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Multiple Perspectives on Functioning of Families Impacted by Traumatic Brain Injury: Exploring Both Parental and Injured Child's Perceptions

Erica Montague

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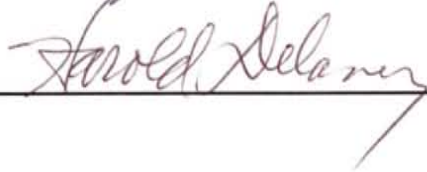
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**MULTIPLE PERSPECTIVES ON FUNCTIONING OF
FAMILIES IMPACTED BY TRAUMATIC BRAIN INJURY:
EXPLORING BOTH PARENTAL AND
INJURED CHILD'S PERCEPTIONS**

BY

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**BACHELOR OF ARTS IN PSYCHOLOGY
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MAY 2002**

THESIS

Submitted in Partial Fulfillment of the
Requirements for the Degree of

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Psychology**

The University of New Mexico
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B.A., Psychology, Trinity University, 2002

ABSTRACT

Pediatric traumatic brain injury (TBI) can have profound effects on a child, including permanent changes to cognition and personality. Despite the attention that pediatric TBI has received in the broader literature, few studies have explored the residual effect that TBI can have on global family functioning. The present study sought to extend the literature on family functioning following pediatric TBI by investigating the perspectives of multiple family members, including the injured child and the parent. It was hypothesized that all family members would view family functioning as more dysfunctional than a non-clinical sample. Fourteen injured adolescents who experienced a moderate to severe TBI at least six months prior to data collection and their parents were enrolled in the study. Ten adolescent siblings also participated. Parents in the current sample reported clinically significant distress in the area of family roles, which addresses responsibility distribution among family members. Injured adolescents reported lower levels of functioning in the areas of affective involvement, communication, and roles, when compared to non-clinical adolescents. Within sample comparisons revealed that injured adolescents reported more problematic functioning than their parents on five of

the seven domains of family functioning. Both parent and adolescent report of poor family functioning was associated with self-reported depressive symptoms. Exploratory analyses investigated the impact of pediatric TBI on the sibling. Overall, results highlight the importance of exploring multiple perspectives of family functioning following pediatric TBI, as each member may be differentially impacted by pediatric TBI.

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Chapter 1

Introduction

Traumatic brain injury (TBI) can impact many areas of a child's functioning, causing deficits in cognition (attention, memory, and processing speed) and changes in personality (behavioral disinhibition and impaired social competency) (Donders & Kuldanek, 1998). In addition, the impact of the injury goes beyond the affected child. Significant lifestyle changes must be made by the family, potentially causing emotional burden, stress, and instability in the home. The role of the family is particularly important to consider for children impacted by TBI. In order to fully understand how a family is functioning, each individual family member must be considered in context, taking into account roles, behaviors, communication styles, and affect. By identifying families who are having trouble in these areas, system-based treatment plans can be created to address global family functioning deficits (Miller, Ryan, Keitner, Bishop, & Epstein, 2000).

Family Functioning and Pediatric TBI

In a recent review of issues relevant to survivors of pediatric TBI, Savage and colleagues (2005) highlight the importance of challenges faced by the family. Families are forced into a multi-faceted role that extends beyond basic care giving. While navigating the intricacies of the medical and educational systems necessary for their child's care, they must concurrently cope with their emotional response to the injury and the uncertainty of what the future holds for their child. The researchers recognize that during the acute phase of medical care, support systems may be in place to help the

family utilize available resources. However, they propose that more information is needed on how these stressors impact families over time, when less acute care is available.

Research on families experiencing pediatric TBI has focused primarily on global measures of family functioning. In a landmark study, Rivara and colleagues (1992) found that more than half of the families they assessed exhibited moderate-to-poor functioning in the area of family relationships and elevated levels of stress immediately following injury. These results indicate moderate risk for the development of more serious problems in family functioning. When compared to mild and moderate cases, families coping with a severe pediatric head injury showed more deterioration in general family functioning over a twelve month period. Another study assessed families at four separate time points following injury: 3-, 6-, 12-, and 24-months (Max et al., 1998). Again, deficits in family functioning surfaced after a time delay. At three months, most families were not experiencing a decrease in family functioning, but by six months the deficits were statistically significant.

This time delay in family functioning deterioration may have clinically relevant implications. Immediately following injury, many children and adolescents will experience rapid, visible gains in physical recovery that may overshadow the presence of cognitive impairments (Savage et al., 2005). By six months post-injury, the injured child may have fewer medical appointments but begin showing more permanent cognitive and behavioral changes. As physical recovery occurs, many parents may expect their child to quickly return to a normal level of behavioral and cognitive functioning as well. As time progresses, hope for improvement decreases, expectations lower, and parents may have trouble coping with their own psychological reactions to their child's problem behaviors

(Max et al., 1998). During the later phases of recovery, the medical community is less capable of providing concrete information regarding cognitive and behavioral prognosis (Savage et al., 2005). Social support and resources have been found to moderate the impact of pediatric TBI on family functioning (Wade et al., 2006). If parents experience the decrease in contact with the medical community as a decrease in available social support, this may be one reason that family functioning deteriorates over time.

A longer follow-up study tracked participants who experienced a moderate or severe TBI or an orthopedic injury (a control group requiring hospitalization) from baseline to six years (Wade et al., 2006). Over time, a decrease in injury-related burden, operationalized as the level of stress a parent experiences due to injury-related transitions such as their child's adjustment and recovery and reactions of extended family members, occurred for all three groups, but the level of burden remained higher for families suffering from moderate and severe TBI. This indicates that with time, some of the initial strain experienced will lessen, but it is unlikely that the family will overcome all obstacles and burdens that result from the injury. The pattern of declining family functioning reported in the previous studies (Max et al., 1998, Rivera et al., 1992) persisted, even across this lengthier time span. Expanding on the previous hypotheses proposed to explain this decrease in function, Wade and colleagues (2006) posit that an injured child's experience of the transition from childhood to adolescence, a time period that is stressful for normally developing children, may increase the likelihood that a family will be negatively impacted by TBI.

Most studies of family functioning in pediatric TBI include only a measure of general family function, often using abbreviated versions of longer measures to screen for

problems (e.g., Wade et al., 1998; Yeates et al., 1997). One exception to this is seen in a study by Max and colleagues (1998) who looked at individual aspects of family functioning reported by the primary caregiver. They found that decrements occurred in the domains of problem solving, roles, communication, and behavior control, with intermittent problems across time in affective responsiveness. Because only the Max et al. (1998) pediatric study has investigated individual components of family functioning, a potentially relevant study from the adult TBI literature will be reviewed. Kreutzer and colleagues (1994) compared families impacted by adult TBI to control families and families impacted by an adult psychiatric illness. The adult TBI families functioned better than the psychiatric families, but had higher levels of dysfunction when compared to controls. Caregivers' endorsement of family problems on individual family functioning scales ranged from 28% on a problem solving domain to 74% on a scale measuring family communication. Although more than 50% of their sample reported healthy overall family functioning, it is clear that individual components, like communication, may be problematic for a majority of families.

Factors Associated With Family Functioning Following Pediatric TBI

Given that multiple studies have found deficits in global family functioning, with some indications of deficits in more specific domains following TBI, it is important to consider what factors might be associated with this impairment. A variety of factors have been explored, including injury severity, family stress, caregiver mental health, and pre-injury family functioning. The factor that has received the most empirical attention is injury severity. This issue quickly becomes complicated, because studies often vary in

their injury-related sample description and participant categorization. For more than a quarter century, the gold standard in classifying head injury severity has been the Glasgow Coma Scale rating (GCS; Teasdale & Jennett, 1974). The GCS takes into account motor response, verbal response, and eye opening as indications of consciousness. With the advent of modern brain scanning techniques, more recent studies may also incorporate the presence or absence of neuroimaging abnormalities in their classification system (Testa, Malec, Moessner, & Brown, 2006). This makes cross-study comparison of studies employing different methodologies more difficult. Beyond classification into mild, moderate, or severe categories, individual studies may vary in the sample characteristics they examine. Some studies treat children and adolescents experiencing either a moderate or severe injury as a single group, comparing them to mild TBI or orthopedic injury (e.g., Testa et al., 2006), while others treat each severity level as a categorically meaningful classification (e.g., Rivara et al., 1992, Wade et al., 2006). For these reasons, data on the relationship between injury severity and family functioning must be interpreted with these methodological issues in mind.

Furthermore, results concerning injury severity are mixed. As mentioned previously, Rivara and colleagues (1992) found a greater progression of impairment over time in families experiencing severe pediatric TBI, with less noticeable deterioration in the mild and moderate TBI groups. Although some differences were seen between all three groups (i.e., with the moderate group functioning less well than the mild group), pre-injury global family functioning and availability of coping resources served as better predictors than injury severity for determining which families were the most adversely affected. Other studies have found little or no relation between family functioning and

injury severity (Anderson et al., 2008), showing that other factors may have more influence on this outcome measure.

