Unhealthy categories was consistent for only about half of the dyads. Similar to the TBI survivors who individually reported Unhealthy family functioning, those dyads in which both individuals reported Unhealthy family functioning appeared to report a higher amount of aggression in the TBI survivor, based on the report of both the TBI survivor and the caregiver. Of the 48% of dyads who did not produce the same categorization of family functioning, there was little pattern to the disagreement. That is, some caregivers reported poorer family functioning than the TBI survivor and some reported better family functioning. However, it is still important to note that approximately one-third of the present sample reported an Unhealthy level of family
functioning, which is consistent with the findings of previous studies (Kreutzer et al., 1994a; Marsh et al., 2002; Testa et al., 2006) and may reflect the long-term impact of TBI on the family system.

Since a previous study had found TSI and family functioning to be related in the caregiver population (Ergh, Rapport, Coleman & Hanks, 2002), we decided to investigate any difference in aggression or family functioning based on the length of time since the injury. Just under half (44%) the TBI survivors’ injuries occurred 10 or fewer years ago. Caregiver/family members did not produce FAD-GF scores that differed significantly by TSI. However, TBI survivors with TSI less than 11 years reported significantly poorer family functioning compared to TBI survivors with TSI greater than 11 years. This suggests that TBI survivors’ perception of family functioning may change more slowly as the length of time since injury increases as compared to caregiver/family members’ perceptions. Previous studies on this topic have been mixed: Ergh et al. (2002) found a significant relationship between TSI and family functioning, but Groom et al. (2001) and Kreutzer et al. (1994a) found that TSI was unrelated to family functioning.

Description and qualitative findings of the present study provided additional information related to long-term, post injury changes. Nearly all of the participants (95%) reported some significant change in the TBI survivor post injury. TBI survivor and caregiver/family member reports of post injury changes generally appeared quite similar with over half of the sample (52%) reporting changes in all areas assessed. Themes of difficulty with anger/irritability, difficulty with memory problems, and difficulty with depression were noted. These themes are consistent with a previous
TBI AND AGGRESSION

qualitative study that found memory problems to be present in 67% of TBI survivors; anger/irritability to be present in 64%; and depression to be present in 57% of TBI survivors 5 years post-injury (Brooks et al., 1986). Notably, the present study suggests that these difficulties persist even several years later.

A possible strength was noted when assessing changes in social interactions. Twenty-six percent (26%) of the TBI survivors and 29% of the caregiver/family members indicated that the TBI survivor was more sociable and talkative following their injury. While this may suggest increased confidence in the TBI survivor in initiating social interactions, it does not necessarily reflect an increase in positive social interactions and relationships. Galski, Tompkins and Johnston (1998) noted a relationship between conversational skills and poor levels of social integration. The authors found that poorer social integration was associated with greater wordiness and number of topics discussed during the TBI participant’s narrative conversation task. While the TBI survivors may be more likely to initiate conversation with someone, the other individual’s receptiveness and the ultimate social integration of the TBI survivor may not be successful due to difficulties with conversational skills. Therefore, while TBI survivors and caregiver/family members may report an increase in social interactions, it is possible that these interactions do not result in meaningful relationships. Specifically, it should be noted that in the present sample of 27 TBI survivors, 6 (22%) were unable or unwilling to identify a caregiver/family member to participate with them in the study. This may speak to the possible difficulties in post-injury relationships for the TBI survivor. Moreover, 11% of the TBI survivors and
10% of the caregiver/family members endorsed themes of a loss or lack of friendships.

Interestingly, this sample's TBI survivors' reports of post-injury changes are more similar to the caregiver/family members' reports than has been found in previous research. It has been reported that up to 45% of survivors of moderate to severe TBI demonstrate self-awareness deficits (Flashman & McAlister, 2002). The present study found no significant difference in reports of aggression or family functioning between the TBI survivors and the caregiver/family members, suggesting self-awareness in the TBI survivors. It is possible that given the significant time since injury, the TBI survivors have had the opportunity on several occasions to receive feedback related to post-injury changes. It is also possible that the level of self-awareness in this sample was greater due to the fact that all participants were recruited from a brain injury support group that meets monthly to discuss various post-injury adjustment issues.

