Psychosocial Functioning of Children Living with a Brain-Injured Parent

By

Rema Andrea Lillie
B.A., Washington University in St. Louis, 1998
M.Sc., University of Victoria, 2005

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Supervisory Committee

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Abstract

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Historically, there has been limited empirical study of children whose parents have suffered an acquired brain injury. This is despite the fact that both clinical opinion and qualitative study suggest that these children may represent a population at risk for a variety of emotional and behavioural problems. The current study set out to evaluate the overall psychosocial functioning of a small subset of children whose parents had suffered an acquired brain injury (TBI, stroke) and who were in the more chronic phase of recovery (average time post-injury = 3.3 years). Factors that have been proposed to impact child psychosocial functioning in this population were assessed including the neurobehavioral profile of the parent with an injury, parental depression, and the child's report of the parental relationship. In all, ten children (average age = 13 years) from seven families with parental ABI were evaluated both on a comprehensive measure of child psychosocial functioning (BASC-2) and a series of qualitative measures. As compared to a normative sample, results of quantitative analyses suggest a group of children not experiencing general clinical distress. In fact, statistical analyses suggest resiliency in the current sample as compared to normative data. At the individual level, two of the children in the sample evidenced behaviour that warrants further clinical evaluation, though this finding may be on par with the base rates of clinical distress seen in the general population. Qualitative analyses provide a richer understanding of the experiences of these children and their families and suggest avenues for further empirical evaluation. Results are presented in the context of other studies to date. Recommendations for clinicians and researchers based on current findings are provided.

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Acknowledgments

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Dedication

To my husband. Thank you for always believing in me, even when I had trouble believing in myself.

To my daughter, Audrey. Getting to know you over the past couple years has been one of the greatest experiences of my life. Thank you for bringing new purpose and meaning to what I do.

And to the survivors of brain injury and their families, you continually inspire me as a clinician, researcher, and person. Thank you for letting me share in your journey.

INTRODUCTION

"Brain injury is an event that leads to a process."

~ Anonymous, family member of a person with a brain injury

Acquired brain injury (ABI) is a life-altering event that often occurs suddenly, typically without warning, and leads to long-term ramifications not only for the injured individual but also for family and loved ones. Starting around the mid 1990s there has been an explosion of research looking at the impact of brain injury on the family members and loved ones most involved in day-to-day care, primarily spouses and parents. In an age when hospitals and rehabilitation programs are under increasing pressure to set limits on the nature, length, and coverage of care (Cavallo & Kay, 2005), many affected individuals are discharged home following hospitalization (Faul, Xu, Wald, & Coronado, 2010; Jacobs, 1988) where family members are often burdened with finding and providing care. The impact of injury on these crucial caregivers is being increasingly acknowledged as an important component of outcome (Gan, Campbell, Gemeinhardt, & McFadden, 2006). However, one group that continues to be overlooked in this burgeoning field involves the children of the injured individual.

ABI is a generic term encompassing various types of brain damage caused by events occurring after birth. The most common forms of ABI include traumatic brain injury (TBI) wherein an injury to the brain is caused by an external force (e.g., motor vehicle collision, falls, assaults), stroke involving the sudden interruption in the blood supply of the brain, and hypoxic injuries entailing the deprivation of oxygen to the brain (e.g., drowning, heart failure). ABI is a worldwide phenomenon affecting a vast number of individuals and their families (e.g., Faul et al., 2010; Public Health Agency of Canada,

2009). For example, the Brain Injury Association of Canada (2004) estimates that close to 4% of Canadians are living with an acquired brain injury. Such injuries often lead to long-term disability and loss of productivity (e.g., Finkelstein, Corso, & Miller, 2006; Public Health Agency of Canada, 2009). Though to the best of my knowledge there are no large-scale statistics directly available, it is likely that many of these individuals have children either prior to or following their injuries. In studies where it is reported, anywhere from 32% (Gan et al., 2006) to 53% (Douglas & Spellacy, 1996) of families with brain injuries include children. The presence of children is important for a variety of reasons, not the least of which include added responsibility for both the caregiver (e.g., feeling pulled between caring for the injured individual and caring for children) and the injured individual (e.g., parental demands). Parental responsibilities could also serve as contributing factors to stress, financial burden, and a demand on resources (e.g., time, logistical demands) within the home. For instance, the occurrence of TBI in particular in families with young children has been suggested to lead to unique challenges (Moore, Stambrook, & Peters, 1993) and increased stress (Douglas & Spellacy, 1996).