Given that pre-injury family functioning and coping resources predicted family outcome above and beyond injury severity, it is possible that problems in family functioning may be the result of an imbalance between the demands of the child's TBI and other life stressors when weighed against the family's resources (Wade, Drotar, Taylor, & Stancin, 1995). When an imbalance occurs, family resources become depleted, stress increases, more complex coping strategies become necessary, and the family begins to function at reduced capacity (McCubbin & Patterson, 1982). During the early stages following injury, families coping with TBI may experience similar alterations in family schedules and routines when compared to an orthopedic control group, but significantly greater psychological and interpersonal problems (Wade, Taylor, Drotar, Stancin, & Yeates, 1997). Not only did the head injury families report greater concerns about their child's future, but they also endorsed an increase in within-family stressful communications (i.e., parents having difficulty communicating with non-injured sibling or grandparents). Although the more concrete stressors are similar between an orthopedic injury and TBI, the psychological factors may serve to deplete the TBI families' coping capacity, leading to family dysfunction.

Family functioning may also be influenced by the primary caregiver's psychological health. Douglas and Spellacy (1996) found that long-term family functioning is closely tied to the well being of the primary caregiver (specifically their level of reported depression) and the caregiver's evaluation of the injured relative. Caregivers have been found to report high levels of depression (Harris, Godfrey,

Partridge, & Knight, 2001), grief (Zinner, Stutts, & Philput, 1997), anger, social isolation and somatic complaints (Zinner et al., 1997), as well as global, clinical distress (Hawley, Ward, Magnay & Long, 2003). Of particular relevance, there is a history of empirical work showing that mothers experiencing high levels of depression and anxiety may provide biased reports of behavioral and emotional problems in their children (Boyle & Pickles, 1997; Najman et al, 2001). It seems unlikely that a parent experiencing clinically significant psychological problems would be able to objectively remove their own distress from their ratings of family functioning.

As mentioned previously, moderate to severe TBI may lead to significant emotional and behavioral alterations, but it is unclear how this might affect global family functioning. Studies have shown increased risk for the experience of depressive symptoms among children and adolescents who experienced moderate and severe head injuries (Kirkwood et al., 2000). Max and colleagues (1998) reported that in addition to qualifying for more novel psychiatric diagnoses, children and adolescents experiencing a severe TBI were more likely to report significant internalizing symptoms (such as depression) when compared to an orthopedic control group and a mild TBI group. Although the injured children demonstrated little insight into their own externalizing problems, behavioral problems were endorsed through parent and teacher report (Max et al., 1998). Despite reported increases in externalizing and internalizing behaviors, no one has addressed how this relates to the family system. Looking beyond the pediatric TBI literature, one study of substance-using adolescents found a strong relationship between increased adolescent externalizing behaviors and poor family functioning (Henderson, Dakof, Schwartz, & Liddle, 2006). The authors argue that the relationship between these

factors is likely bi-directional. Additionally, family cohesion, a positive indicator of family function, has been found to be negatively associated with adolescent externalizing behaviors (Richmond & Stocker, 2006). With regard to internalizing behaviors, one study found that adolescents' perceptions regarding family function were closely related to self-reported symptoms of depression (Millikan, Wamboldt, & Bihun, 2002). Depressed teens were more likely to report negative family relationships.

Finally, several studies have found a relationship between pre-injury family functioning and poor family outcome following TBI. As with injury severity, several limitations are evident when evaluating the reliability and validity of measures of pre-injury family functioning. Because prospective studies are not possible in this area, families must be asked to complete measures of pre-injury family functioning after the injury has occurred. Most studies attempt to have these questionnaires completed as close to the time of injury as possible (Wade et al., 1995). However, the immediate stress and impact of the injury may alter the caregiver's report of pre-injury function. Referred to as a "halo effect", it is unclear whether this might positively or negatively bias responses (Max et al., 1998). Parents might attempt to create an overly positive picture of pre-family functioning, or their view of pre-injury family functioning might be clouded by the current negative circumstances. If both positive and negative reporting occur, the result may be a "mean" rating of family functioning that obscures these biases and is not representative of how the sample is actually functioning. Caution is again recommended when reviewing studies that report pre-injury function based on post-injury reporting.

Following subjects for two years, Max and colleagues (1998) found that retrospective pre-injury family functioning and major family life events or stressors that

occurred prior to injury were the best predictors of post-injury family functioning. Another study found that family functioning was best predicted by measures of the impacted child's pre-injury behavior and adaptive function (Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2008). Rather than referring to their measure as pre-injury function, Testa and colleagues (2006) describe the importance of family distress at the time of discharge from the hospital (essentially the same data gathered by studies claiming to measure pre-injury function). This variable best predicted long-term family functioning at follow-up a year later.

A small number of studies have looked at a children's neurobehavioral outcome, using family functioning as a predictor rather than an outcome variable. One study found that above average family functioning within a pediatric TBI sample served as a buffer for post-TBI deficits in memory and adaptive functioning (Yeates et al., 1997). Family functioning accounted for as much as 25% of the variance in child neurobehavioral outcome.

Family Functioning in Families with other Pediatric Chronic Illnesses

Given the limited research available that specifically addresses family concerns in pediatric TBI, a brief review of family functioning in other pediatric chronic illnesses follows. Children, especially those suffering from a chronic, debilitating illness, must remain under parental care until they reach adulthood. This relationship may extend past what is typically found in Western society, if the child's injury is severe enough to limit their adaptability and independence. However, it is difficult to compare the impact of pediatric TBI to other pediatric chronic illnesses due to the TBI-specific and variable

neurological sequelae. Although the course of the illness and the physical side effects may differ, other pediatric neurological conditions may serve as a starting point for comparisons of the illness' impact on family functioning. In children and adolescents with spina bifida, a condition involving congenital neural tube defects present at birth, an overall count of problem behaviors was closely associated with decreased family functioning (Ammerman, Kane, Slomka, Reigel, Franzen, & Gadow, 1998). Results similar to those found in pediatric TBI have been reported for families coping with Joubert syndrome, a rare genetic pediatric illness that results in physical and intellectual disability (Leuscher, Dede, Gitten, Fennell, & Maria, 1999). Parents' coping skills better predicted family functioning than illness severity. Passive coping strategies such as wishful thinking, self-blame, and avoidance were closely associated with problematic family functioning. As a final comparison, a study investigated the impact of cerebral palsy (CP) on family functioning in a sample of adolescents and young adults, comparing both groups to age-matched controls without physical disability (Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001). This study is unique, because they managed to assess family functioning through the report of the mother, the father, and the impacted child. They found similar levels of dysfunction in both the CP and healthy control groups, with the majority of families functioning well. They suggest that CP does not play a key role in the presence of family problems; adolescent transition is just as likely to cause disruption in the families of healthy children.

Looking across studies of family functioning in a variety of pediatric chronic health conditions, one meta-analysis (Drotar, 1997) found that the majority of studies report a significant, positive relationship between the impacted child's psychological

adjustment and family functioning. This was further supported by a study conducted with chronically ill adults (Boettcher, Billick, & Burgert, 2001). Family dysfunction could not be predicted by illness severity, but was closely related to the patient's level of depression and history of psychological impairment.

Positive Adaptation in Families with Pediatric TBI

Studies in the pediatric TBI literature focus on investigating deficits in family functioning, rather than exploring more positive angles, such as resilience and coping. Several authors have critiqued the available literature, highlighting the need within the field to learn more about positive family adaptation (Drotar, 1997; Perlesz, Kinsella, & Crowe, 1999). Extending beyond the pediatric TBI literature, in a sample of adult TBI survivors and their primary care giver (typically spouse or parent), families who utilized positive appraisal as a coping strategy (i.e., reframing the injury as a manageable challenge) and successfully managed familial tension (i.e., took breaks from caring for their family member, openly expressed emotions, etc.) had better overall adaptation following injury (Kosciulek, 1994). Several studies have found that family functioning is moderated by the availability of social support and resources (Hanks et al., 2007; Wade et al., 2006). Increased structure of the family environment may be a useful coping strategy, allowing the caregiver to feel in control, thus lessening his or her level of perceived burden and heightening his or her view of overall family functioning (Hanks et al, 2007).

Assessing Family Functioning

Drotar (1997) argues that one flaw with the extant literature is the failure to assess family functioning from multiple perspectives. The majority of studies provide data from

a single parent, typically the mother. By asking for only one parent's report, a limited picture is available that may be influenced by the primary caregiver's own emotional/psychological state.

In the TBI field, few studies have investigated the relationship between caregiver response and the response of the impacted child on measures of family functioning. Wade and colleagues (2003) examined a subset of their larger sample to address this issue, including an observer-rating of the dyadic interaction along with measures of parent-reported family functioning. Although the authors anticipated higher levels of conflict, criticism, and distress in the interactions between head-injured children and their parents, there were no differences between this group and the orthopedic control families. However, for the families in the severely head injured group, high levels of conflict and criticism were more closely associated with poor global family functioning, indicating that conflict may have a more distressing impact following TBI.

Although they failed to incorporate the impacted child as a source for assessing family functioning, Rivara and colleagues (1993) did include measures that were completed by parents, teachers, and an interviewer. They highlight the fact that although all sources agreed that functioning of the child declined over the span of one year, they differed in how they quantified and described this decline. Notably, differences were seen between the behavioral ratings completed by parents and teachers at three and twelve months post-injury, with parents reporting more deficits at the early time point and teachers reporting more deficits at the year follow-up. The authors suggest that this discrepancy might indicate a delay in the teacher's recognition of deficits or an increase in the accommodations made by the parents in the home environment to account for

behavioral problems. By including opinions and ratings from multiple observers, a more contextually rich view of the family and their current functioning may be obtained.