Despite the unique features and valuable information provided by the present study, there are several limitations and weaknesses to the study that need to be addressed. First, the sample size was quite small and homogeneous with regards to ethnicity (100% Caucasian); these features limit generalizability. Also, as previously mentioned, the fact that all participants were recruited from a brain injury support group may have impacted the response patterns. The majority of the participants have attended the support group for some time, which may be a factor in the survivors' self-awareness of post-injury changes. Given the nature and focus of the support
group, it is also possible that TBI survivors who choose to attend may be experiencing a unique set of difficulties and strengths.

Given the combined qualitative/quantitative methodology of this study and the uniqueness of sampling long-term TBI survivors, several avenues for future research emerged. First, the possible relationship of aggression, self-awareness, and family functioning should be investigated with a larger sample in order to increase generalizability. The specific themes identified in the qualitative portion of the study also warrant further exploration. Previous studies have identified frequent reports of depression in both the TBI survivor (42%; Kreutzer, Seel & Gourley, 2001) and caregiver/family member (23%; Harris, Godfrey, Partridge and Knight, 2001) up to two and three years post injury, respectively. Depression has also previously been found to be associated with aggressive behaviors following the injury (Baguley et al., 2006; Tateno et al., 2003). However, research has not investigated the possible relationship between the presence of depression, aggression, and self-awareness of changes and the impact this has on family functioning. Moreover, research has not examined the presence and impact of these symptoms many years following the injury.
References


### Demographic Characteristics of TBI Participants (n=27)

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>16</td>
<td>59.3</td>
</tr>
<tr>
<td>Females</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td><strong>Injury Severity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td>Moderate</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td>Severe</td>
<td>21</td>
<td>77.8</td>
</tr>
<tr>
<td><strong>Marital status pre-injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Married/Cohabitating</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td><strong>Marital status post-injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Married/Cohabitating</td>
<td>10</td>
<td>37.0</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>6</td>
<td>22.2</td>
</tr>
<tr>
<td><strong>Employment status pre-injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full-time</td>
<td>21</td>
<td>77.8</td>
</tr>
<tr>
<td>Working part-time</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Student full-time</td>
<td>4</td>
<td>14.8</td>
</tr>
</tbody>
</table>
### Employment status post-injury

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full-time</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td>Working part-time</td>
<td>7</td>
<td>25.9</td>
</tr>
<tr>
<td>Student part-time</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Unemployed due to disability</td>
<td>15</td>
<td>55.6</td>
</tr>
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</table>

### Etiology of Injury

<table>
<thead>
<tr>
<th>Etiology</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor vehicle accident</td>
<td>13</td>
<td>48.1</td>
</tr>
<tr>
<td>Motorcycle, rider</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Bicycle, rider</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Assault</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Sports related accident</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Blow to head, not assault</td>
<td>2</td>
<td>7.4</td>
</tr>
</tbody>
</table>

### Pre-Accident Alcohol Use

<table>
<thead>
<tr>
<th>Alcohol Use</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No to mild or occasional alcohol use</td>
<td>16</td>
<td>59.3</td>
</tr>
<tr>
<td>Moderate to heavy alcohol use</td>
<td>11</td>
<td>40.7</td>
</tr>
</tbody>
</table>

### Pre-Accident Drug Use

<table>
<thead>
<tr>
<th>Drug Use</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Essentially no use of drugs</td>
<td>20</td>
<td>74.1</td>
</tr>
<tr>
<td>Moderate to heavy use of drugs</td>
<td>7</td>
<td>25.9</td>
</tr>
</tbody>
</table>