For decades, clinicians have warned of the potential impact of parental brain injury on children and have identified these children as "at risk" for a variety of behavioral and emotional problems (e.g., Daisley & Webster, 2008; Lezak, 1988; Urbach, 1989). However, there are few empirical studies looking at how children are impacted by parental brain injury. Are children negatively impacted by parental brain injury? If so, how? Are there common outcomes for the group as a whole? Are there factors of the brain injury itself that impact child outcome? Factors of the uninjured parent? What are the potential positive outcomes of parental brain injury? All of these

questions, while discussed in clinical circles and evaluated qualitatively in small studies, have yet to be explored in any rigorous scientific manner.

Similar to the ways in which the psychological and emotional adjustment of caregivers is likely important to the recovery and the adjustment process of the injured individual, the psychosocial adjustment of children is a vital element to the family structure as a whole, and likely has both direct and indirect influences on outcome. For example, a child who is anxious or depressed or is struggling in school may demand additional resources from an already stressed family system. In contrast, other researchers have noted the coexistence of positive outcomes following trauma (e.g., Perlesz, 1999) and there is some evidence to suggest that one possible outcome of parental brain injury is greater independence (Butera-Prinzi & Perlesz, 2004) and positive personal growth on the part of the child (Daisley & Webster, 2008). Clinicians, researchers, and families of injured individuals would all benefit from an understanding of "typical" or "atypical" outcomes for children of parental brain injury. Being able to identify whether these children are "at risk" for difficulties or, equally important, that they are not as a group "at risk," could guide clinical care and future research.

It is likely that the outcomes of children of parental brain injury have been overlooked for several reasons. For one, as would be expected, the individual with the brain injury has traditionally been the focus of study and intervention. It is only over the past decade that the field has developed to such a point as to be able to expand its view more holistically to look at other elements of recovery and adjustment, such as family structure and function. Additionally, psychosocial functioning is a complex variable that will vary tremendously from child to child, even within a single family system. The

complexity of ABI, the variability of outcome, the impact on other members of the family system (e.g., the uninjured parent) in combination with the complexity of child development itself all suggest that this will be a difficult population to study. However, understanding outcomes common to this group as a whole would be an important stepping point to guide clinical care and future research.

Background

Impact of Brain Injury on Caregivers and Families - TBI

In anticipating the impact that brain injury may have on children living in the home, it may be useful to consider the impact of such injuries on other family members. Spouses and parents have historically been the main focus of research in this area. One of the most consistent findings in this domain is that the sequelae most disturbing to families involve the domains of emotional expression, behavioral control, and personality change (e.g., Brooks, 1984, 1991; Marsh, Kersel, Havill, & Sleigh, 1998; Ponsford, Olver, Ponsford, & Nelms, 2003). Repeatedly, these changes in the injured family member are found to be more troubling and stressful to families than physical disabilities or even cognitive changes, though results in terms of the distress due to cognitive problems vary (e.g., Ergh, Rapport, Coleman, & Hanks, 2002; Kreutzer, Gervasio, & Camplair, 1994a). More specifically, aspects of the neurobehavioral profile of the injury that have been suggested to be most troublesome to families are increased irritability, anger outbursts, impulsivity, disinhibition, decreased energy, apathy, "childishness," dependency, depression, rapid mood swings, and impaired social perception and social awareness (Cavallo & Kay, 2005; Lezak, 1988; Urbach, 1989). These changes are often long-lasting and not likely to abate. In fact, there is evidence to suggest that the stress

and distress of caregivers actually increases over time (Brooks, 1991), perhaps as family members begin to acknowledge that a return to "normal" is unlikely or as the resources first available to the family in time of crisis slowly diminish (e.g., Williams, 1991). It could also be the case that the sheer strain of dealing with a chronic disability takes its toll on the caregiver over time.

Research on caregivers of TBI suggest high levels of depression and anxiety as well as high levels of stress and burden (for reviews see Brooks, 1991; Perlesz, Kinsella, & Crowe, 1999; see also Kreutzer et al., 1994a; Linn, Allen, & Willer, 1994; Ponsford et. al., 2003; Ponsford & Schönberger, 2010). Compounding problems are reports of low social interaction and isolation of the family as a whole (Lezak, 1988) as well as financial hardship, which puts significant strain on the family system (Moore et al., 1993). TBI often leads to a shift in the employment status within the family (NIH Consensus Panel, 1999) as many individuals do not return to work or return to a reduced level of performance compared to pre-injury status. Alternately, it is important to note that positive outcomes for families have also been reported (e.g., Adams, 1996) and are often underrepresented in the literature. In many studies, participants are not given the opportunity to comment on the positive changes associated with a TBI.