Although there are no such pediatric TBI studies, in the adult TBI literature, several studies compare the responses of the head injured individual and his or her caregiver on measures of behavioral symptoms. One study found strong agreement on a majority of scales looking at neurobehavioral function (Testa et al., 2006). However, significant discrepancies existed on a measure of somatic complaints and communication, with the head injured individuals reporting more problems in these areas. Because most measures of family functioning include a communication scale, this is further support for eliciting responses from the impacted individual.

Given the lack of research exploring the impacted child's view of family functioning, it is not surprising that studies have failed to explore the impact of pediatric TBI on siblings' view of the family. One study explored family functioning in a sample of young adult siblings of brain injured individuals and found that the siblings reported more family dysfunction than a normative sample (Gan, Campbell, Gemeinhardt, & McFadden, 2006). A review of available literature on sibling response to other pediatric chronic illness found that siblings may experience increased distress and behavioral problems (Williams, 1997). For this reason, sibling perspective on general family functioning is an important avenue for investigation.

A Theoretical Approach to Family Functioning

Although the research addressing family functioning with pediatric TBI samples is limited, a combined review of the literature from adult TBI samples and other pediatric

chronic illnesses suggests that family functioning may be negatively impacted when one family member suffers from a serious neurologically-related event or condition. It is important to consider this potential dysfunction from a theoretical perspective. The McMaster model is a contextual family systems approach which emphasizes the importance of considering the family as a large system composed of smaller subsystems, such as those related to each individual family member, parent-child interactions, and marital relationships, as well as external systems such as extended family, school, and the workplace (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). The family is not considered in isolation; any disturbance to the system has the potential to impact how the family functions as a whole.

Six key dimensions are addressed that relate directly to how well the family system will function. The Problem Solving domain examines how a family resolves both instrumental (managing money, obtaining food) and affective (emotional issues such as depression and anger) problems. The Communication domain considers how well members are able to communicate, verbally and nonverbally, with each other. The Roles domain involves patterns of behavior which family members fulfill to aid overall family functioning. Dysfunction in this domain could involve improper role allocation (i.e., are the family roles assigned properly?) or accountability (i.e., are functions not completed, and if so, what monitoring system is in place?). Affective Responsiveness emphasizes the importance of responding to family members with a full spectrum of emotion and expressing emotion in a consistent and appropriate manner. The Affective Involvement domain examines the extent to which family members value each other. Dysfunction in this domain can occur when family members lack involvement and interest, but it may

also occur when family members are overly involved. The domain of Behavioral Control addresses family rules and standards that are set in place to guide family members' behaviors in the following contexts: physically dangerous situations, situations requiring a family member to make requests of other members, and situations in which family members socialize with individuals outside the family system. Consistency of expectations is important, as is the amount of autonomy tolerated (Ryan et al., 2005). The proposed theoretical structure has been supported by confirmatory factor analyses in nonclinical, psychiatric, and medical samples (Kabacoff et al., 1990; Miller et al., 1985). A seventh dimension, General Functioning, provides a global measure of family functioning. This domain includes information from each of the six dimensions, but is not simply a linear combination of the individual factors (Hayden et al., 1998). Empirical research supports the use of this scale as a measure of overall functioning (Kabacoff et al., 1990; Byles et al., 1988).

Theoretically, the authors argue that this model of family functioning should transcend different languages and cultures, because of the emphasis on context (Ryan et al., 2005). The McMaster model has been used in research settings as a means of characterizing families with members suffering from a variety of chronic health conditions (e.g., Magill-Evans et al., 2001; Max et al., 1998; Wade et al., 2006) and psychiatric illnesses (e.g., Kabacoff et al., 1990; Sawyer et al., 1988). Given that TBI may have a lasting impact on personality and adaptive functioning of an adolescent family member (Donders & Kuldaneck, 1998), the context of the entire family may be changed, potentially resulting in disturbed global functioning of the system (McCubbin & Patterson, 1982).

Chapter 2

Current Study

The current study aims to extend the literature on family functioning and pediatric TBI by investigating reports of family functioning from both the perspective of parents and the injured child.

Aim 1: Characterize parent and child ratings of family functioning using the Family Assessment Device (FAD) by comparing group means to normative FAD data and standardized cut-off scores (used to determine unhealthy functioning).

Hypothesis 1a: It is hypothesized that parents and injured adolescents will score higher, indicating worse functioning, than the selected normative samples in the areas of General Functioning, Problem Solving, Roles, and Communication.

Hypothesis 1b: Given that the McMaster Model of family functioning posits that a disturbance within the family system will result in dysfunction (Ryan et al., 2005), it is hypothesized that family functioning will be rated as unhealthy, particularly in the domains of General Functioning, Problem Solving, Roles, and Communication, by both parents and injured child.

Aim 2: Compare parent and child ratings of family functioning on the Family Assessment Device (FAD) to determine if the two groups rate family functioning in a similar manner. Examining all seven of the FAD scales allows for identification of specific discrepancies between parent and child report, which may be useful when planning future family interventions.

Hypothesis 2: Given previous findings in the pediatric and adult TBI literature, I hypothesize that parents will view the areas of Problem Solving, Roles, and

Communication as more problematic than will the impacted child (Kreutzer et al., 1994; Max et al., 1998). However, evidence from studies on the FAD reveals that adolescents consistently report poorer family functioning across all FAD domains when compared to parent report (i.e., Bagley, Bertrand, Bolitho, & Mallick, 2001; Kolaitis & Liakopoulou, 2005; Sawyer, Sarris, Baghurst, Cross, & Kalucy, 1988). Across the remaining four scales, Affective Responsiveness, Affective Involvement, Behavioral Control, and General Functioning, I predict that the injured adolescents will report more problems.

Aim 3: Explore which variables are related to parent report of general family functioning and impacted child report of general family functioning.

Hypothesis 3a: Based on previous findings, I hypothesize that parent report of general family functioning will be related to parent-reported depressive symptoms, and a measure of the injured child's externalizing behavioral problems. In addition, I hypothesize that poorer family functioning, as indicated by parent report, will be inversely related to parent report of the injured child's social skills, a measure of adaptive function.

Hypothesis 3b: I hypothesize that the injured child's rating of general family functioning will be related to child self-report of depressive symptoms (internalizing behaviors) and parent-report of the child's externalizing behavioral problems. I also hypothesize that poor family functioning, as indicated by injured child report, will be inversely related to child self-report of quality of life.

Aim 4: To explore the magnitude of agreement between parental and child ratings of family functioning, parent reported FAD scores across the seven domains will be correlated with injured adolescent FAD scores.

Hypothesis 4: Based on previous studies of inter-family agreement, I hypothesize that a positive and moderate size correlation will be found between the parent and impacted child's rating of family functioning across the seven FAD domains.

Aim 5: Previous research recommends calculating a 'family mean' score along the various FAD domains to assist in risk identification (Akister & Stevenson-Hinde, 1991). However, it is unclear whether the family mean score is a useful tool for detecting poor family function in this population. Using the 'family mean' score on the general functioning scale, families will be classified as healthy or clinically distressed. Following pair classification, healthy and unhealthy pairs will be compared across the areas of injury severity, parent-reported depressive symptoms, and child-reported depressive symptoms.

Hypothesis 5: I hypothesize that the unhealthy pairs will have more severe injuries, report higher levels of parent-reported depressive symptoms, and higher levels of child-reported depressive symptoms.

Aim 6: Because there is no pediatric TBI literature addressing sibling issues or perspectives, and not all families enrolled in the study will have a sibling in the 12 to 18 year age range, secondary analyses will be conducted on the subset of families with a sibling who completes a FAD (i.e., those with a sibling in the 12-18 year old range who is willing to participate in the study). These analyses will investigate how siblings' report of general family functioning compares to parent and impacted child report (with analyses comparable to the analyses in Aim 1 and Aim 2).

Chapter 3

Methods

Participants

Fourteen adolescents (5 girls, 9 boys) who experienced a TBI and their primary caregivers participated in the study. In addition, non-injured siblings between the ages of twelve and eighteen were invited to participate in the study. Of the fourteen families, ten had siblings in this age range who agreed to participate. Adolescent TBI participants ranged in age from 11 to 18 (mean = 14.36; SD = 2.31). Two eleven-year-old, injured adolescents were included in the study. The FAD is commonly used with adolescents twelve and older, and both subjects were within three months of their twelfth birthdays. In addition, some evidence suggests that, particularly when verbally administered by an examiner, the FAD can be used with school age children (Bihun et al., 2002). The ethnic composition of the adolescent sample was 50% Hispanic (n = 7), 29% Caucasian (n = 4), 14% Hispanic/Caucasian (n = 2), and 7% Native American (n = 1). Based on the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) and clinical records, all adolescents sustained moderate to severe TBI (defined as GCS score below 12) and were at least six months post-injury (mean = 4.77 years, SD = 3.54). Nine of the fourteen participants participated in neuropsychological testing as part of their standard treatment. The average full scale IQ score for these participants was 90.67 (SD = 11.77). Full Scale IQ ranged from the upper limit of the borderline range to high average (range = 78-112). Data were not available for the remaining five participants. Nine participants from the total sample were receiving special services due to their injury, which included physical therapy,

occupational therapy, speech/language therapy, counseling, or a combination of these services. Of the nine participants, six were receiving psychological or counselling services, five were receiving occupational therapy, four were receiving speech/language therapy, and three were receiving physical therapy. Information was not collected regarding type of school (i.e., public or private) or enrollment in special education services. The majority of injuries sustained involved vehicular accidents ($n = 7$; 50%). Mean caregiver education was one to two years of college, and mean family income was between 30,000 and 40,000 US dollars. According to 2008 United States census data, the median family income in New Mexico was \$43,719 (US Census Bureau, 2009). The current sample is representative of the larger state population with regard to ethnicity and income. With regard to family composition, ten (71%) adolescents lived in a home which included both parents, while the remaining four (29%) adolescents lived in a single-caregiver home. Siblings ranged in age from 12 to 18 years. Gender was split evenly, with five male siblings and five female siblings.