### Pre-Accident Psychiatric History

<table>
<thead>
<tr>
<th>Psychiatric History</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No history of severe debilitation</td>
<td>23</td>
<td>85.2</td>
</tr>
<tr>
<td>Single/multiple episode(s)</td>
<td>4</td>
<td>14.8</td>
</tr>
</tbody>
</table>
Table 2

Demographic Characteristics of Caregiver/Family Member Participants (n=21)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>Females</td>
<td>17</td>
<td>81.0</td>
</tr>
<tr>
<td><strong>Relationships to TBI survivor</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>5</td>
<td>23.8</td>
</tr>
<tr>
<td>Child</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Sibling</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Aunt</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Friend/Acquaintance</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td><strong>How well acquainted with TBI Survivor</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretty Well</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Very Well</td>
<td>18</td>
<td>85.7</td>
</tr>
</tbody>
</table>

*Note. Information obtained from the HI-FI Demographic and SO Interview Form*
Table 3

Means, Standard Deviations, and T-Test Results of TBI Survivors’ and Caregiver/Family Members’ Ratings on AQ/AQ-P, and FAD-GF.

<table>
<thead>
<tr>
<th></th>
<th>TBI Survivor</th>
<th>Caregiver/Family Member</th>
<th>df</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n = 21</td>
<td>n = 21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AQ/AQ-P</td>
<td>66.90 (19.33)</td>
<td>63.24 (19.92)</td>
<td>20</td>
<td>.90</td>
<td>.38</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>2.15 (.62)</td>
<td>1.95 (.71)</td>
<td>20</td>
<td>-1.16</td>
<td>.26</td>
</tr>
</tbody>
</table>
Table 4

Means and Standard Deviations of TBI Survivor and Caregiver/Family Member

AQ/AQ-P Total Scores for Dyad Groupings

<table>
<thead>
<tr>
<th></th>
<th>AQ</th>
<th>AQ-P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>(SD)</td>
<td>(SD)</td>
</tr>
<tr>
<td>Healthy Family Functioning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agreed</td>
<td>60.67</td>
<td>54.17</td>
</tr>
<tr>
<td>n=6</td>
<td>(15.62)</td>
<td>(13.03)</td>
</tr>
<tr>
<td>Unhealthy Family Functioning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agreed</td>
<td>72.00</td>
<td>84.40</td>
</tr>
<tr>
<td>n=5</td>
<td>(29.17)</td>
<td>(20.82)</td>
</tr>
<tr>
<td>Disagreed Family Functioning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=10</td>
<td>68.10</td>
<td>58.10</td>
</tr>
<tr>
<td></td>
<td>(16.56)</td>
<td>(16.19)</td>
</tr>
</tbody>
</table>

Note. Healthy vs. unhealthy family functioning was determined by the FAD-GF scores. The FAD-GF scores less than or equal to 2 were categorized as healthy family functioning and scores greater than 2 were categorized as unhealthy family functioning.
Table 5

*Means, Standard Deviations, and T-Test Results Comparing Healthy and Unhealthy Family Functioning on AQ.*

<table>
<thead>
<tr>
<th>AQ/AQ-P Total Score</th>
<th>$M$</th>
<th>$t$</th>
<th>$df$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reporting Unhealthy Family Functioning</td>
<td>72.64</td>
<td>2.26</td>
<td>25</td>
<td>.03</td>
</tr>
<tr>
<td>Reporting Healthy Family Functioning</td>
<td>56.63</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver/Family Members Reporting Healthy Family Functioning</td>
<td>56.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver/Family Members Reporting Unhealthy Family Functioning</td>
<td>77.71</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6

Means, Standard Deviations, and T-Test Results of TBI Survivor and Caregiver/Family Member FAD-GF Scores for Time Since Injury