With regard to the overall participation rate for the study, statistics are not available for the originally collected data ($n = 13$). One family from the original sample was excluded from subsequent analyses, because the adolescent was unable to understand the FAD (the primary measure of interest for the study). During the second wave of data collection, 72 families were contacted with a letter describing the purpose of the study which was followed by a phone call to determine interest in participation. Of the 72 letters sent, 26 were returned due to insufficient or incorrect addresses. Eight families refused to participate, while the majority did not answer or return phone calls. Three families were enrolled. However, one of the three was excluded from subsequent analyses

due to mild injury severity (although the family reported that the subject sustained a moderate TBI, medical records indicated that her injury was mild).

Procedure

Recruitment for the study occurred in two waves. During the first wave, adolescents (and their parents/guardians) were consecutively recruited from a pediatric TBI clinic at a pediatric rehabilitation hospital. During the second data collection wave, families who were previously seen for a neuropsychological evaluation at a university-based child neuropsychology clinic were contacted by letter and a follow-up phone call. Potential participants were informed that participating in the study was voluntary and that declining to participate would not affect access to health care services. Once informed consent and assent were obtained, a trained research assistant administered the questionnaires to the injured adolescent in an interview format. The research assistants were trained to ensure that, through the informed assent procedure, the children understood the nature of the study and what kind of information they would be asked to provide. Research assistants were trained to read the questionnaires aloud to the adolescents and to clarify any misunderstandings. Because most questionnaires involved multiple response options for each item, a visual aid was provided to assist the adolescent in selecting an answer. As a group, the adolescents appeared to understand the questions and did not display confusion. To ensure that the adolescent and parent did not influence each other's response, they were placed in separate rooms. Although parents were provided with the option of having the questionnaires administered by the trained research assistant, all parents chose to self-report their responses. When a sibling was

available to complete questionnaires, a trained research assistant offered to administer the items in an interview format, in a room separate from other family members. Many siblings chose to complete questionnaires on their own. Most families chose to complete the study at the hospital clinic or at the University of New Mexico Psychology Department. Two families opted to complete the study at their home. Mothers, fathers, and all siblings (aged twelve and older) were invited to participate in the study. In some instances, both parents or multiple siblings participated by completing questionnaires. Random selection was employed to select one parent and one sibling for inclusion in the current study. Participant families were compensated \$30. This study was part of a larger psychosocial study and was approved by the sponsoring university's Institutional Review Board.

Measures

Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983)

The FAD is a self-report questionnaire designed to examine family functioning. The test consists of 60 items, and is appropriate for respondents age twelve and older. Family members rate how well each of the 60 statements describe their family by choosing either “strongly agree”, “agree”, “disagree”, or “strongly disagree”. The FAD provides an overall measure of family functioning, the General Functioning scale (GF), as well as six different subscales which address family functioning in the areas of Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavior Control. The FAD has been used as a brief screening measure to aid in detecting clinically distressed families. The measure is commonly used with adults and children

aged twelve and older. However, recent evidence suggests that the measure, when administered by an examiner, may be useful with school-aged children as young as seven years old (Bihun, Wamboldt, Gavin, & Wamboldt, 2002). The FAD has been used in a variety of populations, including families affected by pediatric TBI (e.g., Max et al., 1998; Wade et al., 2006). Although measure has been translated into more than 20 different languages, caution is recommended when employing the measure in non-Western cultures (Ryan et al., 2005). The measure has shown high internal consistency, acceptable test-retest reliability, and good validity (Kabacoff, et al., 1990; Miller et al., 2000; Miller et al., 1985).

Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961)

The BDI is a self-administered, 21-item, multiple choice questionnaire that measures attitudes and symptom characteristics of depressed patients. Each item requires a rating response on an ordinal scale from 0 to 3, where 0 represents an absence of symptoms and 3 indicates the most severe level. This measure has demonstrated good reliability and validity with adult samples (Beck, Steer, & Garbin, 1988).

The Behavior Assessment System for Children (BASC; Reynolds & Kamphaus, 1996)

The BASC is a measure of behavioral problems, emotional disturbance, and adaptive functioning of children between the ages of four and eighteen. The 126-item, parent-report version for adolescents between the ages of 12 and 18 asks parents to rate behaviors by frequency (“never occurs”, “sometimes occurs”, “often occurs”, or “almost always occurs”). It includes five composite scores: externalizing problems (aggression, hyperactivity, and conduct problems), internalizing problems (anxiety, depression, and somatization), school problems (attention problems and learning problems), adaptive

skills (adaptability, leadership, social skills, and study skills), and total problems. This instrument has been shown to have high internal consistency and test-retest reliability (Sandoval & Echandia, 1994). For the current study, the Externalizing composite score and Social Skills subscale will be used.

Children's Depression Inventory (CDI; Sitarenios & Kovacs, 1999)

The CDI is a self-report measure designed to assess a range of depressive symptoms commonly reported by children, including disturbed mood, hedonic capacity, vegetative functions, self-evaluation, and interpersonal behaviors. The short form of this questionnaire includes 10 items, each rated on a scale of 1 to 3. This measure is designed for use with children 7 to 17 years of age, and has shown adequate reliability and validity (Volpe & DuPaul, 2001).

Pediatric Quality of Life Inventory (PedsQL; Varni et al., 2001)

The PedsQL is a 23-item self-report questionnaire, with a parallel parent-proxy version, that measures health-related quality of life (HRQOL). The PedsQL consists of three primary domains: Physical Health, Psychosocial Health (which includes Emotional, Social, and School Functioning), and Total Score. Scales are scored from 0 to 100, with higher scores indicating better HRQOL. It has demonstrated good internal consistency, reliability, and validity in a wide range of pediatric health conditions (Varni et al., 2001). The parent-proxy report has demonstrated good internal consistency, test-retest reliability, and construct validity with a pediatric TBI sample (McCarthy et al., 2005). For the current study, the impacted child's self-reported total score will be used.

Statistical Analyses

Prior to beginning statistical analyses, reliability of the FAD scales was determined for each group. Adjusted scale scores were determined for scales with low internal consistency estimates. For Aim 1, descriptive statistics (means and standard deviations) were calculated for injured child and parent ratings of family function across the seven scales of the FAD. The parent means were compared to the means of a non-clinical normative sample (Kabacoff et al., 1990), through one sample t-tests. An adjusted p-value was used ($p < .007$). Child ratings were compared to a normative sample of community adolescents (Sawyer, Sarris, Baghurst, Cross, & Kalucy, 1988). An adjusted p-value was used ($p < .007$). In addition, the parent and injured child means were compared to recognized cut-off scores (Miller et al., 1985) and classified as “healthy” or “unhealthy”. For Aim 2, paired sample t-tests were employed to determine if a significant difference between parent and child ratings of family functioning existed along the seven FAD scales (Problem solving, Communication, Roles, Affective responsiveness, Affective involvement, Behavioral control, and General Functioning). An adjusted p-value was used ($p < .007$). To address Aim 3, Pearson product-moment correlations were calculated to determine which variables related to problematic family functioning. Given the large number of tests run for this aim, correlations are presented descriptively. Parent-reported scores on the seven domains of the FAD were correlated with parent reported symptoms of depression (total score of the BDI), parent report of child’s externalizing behaviors (BASC Externalizing scale), and parent report of child’s adaptive social skills (BASC Social Skills scale). Pearson product-moment correlations were calculated to determine the relationship between adolescent report on the seven domains of the FAD

and adolescent self-report of depressive symptoms (CDI total score), parent report of child externalizing behavioral problems (BASC externalizing scale), and child-report of overall quality of life (PedsQL total score). To address aim 4, a Pearson correlation coefficient was calculated to determine the magnitude of agreement between parent and adolescent scores on the FAD-GF. To address aim 5, parent and adolescent scores on the FAD-GF were averaged, yielding a mean score for each dyad. Using the recognized cut-off scores, each dyad was classified as healthy or at-risk for clinical distress. Following classification, t-tests were run to determine if the healthy and at-risk groups differed on injury severity, parent-reported depressive symptoms (BDI total score), or child-reported depressive symptoms (CDI total score). A p-value of .017 was used to detect significance. All analyses were run with adjusted FAD scale scores, then re-run with original (unadjusted) scores.

Secondary (Sibling) Analyses

A secondary set of analyses were run for families enrolled in the study who had a sibling of similar age to injured adolescent. To explore disparities and convergence between the sibling, the impacted child, and the parent, analyses used to explore Aim 1 and Aim 2 were conducted with a subset of the total sample: parents, impacted children, and siblings.

Chapter 4

Results

Prior to beginning analyses planned to address the aims of the current study, internal consistency estimates for each scale of the FAD were calculated separately for parents and injured adolescents. Regarding Cronbach alphas computed for parent report along the seven domains, four domains reached acceptable reliability (Problem Solving, Affective Responsiveness, Affective Involvement, and General Functioning), ranging from 0.75 to 0.81. Three scales, Communication ($\alpha = 0.42$), Roles ($\alpha = 0.65$), and Behavioral Control ($\alpha = 0.58$), were unacceptable. Investigating the weights of individual items, scale reliability was improved by removing one to two items per scale (Communication- two items removed, alpha increased to 0.69; Roles- one item removed, alpha increased to 0.71; Behavioral Control- one item removed, alpha increase to 0.70). Original means for these three scales were compared to the means following item deletion. Given that the scale means were not statistically different, the following analyses were conducted with the adjusted (more reliable) scales.

Cronbach alpha values for six of the injured child domains (Problem Solving, Communication, Roles, Affective Involvement, Behavioral Control, and General Functioning) were acceptable, ranging from 0.77 to 0.89. The Affective Responsiveness alpha only reached 0.67. Item deletion did not substantially improve the alpha value for this scale, so the scale was used in its entirety. Alpha values for all seven scales were calculated without the two eleven-year-old participants, and consistency estimates did not differ.

Means and standard deviations for parent and injured child report are presented in Table 1. With regard to aim 1, parent scores were compared to normative data collected from a nonclinical sample (Kabacoff et al., 1990). Parent scores were not statistically different from the normative sample. After adjusting the p value for number of tests run, the mean value for Roles approached significance, $p < .05$ ($p = .013$), but did not meet the $p < .007$ criteria. Cohen's d was calculated for all contrasts, revealing a large effect, $d = 1.60$ for Roles in the expected direction, with parents reporting more problems than the community sample. Although only this one difference approached statistical significance with the one sample t tests, two other scales, Affective Responsiveness and Behavioral Control, demonstrated robust effect sizes, $d = -0.92$ and $d = -0.81$ respectively. The effect sizes calculated for Communication and Affective Involvement were quite small, revealing little difference between the two samples. Along the domains of Affective Responsiveness, Behavioral Control, Communication, and Affective Involvement, differences were not in the predicted direction. Parents in the TBI sample reported fewer problems in these four domains than control parents. Effect sizes for Problem Solving and General Functioning were small but in the expected direction.

Because adolescents were not included in the previously mentioned normative sample, an alternative community-based comparison data set was chosen based on sample size and age of subjects (Sawyer et al., 1988). Using one sample t-tests, the injured adolescents' mean scores on the FAD scales were not significantly different from those of the community sample. Affective Involvement ($t = 2.45$; $p = .029$) approached significance, but did not meet the $p < .007$ criteria. Cohen's d was calculated for all contrasts, revealing a large effect size, $d = 1.36$ for Affective Involvement. Although the

one-sample t-tests were not significant, effect size calculations revealed large effect sizes along the domains of Communication and Roles, $d = 0.82$ and $d = 1.02$, respectively. Medium effect sizes were found for Problem Solving ($d = 0.77$) and General Functioning ($d = 0.77$). All effects were in the predicted direction, with the injured adolescents reporting more problems in all domains.

Comparing the parent means to accepted cut-off scores (Miller et al., 1985), “unhealthy” functioning was observed on one scale, Roles. Injured child report exceeded the cut-off values on the six reliable FAD scales: Problem Solving, Communication, Roles, Affective Involvement, Behavioral Control, and General Functioning.

To address Aim 2, paired sample t-tests were run to compare parent and injured adolescent report on the seven FAD scales. An adjusted p value ($p < .007$) was used to correct for the number of tests run. No significant differences were detected. Scores on the Communication scale approached significance ($t = -2.35$, $p < .05$), and effect size calculations revealed a large effect, $d = 0.91$. Medium effect sizes were also calculated for the domains of Problem Solving ($t = -1.86$; $d = 0.64$), Affective Responsiveness ($t = -2.24$; $d = 0.60$), Affective Involvement ($t = 2.01$; $d = 0.64$), and General Functioning ($t = -1.75$; $d = .50$), with adolescents reporting higher scores (i.e., more problematic functioning) across all five domains.

To address Aim 3, Pearson correlations were calculated to determine which variables most closely related to parent report of family function. Results are presented in a correlation table (Table 2). Given the large number of correlations run, results are presented descriptively, capturing trends in relationships between variables of interest and family function. Descriptively, parent scores on the BDI ranged from 0 to 20, $M = 8.86$,

SD = 6.09, with the mean score falling in the mild symptom range. BASC Externalizing raw scores ranged from 5 to 65, $M = 26.64$, $SD = 16.60$. Social Skills raw scores ranged from 5 to 32, $M = 18.79$, $SD = 8.16$. Parent report along the General Functioning and Roles domains was highly correlated with parent report of depression (BDI Total score), $r = 0.58$ and $r = 0.58$ respectively. In addition, parent report on the Problem Solving and Communication domains was highly correlated with parent report of adolescent social skills, $r = 0.48$ and $r = 0.41$ respectively. BASC Social Skills raw scores ranged from 5 to 32, $M = 18.79$, $SD = 8.16$. The remaining correlations, including all correlations between the FAD domains and BASC Externalizing scale, fell in the small to medium effect size range.

Pearson correlations were also calculated to determine which variables most closely related to injured child report of problematic family function. Results are presented in a correlation table (Table 2). CDI scores ranged from 0 to 9, $M = 2.71$, $SD = 2.55$, with the mean score falling in the mild symptom range. Adolescent report on the PedsQL ranged from 54.35 to 96.74, $M = 73.91$, $SD = 15.04$. Child report of depressive symptoms was strongly correlated with several domains of the FAD including General Functioning, $r = 0.48$, Problem Solving, $r = 0.58$, Communication, $r = 0.44$, Affective Responsiveness, $r = 0.43$, and Affective Involvement, $r = 0.37$. Large negative correlations were found between the child-reported Total Score on the PedsQL and several domains of the FAD including General Functioning, $r = -0.54$, Problem Solving, $r = -0.68$, Communication, $r = -0.50$, Roles, $r = -0.66$, and Affective Involvement, $r = -0.51$. Adolescent report of family function was not strongly related to parent report of externalizing problems.

To address Aim 4, concordance between parent and injured child report of family functioning, Pearson correlations were calculated between parent report and injured child report on the seven FAD domains. Results are presented in a correlation table (Table 3). Correlations between adolescent and parent report on the General Functioning, Affective Responsiveness, and Affective Involvement domains were correlated in the expected direction, reaching Cohen's criteria for large effect size, $r = 0.44$, $r = 0.49$, and $r = 0.31$, respectively. For the remaining four domains, small correlations were detected, not always in the hypothesized (positive) direction: Problem Solving, $r = 0.21$, Communication, $r = -0.04$, Roles, $r = 0.18$, and Behavioral Control, $r = -0.09$.

With regard to Aim 5, a mean score was calculated for each family, averaging the parent-reported score and the injured child's reported score on the FAD General Functioning scale. The mean score for each family was compared to the established cut-off score (Miller et al., 1985), and families were classified as healthy or clinically distressed. Seven of the fourteen families met or surpassed the cut-off score. In addition to meeting the cut-off score on the General Functioning scale, these seven families also were the only families to report problematic functioning on four or more of the seven FAD scales. Healthy and clinically distressed families were compared across injury severity, parent reported depressive symptoms (BDI Total Score), and injured child's reported depressive symptoms (CDI Total Score) to determine if differences existed between the two groups. The two groups did not differ with regards to injury severity. T-tests were not significant for parent or child reported depressive symptoms. However, qualitatively, the clinically distressed families reported more parent and child-reported depression; $t = -2.16$ and $t = -2.87$ respectively. Effect sizes were calculated, revealing

large effects for differences between the groups on the BDI Total Score, $d = -1.16$, and on the CDI Total Score, $d = -1.54$.

Results across all five aims were run without the two eleven-year-old participants, and results did not differ significantly. In addition, results were re-run with the original, un-corrected FAD scales, and results remained substantively unchanged.

Finally, exploratory analyses were run to address Aim 6. Sibling data were available for ten families. Prior to beginning these additional analyses, consistency estimates for sibling report of family function along the seven domains of the FAD were calculated. Only the Problem Solving domain reached an acceptable alpha value ($\alpha = 0.88$). The remaining six scales, Communication ($\alpha = 0.61$), Roles ($\alpha = 0.55$), Affective Responsiveness ($\alpha = 0.38$), Affective Involvement ($\alpha = 0.69$), Behavioral Control ($\alpha = 0.61$), and General Functioning ($\alpha = 0.27$) were unacceptable. Investigating the weights of individual items, scale reliability was improved by removing one to three items per scale (Communication- two items removed, alpha increased to 0.70; Roles- two items removed, alpha increased to 0.70; Affective Responsiveness- one item removed, alpha increased to 0.61; Affective Involvement- one item removed, alpha increased to 0.75; Behavioral Control- two items removed, alpha increase to 0.72; General Functioning- three items removed, alpha increased to 0.71). Original means for the seven scales were compared to the means following item deletion, and did not appear substantively different.