<table>
<thead>
<tr>
<th></th>
<th>TSI ≤10 M (SD)</th>
<th>TSI &gt;11 M (SD)</th>
<th>df</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAD-GF Scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TBI Survivor*a</td>
<td>2.37 (.65)</td>
<td>1.83 (.38)</td>
<td>25</td>
<td>2.71</td>
<td>.01</td>
</tr>
<tr>
<td>Caregiver/Family Memberb</td>
<td>2.04 (.72)</td>
<td>1.85 (.73)</td>
<td>19</td>
<td>.62</td>
<td>.55</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>TSI ≤10 M (SD)</th>
<th>TSI &gt;11 M (SD)</th>
<th>df</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AQ/AQ-P</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TBI Survivor</td>
<td>62.75 (20.61)</td>
<td>63.47 (19.25)</td>
<td>25</td>
<td>-.09</td>
<td>.93</td>
</tr>
<tr>
<td></td>
<td>n=12</td>
<td>n=15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver/Family Memberb</td>
<td>61.09 (23.75)</td>
<td>65.60 (15.59)</td>
<td>19</td>
<td>-.51</td>
<td>.62</td>
</tr>
<tr>
<td></td>
<td>n=11</td>
<td>n=10</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* aTBI Survivors TSI ≤10 (n=12) and TBI Survivors TSI >11 (n=15)

bCaregiver/Family Members TSI ≤10 (n=11) and Caregiver/Family Members TSI >11 (n=10)
Table 7

Post Injury Changes in the TBI Survivor Reported by TBI Survivors and Caregivers/Family Members

<table>
<thead>
<tr>
<th></th>
<th>TBI Survivor</th>
<th>Caregiver/Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=27</td>
<td>n=21</td>
</tr>
<tr>
<td>Physical Problems</td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>n 23</td>
<td>17</td>
</tr>
<tr>
<td>%</td>
<td>85.2</td>
<td>81.0</td>
</tr>
<tr>
<td>No</td>
<td>n 4</td>
<td>4</td>
</tr>
<tr>
<td>%</td>
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<td>19.5</td>
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<tr>
<td>Changes in Behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>n 23</td>
<td>18</td>
</tr>
<tr>
<td>%</td>
<td>85.2</td>
<td>85.7</td>
</tr>
<tr>
<td>No</td>
<td>n 4</td>
<td>3</td>
</tr>
<tr>
<td>%</td>
<td>14.8</td>
<td>14.3</td>
</tr>
<tr>
<td>Difference in Thinking</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>n 24</td>
<td>20</td>
</tr>
<tr>
<td>%</td>
<td>88.9</td>
<td>95.2</td>
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<tr>
<td>No</td>
<td>n 3</td>
<td>1</td>
</tr>
<tr>
<td>%</td>
<td>11.1</td>
<td>4.8</td>
</tr>
<tr>
<td>Difference in Social Interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>n 20</td>
<td>15</td>
</tr>
<tr>
<td>%</td>
<td>74.1</td>
<td>71.4</td>
</tr>
<tr>
<td>No</td>
<td>n 7</td>
<td>6</td>
</tr>
<tr>
<td>%</td>
<td>25.9</td>
<td>28.6</td>
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</tbody>
</table>

*Note.* Information obtained from the HI-FI PHI and SO Interview Forms.
Table 8

*Impact on the Family as Reported by Caregiver/Family Members (n=21)*

<table>
<thead>
<tr>
<th>TBI Survivor More Dependent Financially</th>
<th>Caregiver/Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Change in Dependence</td>
<td>n 7</td>
</tr>
<tr>
<td>%</td>
<td>33.3</td>
</tr>
<tr>
<td>A Little More Dependent</td>
<td>n 6</td>
</tr>
<tr>
<td>%</td>
<td>28.6</td>
</tr>
<tr>
<td>Much More Dependent</td>
<td>n 8</td>
</tr>
<tr>
<td>%</td>
<td>38.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TBI Survivor More Dependent Socially</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Little Less Dependent</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>No Change in Dependence</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>A Little More Dependent</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>Much More Dependent</td>
</tr>
<tr>
<td>%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TBI Survivor More Dependent Emotionally</th>
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</thead>
<tbody>
<tr>
<td>No Change in Dependence</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>A Little More Dependent</td>
</tr>
<tr>
<td>%</td>
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<tr>
<td>Much More Dependent</td>
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<tr>
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*Note.* Information obtained from the HI-FI Impact on the Family Interview Form.
Table 9