Sibling report along the seven FAD domains was compared to the same adolescent community-based normative sample used for comparison with the injured adolescent group (Sawyer et al., 1988). Although the one-sample t-tests were not

significant, effect size calculations revealed large effect sizes along the domains of Affective Responsiveness and Affective Involvement, $d = 1.1$ and $d = 0.93$, respectively. A medium effect size was found for General Functioning ($d = 0.63$). Sibling report exceeded the cut-off values on four FAD scales: Communication, Affective Responsiveness, Affective Involvement, and General Functioning.

Paired sample t-tests were run to compare parent and sibling report on the seven FAD scales. An adjusted p value ($p < 0.007$) was used to correct for the number of tests run. No significant differences were detected. Scores on the Roles domain approached significance ($t = 2.67$, $p < 0.05$), with parents reporting more problematic functioning. Effect size calculations revealed a large effect, $d = 0.85$. An additional large effect size was calculated for the Affective Responsiveness domain, with siblings reporting poorer function in this area ($t = -2.03$, $d = -1.4$).

Paired sample t-tests were run to compare injured adolescent and sibling report on the seven FAD scales. An adjusted p value ($p < 0.007$) was used to correct for the number of tests run. No significant differences were detected. Effect sizes were calculated and the majority fell in the small range. One medium effect size was detected along the Affective Responsiveness scale, with siblings reporting more problematic functioning ($t = 2.03$; $d = 0.74$).

Chapter 5

Discussion

Before addressing the results with regard to the aims of the study, the reliability of the FAD must be examined in relation to the current population. Parent report failed to meet acceptable reliability in the areas of Communication, Roles, and Behavioral Control. Injured adolescents met reliability criteria on all domains except for Affective Responsiveness, while sibling report failed to meet criteria on six of the seven domains. Although item-deletion methods allowed for adequate corrections, this raises the question of why parent and sibling report would be so inconsistent. One qualitative difference between the three groups (parents, injured adolescents, and siblings) occurred during data collection. Research assistants required that injured adolescents complete the questionnaires with assistance, given the possibility of cognitive impairment due to their injury. The FAD was administered to all adolescents in an interview format, so an experimenter was able to answer questions if problems with comprehension resulted. With this procedure in place, the FAD appears to be an appropriate measure for use with brain injured adolescents, demonstrated by good reliability across six of seven domains.

Parents and siblings had the option of completing questionnaires alone. Given that injured adolescents could ask for clarification on items and they were forced to respond to each item slowly, their report may have been more accurate, akin to an interview format. Additionally, the current literature raises questions about the acceptability of using the FAD for minority individuals. One recent article found that alpha values for Hispanic parents seeking mental health services for their children were significantly lower than alpha values for Caucasian participants completing all seven scales of the FAD (Aarons,

McDonald, Connelly, & Newton, 2007). The authors caution that the poor psychometric properties of this measure draw into question the utility of the measure in non-majority cultures, however, they also mention another important difference in their population. The mean education for Caucasian participants in their sample was higher than the mean education level for Hispanic participants (Aarons et al., 2007). A similar trend was found in our current sample, with Caucasian parents averaging between a Bachelor's degree and some graduate education, while Hispanic parents averaged between a high school diploma and two years of college. Further study is required to determine if the FAD fails to capture the structure of family functioning in minority families or if the items themselves are difficult to interpret. The FAD items contain many double negatives, and individual items require careful consideration from the respondent. If a parent rushed through the questionnaire, some items may have been misinterpreted. For example, one item which negatively impacted overall reliability along the Communication domain was "We often don't say what we mean". It seems that a simpler phrase could be employed to explore this aspect of family communication.

Parent Report of Family Functioning

To fully characterize this sample, parent scores were compared to normative data collected from a nonclinical sample of parent respondents (Kabacoff et al., 1990). This sample was chosen for two reasons. First, it was a large scale study compared with most publications completed using the FAD. Second, the authors conducted a psychometric study of the FAD, finding adequate evidence for the theoretical factor structure employed in this study and other studies that approach family functioning using the McMaster

model. Despite these strengths, there are some limitations to using this sample for a comparison with the current TBI sample. The article was published twenty years ago. Although no empirical evidence was available within the field of psychology addressing how family structure has changed since 1990, it is possible that shifts in politics, technology, and society may have altered the way that families function. Additionally, the chosen comparison sample provided very limited demographic information on the participants, and did not include any indication of race or ethnicity (Kabacoff et al., 1990). Given the location of data collection (Rhode Island) and the failure to include ethnicity as a demographic variable, it is hypothesized that the sample was primarily Caucasian. The only study which reported the inclusion of an ethnically diverse sample failed to combine Caucasian and Hispanic participants' responses along the seven FAD scales (Aarons et al., 2007). Instead, the study reported results by ethnicity, and given the current study's small ethnic group subsamples, as well as its inclusion of ethnic groups not represented in the Aarons and colleague (2007) study (e.g., biethnic Hispanic/Caucasian, Native American), separate analyses by small ethnic subsamples was unwarranted. However, these issues underscore the need for updated normative data on the FAD, particularly with an ethnically diverse population.

Despite expectations that parents would report worse functioning along the domains of Problem Solving, Roles, Communication, and General Functioning, parent scores were not statistically different from the normative sample, with one exception. Effect size calculations revealed that parents in the current sample reported more dysfunction in the area of Roles. As mentioned previously, the Roles domain is concerned with the ability of individual family members to carry out repetitive and habitual duties

that help the family system function (Ryan et al., 2005). A parent coping with an adolescent who has sustained a TBI may have increased responsibilities as a caregiver, causing dissatisfaction with their increased role and the potentially decreased role of their injured child (Ryan et al., 2005). Although qualitative differences might be expected on this domain, a review of individual items revealed that the Roles domain includes both concrete items (e.g., “We discuss who is to do household jobs” and “We sometimes run out of things we need”) and items which require an analysis of how feelings relate to assigned duties (e.g., “We are generally dissatisfied with the family duties assigned to us”). This combination of concrete-behavioral and emotion-evaluative items is consistently seen in other FAD domains, and hence, compared with other domains, the Roles domain does not appear qualitatively different in terms of item content. Although the one-sample t-tests were not statistically significant, two additional scales demonstrated robust effect sizes. Parents in this sample reported better functioning on the domains of Affective Responsiveness and Behavioral Control than parents in non-clinical families.

Accepted cut-off scores were applied to the mean scores for parent report along the seven domains of family functioning to determine whether or not they reported clinical levels of distress. Cut-off scores were taken from a widely cited publication, in which experienced family therapists conducted comprehensive evaluations of heterogeneous families, classifying them as healthy or unhealthy (Miller et al., 1985). These families also completed the FAD questionnaire, and cut-off scores were statistically determined using a combination of questionnaire domain means and clinician ratings. In the current study, parent report only met the clinical cut-off score on one

domain, Roles, strengthening the finding that this area is particularly problematic for parents of children suffering from a moderate to severe TBI.

Despite expectations that parents of adolescents with TBI would view family function as unhealthy in the areas of General Functioning, Problem Solving, Roles, and Communication (Max et al., 1998), only one domain, Roles, appears to be significantly impacted. In fact, in the present study, parents report descriptively fewer problems in the areas of Affective Responsiveness and Behavioral Control when compared to non-clinical families. This is surprising given the context of previous findings in TBI samples which show decreases in family function over time (Max et al., 1998; Rivera et al., 1992), up to six years post injury (Wade et al., 2006). On average, adolescents in the current sample were injured more than four years before participating in the study. Thus, it was hypothesized that they would report significantly poorer functioning than non-clinical controls. Several different interpretations of these results are plausible. No measure of pre-injury family function was available for comparison, and only one time point was captured with our measure of family functioning. Thus, frame of reference over time, which may strongly influence current function, could not be measured given the current study design. Parents of injured adolescents may be reporting on current family function as compared to family function immediately following the injury, instead of comparing current function to pre-injury functioning. If the adolescent has made progress in adjusting to the cognitive and emotional sequelae of TBI, parents may be reporting on improvements in how the family system is functioning. As mentioned in the introduction, it is extremely difficult to retrospectively measure pre-injury function. Future studies

could focus on finding creative ways to measure this accurately, as well as following families more consistently over time to track alterations in family function.

Additionally, it is difficult to select a comparison population. Previous research with adult TBI caregivers found that the caregivers reported less family dysfunction than a psychiatric caregiver sample, but more dysfunction than a control sample (Kreutzer et al., 1994). TBI shares some characteristics with mental illness, in that onset can be sudden, and significant behavioral changes may follow. However, parents of adolescents suffering from mental illness report significantly greater difficulties in family function than non-clinical families (Sawyer et al., 1988), a trend that our sample does not follow. TBI may be more similar to other chronic illnesses, such as cerebral palsy (Magill-Evans et al., 2001), where parent report of family function is remarkably similar to control families. It is possible that parents view TBI as less controllable than mental illness, placing less responsibility on the adolescent for difficulties in the family and providing more supports for adjustment to occur within the family system.

Alternatively, it is possible that parents in our sample are underreporting problems in family functioning. Sawyer and colleagues (1988) suggest that parent report of family functioning should be interpreted with some caution, as they may be invested in the minimization of family pathology. Although parents were assured that their responses would be confidential, it is possible that they felt the need to bolster the image of their family by failing to report significant levels of distress. It is especially surprising that they report better functioning than non-clinical families in the areas of Affective Involvement and Behavioral Control. If parents are underreporting overall, dysfunction in the area of Roles may be truly problematic and worthy of clinical attention.