*Post Injury Qualitative Themes Reported by TBI Survivors and Caregiver/Family Members*

<table>
<thead>
<tr>
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<th>Caregiver/Family Members n=21</th>
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</tr>
<tr>
<td>%</td>
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<td>14.3</td>
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<tr>
<td>Depression/Emotionality</td>
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<td></td>
</tr>
<tr>
<td>n</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>%</td>
<td>14.8</td>
<td>14.3</td>
</tr>
<tr>
<td>Physical Difficulties</td>
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<td>n</td>
<td>1</td>
<td>4</td>
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<td>%</td>
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<td>19.0</td>
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<td></td>
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<td>Balance/Difficulty Walking</td>
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</tr>
<tr>
<td>n</td>
<td>7</td>
<td>10</td>
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<td>%</td>
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<td>47.6</td>
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<td>Bodily Pain</td>
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<td>%</td>
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<td>Left or Right Side Weakness</td>
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<tr>
<td>%</td>
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<td>Hearing/Vision Problems</td>
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<td>10</td>
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<tr>
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<tr>
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<td>2</td>
</tr>
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<td>%</td>
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<td>%</td>
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(continued)
(Table 9 continued)

<table>
<thead>
<tr>
<th>Changes in Thinking</th>
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<th>Caregiver/Family Members</th>
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<td>%</td>
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<td>%</td>
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<td>9.5</td>
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<td>Difficulties with Math</td>
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<tr>
<td>n</td>
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<td>1</td>
</tr>
<tr>
<td>%</td>
<td>11.1</td>
<td>4.8</td>
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<tr>
<td>Slow Cognitive Processing</td>
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<tr>
<td>n</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>%</td>
<td>7.4</td>
<td>7.4</td>
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<tr>
<td>Difference in Social Interactions</td>
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<tr>
<td>More Talkative/Social</td>
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<tr>
<td>n</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
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<td>Less Social</td>
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</tr>
<tr>
<td>n</td>
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<td>2</td>
</tr>
<tr>
<td>%</td>
<td>14.8</td>
<td>9.5</td>
</tr>
<tr>
<td>Loss/Lack of Friendships</td>
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<tr>
<td>n</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>%</td>
<td>11.1</td>
<td>9.5</td>
</tr>
</tbody>
</table>

Note. Themes that emerged from follow-up open-ended questions posed following a positive endorsement (yes response) to the general question of change in each specific area.
Table 10

Quotes of Anger/Aggression Post Injury

TBI Survivors

“The biggest issue that I deal with on a regular basis is the underlying cauldron of anger....when I first got out of the hospital my idea then was a pair of gloves and a bat would take care of everything.”

“It almost seems like I get more irritable, over silly stuff.”

“I also have a short fuse and get angry faster”

“Particularly with my daughter, more easily just becoming angry with her about things that I never cared about before.”

“Like I said before, I was never angry. Sometimes it don’t take a whole lot to set me off (now).”

“I’ve always been relatively calm, but I have been more aggressive since the injury.”

“I’ve always been a person that speaks her mind, but since my brain injury its definitely...impulsivity is an issue...at work if I was frustrated about something or whatever and dropping the f-bomb.”

“I fight back. If someone says something, I hit them.”

“Everyone was scared I would not be the person I was, but I’m the same. My temper is really bad, and I have even worse anger problems now.”

(continued)
Caregiver/Family Member

"He's much more easier to become angry...he has a shorter fuse."

"If I bring up something, in a heartbeat we can get into an argument because he can’t see it in himself. He gets very confrontational...I have to be very careful because if I say something about this being related to the head injury, he gets very upset."

"She gets angry more easily."

"He seems to be less patient. He gets frustrated easier, more quickly."

"He’s very different with his daughter...he calls her names...he threatens to smack her...the inappropriate behavior with his daughter is the biggest thing...its been hard to stay because of the verbal abuse."

"She blows off the top of her head really quick...she is very short tempered."

"It came to the point that he got really abusive toward the dog."
Table 11

*Quotes of Memory Problems Post Injury*

**TBI Survivors**

"I can't remember anything."

"I can't remember peoples names...I have trouble remembering all kinds of things...I have to think of special ways to remember."

"I just can't remember."

"I couldn't remember after I read a paragraph and now I can forget instantly about things."

"Every mental activity is more difficult. Things like working memory are difficult."

"The memory thing...you don't remember...you remember you have it but you don't know where you put it."

**Caregiver/Family Members**

"He was telling me that at wok when he tries to do something he gets lost in the middle. He started putting things in a certain way that it would help him remember what he was working on."

"Her memory...is a difficult area for her."

"Memory issues for sure...there are certain things that he remembers and others that he doesn't at all."

"The memory of a lot of things are just not there...I think day to day he is pretty good but two weeks ago, a year ago, two months ago, or 5, 10 or 20 years is not good."

(continued)
Caregiver/Family Members

"Well right after the injury she had a lot of trouble remembering...she would ask a
question and not remember asking it or not remember what we said...and now that
happens occasionally."

"She has short term memory deficit."
Table 12
Quotes of Depression/Anxiety/Emotionality Post Injury

TBI Survivors

“I just can’t shake the depression and I did not have the prior...I’m just not a happy person.”

“Definitely emotionally...(I) feel more emotions.”

“I’m more emotional, more tearful and my speech therapist told me I need to learn to control that.”

Caregiver/Family Members

“He’s more emotional.”

“He has more emotional outbursts, like depression...he feels like he doesn’t belong...there’s a loss of friendship.”

“She complains a lot more and is more negative about things...everyone is out to get her...she’s just not happy.”
Table 13

Quotes of More Sociable Nature Post Injury

TBI

“I would have to say if anything (I’m) just more talkative than I was before.”

“Put me around any group, religion, race and I get along with anybody.”

“Well I’m more apt to talk now. I was more...before I would respond to the question and now I’m more likely to ask the question.”

“I’m more social now. I’m not type A anymore.”

“It’s easier for me to talk to people.”

“I make friends everywhere I go...I’m more outgoing.”

Caregiver/Family Members

“(He’s) better in social situations...(he’s) more talkative.”

“He might be a little better socially than before the accident.”

“She is much more social.”

“He is very social, very friendly...he likes people...whereas before I don’t think he really cared that much for people.”
Appendix A

The Aggression Questionnaire (AQ) is available in the public domain. See

Appendix B

Appendix C

The Family Assessment Device (FAD) is protected by copyright so it is not reproduced in this document. This measure is available through Brown University Family Research Program. Contact Christine E. Ryan, Ph.D. at Christine_Ryan@Brown.edu to obtain further information.
Appendix D

The N.Y.U. Head Injury Family Interview was developed under funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (Grant No. H133B0028) to New York University Medical Center. Use, modification, or translation of the HI-FI requires permission of the authors: Thomas Kay, Marie M. Cavallo, and Ora Ezrachi; therefore, it is not reproduced in this document. Please contact Dr. Ezrachi (Ora.Ezrachi@nyumc.org) for further information about the HI-FI.
Appendix E

The Disability Rating Scale (DRS) is available in the public domain. See Rappaport, M., Hall, K.M., Hopkins, K., Belleza, T., & Cope, N.D. (1982). Disability rating scale for severe head trauma: Coma to community. *Archives of physical medicine and rehabilitation, 63*(3), 118-123.
Appendix F
February 11, 2009

Lesly Hendershot, MA
4369 Long Lake Drive #1302
Batavia, Ohio 45103

Dear Ms. Hendershot:

Thank you for responding to the IRB’s request for more information regarding your protocol #0556, *Aggression in Traumatic Brain Injury: Differences in perceptions and impact on family functioning.*

The Reviewers found that your response was sufficient to address their concerns related to human subjects protections. Please provide us a letter instructing that your response letter of February 4, 2009 be appended to the protocol itself.