Unfortunately, the FAD does not include a measure of respondent validity. It might be useful in the future to incorporate a parent-report measure that includes a scale assessing positive impression management. The use of a clinical interview may be another option to better explore whether parents are accurately reporting family distress or underreporting. One extensive study of family functioning was conducted with families of adolescents at-risk for developing mental illness (Hayden et al., 1998). They incorporated the FAD parent-report, a clinical interview that maps onto the FAD domains, and an unstructured videotaped interaction between family members. Results indicated that the clinical interview and the parent self-report on the FAD were highly correlated. However, family coded interactions were only moderately correlated with FAD report. Parent report may mask some familial dysfunction, which could be better captured in the TBI population through a more extensive, multi-tool assessment.

Injured Adolescents' Report of Family Functioning

After characterizing parent-report on the measure of interest, injured adolescents were compared to a group of non-clinical adolescents (Sawyer et al., 1988). This sample was chosen because it was the largest non-clinical adolescent sample available for comparison. However, as with the selected parent-normative group, the adolescent normative sample is out-dated (collected over twenty years ago) and primarily Caucasian (the sample was collected in South Australia). Similar levels of functioning were reported in the areas of Problem Solving, Behavioral Control, Affective Responsiveness, and General Functioning. More problematic functioning was reported in the area of Affective Involvement, with moderate differences also detected in the domains of Communication

and Roles. Previous research has focused on caregiver report of family function, so this study adds to the body of literature by characterizing injured adolescents' experience of family function as compared to control adolescents. Although it is difficult to place these findings in the empirical literature, it is possible to hypothesize as to why an adolescent who is coping with the sequelae of brain injury might find family adjustment along the domains of Affective Involvement, Communication, and Roles particularly problematic. With regard to affective involvement, adolescents may feel that their relationship with their parents and siblings have changed since injury. Parents may be over-involved (Ryan et al., 2005), as a means of protecting the adolescent from further harm. Qualitatively, several adolescents reported that since their injury, parents were more protective and less likely to allow them to participate in chosen activities without supervision. Cognitive problems resulting from the injury could impact the injured adolescent's ability to communicate appropriately or expressively with family members. With regard to roles, although there is no empirical literature to support this contention, the adolescent may feel overwhelmed by being unable to live up to family expectations, or they may feel resentful if a loss of responsibility has occurred.

In contrast to the finding that parent FAD scores only reached the clinical "cut-off" on one domain, injured adolescents reported clinically significant problem functioning on six of seven scales, including Problem Solving, Communication, Roles, Affective Involvement, Behavioral Control, and General Functioning. Although the measure has been used for research purposes since it was first published in 1983, the accepted clinical cut-off scores have not been updated since 1985 (Miller et al., 1985). The cut-off scores were based on parent or adult report only. Ideally, new adolescent

clinical cut-off scores would be empirically derived to accurately understand what is driving the elevated adolescent scores.

However, the current cut-off scores may have some validity as a means of differentiating between clinical and non-clinical samples. In a sample of community-based adolescents, only one domain reached the clinical cut-off (Communication), whereas a sample of adolescents referred for psychiatric issues met the clinical cut-off scores for all seven domains (Sawyer et al., 1988). Since FAD scores in the previously mentioned study successfully differentiated between clinical and non-clinical families, the injured adolescents are likely experiencing difficulties in these areas of family functioning. Given the discrepancies between parent-report of clinically significant problems and adolescent report of unhealthy functioning in our sample, future studies should focus on behavioral measures that could evaluate the accuracy of each informant's report. Particular attention should be paid to whether actual dysfunction exists or if adolescent report is unduly influenced by factors related more to their injury and less to the family system.

Differences Between Parent and Injured Adolescent Report of Family Functioning

Parent and injured adolescent report on the FAD were compared across the seven domains, to determine whether parents and adolescents viewed family function similarly. Despite expectations that parents would report more problems in the areas of Problem Solving, Roles, and Communication, no significant differences between the groups were detected. Given the small sample size, effect sizes were calculated and results suggest that adolescents report more problematic functioning in the areas of Communication, Problem

Solving, Affective Involvement, and General Functioning than their parents. Clinical and non-clinical adolescents commonly rate family functioning as significantly less healthy than their parents, highlighting the importance of obtaining self-report from multiple family members (Sawyer et al., 1988). Each member may have a slightly different interpretation or experience of family relationships. Relying on the report of a single family member may provide a biased view of the family or neglect the other individuals whose membership is vital to the successful functioning of the family system.

Factors Associated with Parent and Injured Adolescent Report of Family Functioning

Given the small sample size obtained for this study, it was not possible to test which variable best predicted the report of unhealthy family functioning. Instead of conducting a regression analysis, correlations were calculated between the seven domains of the FAD and expected predictor variables for parent and injured adolescent report. With regard to parent report, it was expected that parent report of depressive symptoms might influence their view of family functioning (Douglas & Spellacy, 1996). Large correlations were found between parent report of depressive symptoms and FAD scores on the General Functioning and Roles domains, with parents who experienced more symptoms of depression reporting poorer family function in these areas. Long term family functioning has been found to be closely tied to the primary caregiver's mental health (Douglas & Spellacy, 1996). The current sample reported, on average, minimal symptoms of depression, with a range of no depressive symptoms to moderate reports of depression. Parents who are depressed may have more limited ability to cope with alterations in the family system, therefore (experiencing and) reporting more problems. For our sample,

low levels of depression may act as a protective factor, explaining the similarity between their scores on the FAD and the normative sample. Despite the proposed explanations for the relationship between family functioning and parent-reported depression, the current dataset is not able to address the potentially causal or bi-directional nature of this association. It is unclear whether poor family functioning leads to higher levels of depression in the parent or if parents who are experiencing depressed mood rate family functioning in a more negative manner. It was also anticipated that parents who reported more problem behaviors exhibited by the injured child would also report poorer family functioning (Ammerman et al., 1998). However, these variables did not correlate significantly with the General Functioning scale. As a final prediction, it was expected that parents who reported that their injured child had better social skills, a proxy measure of adaptive function, would report better family functioning. Poorer family functioning along the domains of Problem Solving and Communication was associated with parent-report of lower social skills in their injured adolescent. Although many other potential predictors could influence parent-report of family functioning, it appears, from this limited analysis, that both parent and injured child characteristics influence, to some extent, parent report of family functioning. Previous findings in non-TBI samples suggest that parent-reported depression may bias their report of behavioral and emotional problems in their children (Boyle & Pickles, 1997; Najman et al., 2001). The nature and directionality of this relationship deserves further exploration in this population. One potential way to explore the accuracy of parent-report of child characteristics would be to include ratings from an outside observer, either a teacher who knows the child well or a trained clinician.

Additional correlations were calculated to gain some insight into which variables related to the injured adolescents' report of family functioning. A measure of health-related quality of life was negatively correlated with the domains of General Functioning, Problem Solving, Communication, Roles, and Affective Involvement. This indicates that adolescents who viewed their quality of life as higher reported fewer family problems overall, felt that their family was able to solve problems functionally, communication was open, roles were correctly allocated within their family system, and appropriate levels of individuation were achieved. Health-related quality of life (HRQOL) examines both physical health and psychosocial health, which includes items related to emotional, social, and school functioning (Varni et al., 2001). Although no studies have examined the relationship between child-reported HRQOL and family functioning in a pediatric TBI sample, worse family functioning was a significant determinant of HRQOL in a sample of children diagnosed with hydrocephalus (Kulkarni, Cochrane, McNeely & Shams, 2008). Additionally, injured adolescent report on the domains of General Functioning, Problem Solving, Communication, Affective Responsiveness, and Affective Involvement was significantly correlated with self-reported symptoms of depression. Although the overall level of depressive symptoms reported by the injured adolescents was low, three respondents met a clinically significant level of symptoms on the short form (score of 5 or more; 21% of current sample). Perceptions of family functioning and adolescent depression have been reported in other health populations, including adolescents diagnosed with arthritis (Cuneo & Schiaffino, 2002) and sickle cell disease (Brown & Lambert, 1999). It is unclear from the current results whether self-reported depressive symptoms are causing the injured adolescent to report more family functioning problems,

or if poorer family functioning is increasing report of depressive symptoms. This is an area that requires more attention in the literature. Although the relationship between parent reported depressive symptoms has been documented previously, child-reported depression should be more fully explored in the context of family relationships and perceptions of family functioning. Adolescent report of family functioning was not related to parent report of externalizing problem behaviors.

Parent-Injured Adolescent Concordance on the FAD

Although results suggest that injured adolescents report more problematic family functioning than parents, this does not address issues of parent-child concordance. It was hypothesized that despite differences in group means, parents and adolescents would demonstrate moderately concordant views of family functioning, demonstrated by positive, moderate correlations in scores on the seven FAD domains. Moderate, positive correlations were found on the General Functioning, Affective Responsiveness, and Affective Involvement domains. However, for the remaining four scales, small correlations were calculated, indicating that parents and injured adolescents may view family functioning in the areas of Problem Solving, Communication, Roles, and Behavioral Control quite differently.