As a suggestion, though not a requirement, you may want to add one additional safeguard, such as asking the participants to describe the study to the investigator following the informed consent process in order to assure that they understand the nature of the study.

Sincerely,

Charles Grossman, PhD
Vice Chair, Institutional Review Board

C: Kathleen Hart, PhD, ABPP, Faculty Advisor
Appendix G

Informed Consent

Study Title: The experience of a Traumatic Brain Injury: TBI survivors' and caregiver/family members' perspectives.

Investigator: Lesly Hendershot, M.A. (513) 543-7050

Contact Information: Kathleen Hart, Ph.D. (513) 745-3278

You are being asked to participate in a study conducted through Xavier University. The University requires that you give your signed agreement to participate in the study. The investigator will explain in detail the purpose of the study, the procedures to be used, and the potential benefits and risks of participation. You may ask any questions you have about the study. You have the right to refuse participation in the study. You also have the right to withdraw from the study at any time without explanation or penalty.

A basic explanation of the study is written below. Please read this explanation and discuss any questions that you may have. If you decide to participate in the project, please sign the form below in the presence of the person who explained the study to you. You will be given a copy of this form to keep.

For this study, we are interested in the TBI survivors' and their caregivers/family members' experiences following the injury. To learn about your experiences, you will be interviewed for about one hour. Some basic demographic information will be collected (e.g., age, marital status, race/ethnicity, etc.) as well as information related to the injury. You should be able to freely and easily answer the questions asked, but you may choose to not answer any questions. This interview will be conducted in a separate room to ensure privacy. The interview will be audio taped so that we can devote full attention to the conversation.

In addition to the interview, you will also be asked to complete two questionnaires. One questionnaire will ask questions about the family and the other will ask questions about behaviors in the TBI survivor. Through the interview and questionnaires we hope to better understand your experiences.

There are minimal risks of participating in this study. Some people may get upset when discussing personal issues related to their lives. If this occurs you are free to refuse to answer any questions or discontinue participation in the study. The potential benefits of participation include the opportunity to help others understand your TBI experience.

All information gathered will be kept confidential. Your name will not be associated in any way with the study. Any identifying information will not be included in the data analysis. Audio recordings of the interviews will be stored separately from consent and demographic information forms. These recordings will be kept in a locked cabinet, accessible only to the interviewer. Transcripts of the interviews will be kept, but the original tapes will be destroyed. Any quotes used from the interview will not include identifying information so as not to reveal your
identity. As indicated above, you have the right to refuse participation or withdraw from the study at any point without penalty or explanation.

It is not possible to identify all potential risks in a research procedure, but reasonable safeguards have been taken to minimize both the known and potential unknown risks.

Signature ___________________________ Date __________

Family Member Signature ___________________________ Date __________

Witness Signature ___________________________ Date __________

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY XAVIER UNIVERSITY'S INSTITUTIONAL REVIEW BOARD.

XAVIER UNIVERSITY
Institutional Review Board  APPROVED FEB 11 2007
Appendix H

Quotations Non-Supportive of Identified Themes

TBI Survivors- Physical Changes

"My neurologist said I have an overactive bladder."

"I just go a little slower."

"I get headaches."

"I had strange feelings of uncomfortable. And it was an illness called OCD."

"I don’t know if it’s a result but I had bypass in 2004. Quadruple bypass. I was picking up a garden hose and I had chest pain."

Caregiver/Family Members-Physical Changes

"Her speech was really affected."

"(He has) sensory problems, being oversensitive, migraines and nausea."

"He has gained weight which upsets him."