No comparison studies of parent and child concordance on measures of family functioning were available in the TBI literature. Qualitative differences in parent and adolescent report of family functioning have been reported in non-clinical families and families coping with mental illness (Sawyer et al., 1988). However, few studies have addressed actual parent-child concordance. One study of families impacted by pediatric

sickle cell disease explored parent and child agreement on a measure of family cohesiveness and adaptability (Brown & Lambert, 1999). Although their measure of family functioning was less extensive than the FAD, low concordance was found on both scales. They argue that if low levels of concordance exist, relying on report from one family member may compromise the accurate diagnosis of family dysfunction in a given family (Brown & Lambert, 1999). The moderate, positive correlations found between parent and child report along the General Functioning, Affective Responsiveness, and Affective Involvement domains suggest that parent and injured adolescents share relatively similar experiences within the family system. However, the correlations are not high enough to recommend that report from only the parent or the injured adolescent would adequately capture global family functioning.

Clinical Utility of Parent and Injured Adolescent Mean Scores on the FAD

To further explore the utility of considering multiple family member reports of family functioning, family mean scores were calculated for each parent-child dyad on the General Functioning scale. Pairs were classified as either healthy or clinically distressed based on the family mean, and the two groups were compared across several variables of interest. Half of the parent-child dyads were classified as clinically distressed. Despite expectations that adolescents from clinically distressed families would be more likely to have experienced a severe TBI, no differences in injury severity were detected between the healthy and clinically distressed dyads. Previous research on family functioning and injury severity is mixed, with some support for our finding that family dysfunction may not be significantly related to moderate or severe injury classification (Anderson et al.,

2008). Although inferential tests did not meet statistical significance, large effect sizes were found between the two groups on both parent and child reported depressive symptoms, suggesting that families who meet the criteria for clinical distress in family functioning are more likely to be experiencing emotional distress. This relationship between psychological adjustment and family functioning is well documented (Drotar, 1997), and highlights the importance of screening for mental health problems in families impacted by TBI.

Exploratory analyses were run with a subset of families who had a sibling of similar age to the injured adolescent. Sibling report of family functioning appeared more similar to the adolescent normative sample than the injured adolescents. Siblings reported more problems on only two scales, Affective Responsiveness and Affective Involvement, with a moderate difference exhibited on the General Functioning domain. Siblings of head injured individuals in other samples have reported greater family dysfunction on alternate measures of family functioning (Gan et al., 2006), but no studies of sibling report were available using the FAD. Siblings may experience a decrease in parental support following the injured adolescent's TBI. If more resources in the family are being used to cope with injury related deficits, parents may have less time to respond to siblings in a consistent and appropriate emotional context (Ryan et al., 2005). Given the lack of prior empirical findings with pediatric TBI siblings and the small sample size, results are difficult to interpret. More research on the impact of TBI on sibling function and view of the family is warranted to better understand the sibling's experience.

Finally, siblings' report on the seven FAD domains was compared to parental and injured adolescents' report. Parents and siblings report remarkably similar scores.

Differences were detected in only two domains. Parents reported more difficulties in the area of Roles than siblings, and siblings reported more difficulties in the area of Affective Responsiveness. Siblings also report similar levels of family function to the injured adolescents, with the exception of Affective Responsiveness, where they report more problematic functioning. The Affective Responsiveness domain includes items that address consistency and appropriateness of family members' emotional responses to each other (Ryan et al., 2005). Unfortunately, the FAD fails to differentiate between whether the respondent feels all family members are contributing to deficits in this domain. It is possible that the sibling may feel some neglect from the parent or it could be alterations in sibling relationships that are driving the clinical difficulties in this area. Some caution is warranted when interpreting the sibling results, given the inconsistency in response across six of the seven FAD scales. Small sample size is likely related to the problems with alpha values, but response inconsistency could also be related to a lack of understanding by siblings when responding to FAD items. The current sample was too small to fully explore concordance between sibling, parent, and injured adolescent report. Future studies should aim to examine whether sibling report of family function correlates more highly with parent or injured child report.

Limitations

This study is limited in its generalizability due to small sample size and limited power to detect effects. In addition, a large number of families refused to participate (either by directly refusing or passively refusing following the receipt of a letter and follow-up phone calls). Many recruitment letters were returned due to insufficient or

incorrect addresses. Families who moved following their child's initial treatment or who did not have a permanent address were automatically excluded from this sample. In spite of this, the current sample appears to be fairly representative of the larger state population in terms of ethnic composition and socioeconomic status. However, it is unclear whether the characteristics of the non-participating families differ significantly from the families who agreed to participate. Families were offered the option of a home visit to make participation easier, but parents may have been reluctant to invite research assistants to their homes. In the future, more families may be willing to participate if the study procedures can take place in conjunction with a routine check-up that is part of standard care following a TBI.

For the families enrolled in the study, no measure of pre-morbid functioning was available. Families were contacted after injury, rather than being recruited when the injury initially occurred. Given the range of time since injury, it would have been difficult to interpret parents' or injured adolescents' reports of pre-injury functioning. Reliance on a single method (self-report) is an additional limitation, highlighting the need for future studies employing multiple methods (e.g., behavioral observation, teacher report, clinician report).

These preliminary findings suggest that it may be important to further assess the relationship between parent, child, and sibling report of family functioning in families impacted by a pediatric traumatic brain injury. Previous findings have highlighted the importance of age in perception of family functioning, with older adolescents reporting poorer family function (Sawyer et al., 1988). The small sample size employed in this study made it difficult to explore the effect of age on adolescent self-report. In future

studies, it will be important to explore this factor. In addition to considering age of adolescent at the time of assessment, other age-related variables of interest would include age at injury and time since injury. Parents' expectations regarding their child's recovery may be impacted by these two variables, which could in turn mediate the impact of TBI on global family functioning.

An additional concern highlighted in the discussion is the need for updated normative data on the FAD. Although the factor structure was supported in several early studies with Caucasian families, it is unclear whether these factors are an adequate fit for ethnically diverse samples (Aarons et al., 2007). It would be beneficial to collect a normative, non-clinical sample that includes ethnically and culturally diverse families. Updated normative data would also eliminate the need to compare present day families to samples collected over twenty years ago. Furthermore, in order to fully understand the effect of TBI on family functioning, other clinical populations could be selected for empirical comparison. The present study discussed qualitatively the similarities and differences between TBI and other illnesses that might affect family functioning (i.e., CP and adolescent mental illness). It would be interesting to quantitatively compare family responses on the FAD across pediatric chronic illness populations to empirically determine group differences. This would also allow for a better understanding of TBI, as it currently remains unclear whether there is a unique form of family distress associated with TBI, or if other pediatric chronic illnesses result in similar alterations to family function.

Despite limitations, this study aimed to characterize family functioning following TBI from multiple perspectives. Results highlight the importance of including report from

parent, injured adolescents, and siblings, as each family member may report slightly different experiences within the family system. In conjunction with the larger body of empirical literature, the importance of measuring family member emotional distress is reiterated, as emotional symptoms likely relate to individual member's report of overall family functioning.

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Table 1

Means and Standard Deviations for Parent, Injured Child, and Sibling Report on FAD Domains

FAD Scale	Parent Report	Injured Child Report	Sibling Report
Problem Solving	1.98 (0.37)	2.30 (0.61)	2.15 (0.47)
Communication	2.08 (0.37) ^a	2.47 (0.48)	2.39 (0.46) ^a
Roles	2.44 (0.36) ^a	2.40 (0.47)	2.22 (0.36) ^a
Affective Responsiveness	1.89 (0.42)	2.14 (0.40)	2.36 (0.46) ^a
Affective Involvement	2.08 (0.43)	2.42 (0.61)	2.25 (0.52) ^a
Behavioral Control	1.78 (0.39) ^a	1.98 (0.36)	1.83 (0.39) ^a
General Functioning	1.88 (0.36)	2.08 (0.47)	2.03 (0.41) ^a

^a Indicates that means and standard deviations were derived from adjusted scales computed to improve scale consistency

Note. Significance testing was based on an adjusted p level of .007 for each group. No significant differences were detected.

Table 2

Pearson Correlations between Parent and Injured Child Internalizing and Externalizing Problems and FAD Domains

	PS	Comm	Roles	Aff Res	Aff Inv	Beh Con	Gen Fx
Parent Report							
BDI Total ¹	0.30	0.13	0.58	0.15	0.27	0.38	0.58
BASC Ext ²	-0.16	-0.15	0.24	-0.23	-0.32	0.18	0.17
BASC Soc Skills ³	0.48	0.41	-0.17	-0.03	0.12	-0.36	-0.04
Injured Child Report							
CDI Total ⁴	0.58	0.44	0.52	0.43	0.37	0.18	0.48
BASC Ext ²	0.26	-0.06	0.14	-0.29	0.34	-0.34	0.13
PedsQL Total ⁵	-0.68	-0.50	-0.66	-0.26	-0.51	0.02	-0.54

¹Beck Depression Inventory Total Score. ²BASC Externalizing. ³BASC Social Skills. ⁴Child Depression Inventory Total Score. ⁵Pediatric Quality of Life Inventory Total Score

Note. *p* values are not presented. Given the large number of correlations calculated, significance testing was not completed.

Table 3

Pearson Correlations between Parent and Injured Child on the FAD

	PS	Comm	Roles	Aff Res	Aff Inv	Beh Con	Gen Fx
PS	0.21						
Comm		-0.4					
Roles			0.18				
Aff Res				0.49			
Aff Inv					0.31		
Beh Con						-0.09	
Gen Fx							0.44

Note. *p* values are not presented. Given the large number of correlations calculated, significance testing was not completed.