TBI Survivors- Behavioral Changes

"I probably appreciate life more."

"I didn’t make good decisions."

"I am a little bit more calmer, subdued."

Caregiver/Family Members-Behavioral Changes

"She is more docile and more forgiving."

"I would say he is a little bit more laid back."

"She goes to church now."
TBI Survivors- Changes in Thinking

“Personally, I think I am always the majority of the time, I’m a little too wishful thinking.”

“I get distracted easily.”

Caregiver/Family Members-Thinking Changes

“He can’t find the words to express what he wants to say.”

“She plans out conversations with doctors, very organized.”

TBI Survivors- Changes in Social Interactions

“I’m a lot more patient with people.”

“I am more insecure now.”

Caregiver/Family Members- Changes in Social Interactions

“She is just not as sparkey (sic) as she was. She doesn’t have the intellectual ammunition that she had before.”
Summary

**Title:** Aggression in Traumatic Brain Injury: Difference in Perception and Impact on Family Functioning

**Problem.** Although previous studies have assessed the prevalence of aggression in the TBI population post injury (Baguley et al., 2006; Tateno et al., 2003), few studies have examined specifically how aggression may impact family functioning. Moreover, previous studies have failed to investigate the specific relationship between aggression, awareness of this behavioral change, and the impact this has on family functioning. Finally, very few studies have examined the long-term impact of TBI on the family system or have provided a qualitative assessment of the post-injury changes as reported by the TBI survivor and the caregiver/family member many years after the injury has occurred. The current project was designed to provide additional information of the post-injury adjustment of TBI survivors through both qualitative and quantitative data.

**Method.** Twenty-seven (27) TBI survivors and 21 caregiver/family members were recruited from the support groups conducted through a local agency. The mean time since injury for this sample was 13.59 years (SD=9.38), and the majority (77.8%) had experienced severe injuries, as determined by the length of coma (LOC) and/or duration of post traumatic amnesia (PTA). Participants were interviewed individually using the Head Injury Family Interview (HI-FI), which provided pre and post-injury descriptive statistics and a structured approach to qualitative analysis of long-term
post-injury changes. TBI survivors and caregiver/family members also completed the Aggression Questionnaire or the Partner Aggression Questionnaire (AQ/AQ-P) and the Family Assessment Device.

Paired-samples t-tests were conducted to examine possible differences in reports of aggression and family functioning between TBI survivors and caregiver/family members. A paired-samples t-test was also conducted to investigate possible differences in reports of aggression and family functioning based on time since injury. Independent samples t-tests were conducted to examine possible differences in reports of aggression between participants that report healthy compared to unhealthy family functioning. Finally, qualitative data was analyzed using Auerbach and Silverstein’s (1999) grounded theory method. All themes were supported by direct quotations and percentages of recurrent themes were also calculated.

**Findings.** Results showed no significant differences between the reports provided by the TBI survivors and the caregiver/family members in the areas aggression and family functioning. However, TBI survivors who reported an unhealthy level of family functioning endorsed a significantly higher level of aggression than TBI survivors who reported healthy family functioning. Additionally, TBI survivors with TSI less than 11 years reported significantly poorer family functioning compared to TBI survivors with TSI greater than 11 years (eta=0.11). Themes that emerged related to long-term changes in the TBI survivor post-injury included the presence of anger/irritability, memory problems, and depression and increased emotionality.
Implications. The present study provides a description of a unique sample of TBI survivors many years post injury. Failure to find differences in report on family functioning and aggression, which has been found in studies of TBI survivors with lowers TSI, suggests that passage of time and possible opportunity for feedback related to behavioral changes may increase self-awareness and, perhaps, overall adjustment. However, given the themes that emerged related to long-term changes (the presence of anger/irritability, memory problems, depression, and increased emotionality), many challenging areas remain, even if self-awareness improves. Thus, professionals working in this area must remain cognizant of these struggles and focus treatment and intervention appropriately.