Findings surrounding the impact of initial injury severity, including such measures as the Glasgow Coma Score, duration of post-traumatic amnesia (PTA) and loss of consciousness (LOC), are mixed. With some contrary results (e.g., Douglas & Spellacy, 1996), initial injury severity does not appear to predict relatives' self-ratings of depression and anxiety (e.g., Kreutzer, Gervasio, & Camplair, 1994b). Instead, it is likely that severity of longer-term neurobehavioral sequelae (e.g., cognitive dysfunction,

aggression, socially disinhibited behavior) is a more powerful predictor of caregiver functioning (Kreutzer et al., 1994b; Linn et al., 1994). Similarly, findings regarding the time post injury have been equivocal (Blais & Boisvert, 2005); though some have argued that caregiver problems actually increase over time (see Brooks, 1991 for a review).

More recent research has shifted to an examination of potential mediators and moderators of impact. Identifying external factors that may influence outcome may provide a means of proactively identifying those families who experience more difficulty or highlight possible avenues for intervention. Perceived social support has been shown to impact the occurrence and/or effects of caregiver psychological distress showing both direct and moderating mechanisms (Ergh et al., 2002). Caregivers with low social support report the lowest levels of life satisfaction. Additionally, perceived social support has been shown to moderate the relationship between caregiver life satisfaction and certain patient characteristics, such as cognitive dysfunction and unawareness of deficits (Ergh, Hanks, Rapport, & Coleman, 2003). Coping skills have been suggested to serve as cognitive mediators of adjustment in people with TBI and their family members (Verhaeghe, Defloor, & Grypdonck, 2005). Differing types and levels of coping skills employed have been put forth as an explanation for how some families seem to fare well in adjusting to life following a brain injury while others suffer more pronounced difficulties. For example, a study by Stebbins and Pakenham (2001) of 116 caregivers of persons with TBI suggests that maladaptive schema, particularly in the area of worry (e.g., irrational and excessive worry over possible misfortune and future accidents), are associated with increased caregiver distress. Other mediators of spouse and caregiver distress include family functioning itself which can serve as a buffer from the distress

caused by neurobehavioral symptoms in those families with more internal resources (e.g., problem solving, communication, affective responsiveness; Anderson, Parmenter, & Mok, 2002).

Several approaches to provide support for families of persons with brain injuries have been assessed, though one review (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007) suggests that the body of research is currently lacking methodological rigor. Despite an abundance of anecdotal, descriptive, and quasi-experimental support, there is at present no single recommendation for any specific intervention method for family caregivers of individuals with brain injuries.

Impact of Brain Injury on Caregivers and Families - Stroke

As compared to the literature on TBI, findings in the stroke literature regarding the impact on caregivers are more equivocal. While high rates of depression and anxiety as well as high levels of stress and burden have consistently been reported, the longitudinal progress of these symptoms remains unclear (for a review see Gaugler, 2010). While some studies have suggested a decrement within the first few years post-stroke, others have found the opposite effect (for reviews see Gaugler, 2010; Han & Haley, 1999). Unfortunately, as compared to the TBI literature, outcome has not been consistently followed over the longer-term (e.g., longer than 2 years post-injury).

Despite the variability apparent in the literature related to caregiver outcome, the stroke population shares several key psychosocial features that have been deemed of primary significance in the TBI literature. For example, similarly to TBI, financial hardship and a change in employment status are common after injury, including in individuals of child-rearing age (Essue et al., 2012), and social isolation has been

identified as a critical risk factor for more pronounced difficulties (Ouimet, Primeau, & Cole, 2001). While positive outcomes have been reported (see Gaugler, 2010 for a review), it is likely that, depending on location and severity of the injury, stroke survivors may suffer many of the same sequelae found to be most disturbing to families of TBI (e.g., changes in emotional expression, behavioral control, personality change, etc).

Impact of Parental Brain Injury on Children

Qualitative Studies and Clinical Opinion

For decades, clinicians have commented on the potential impact of a parent's ABI on children. Lezak (1988), in describing the impact of a brain injury on the family, highlights some of the major changes in the home most relevant to children including a reduction in parental attention, a sharp increase in responsibilities, and uncomprehended shame and guilt. She describes the frustration and anger that such children likely experience at having a family who is "different" combined with the isolation of not being able to bring friends home or participate in school or community activities. She notes that while younger children may feel the brunt of an injured father's frustrations and anger, older children and teenagers are more likely to escape the home by running away, delinquency and truancy, or dropping out of school. She postulates that a parental brain injury may place teen girls at risk of early pregnancy. Interestingly, whereas clinical opinion dictates that it is the older, adolescent children in the home who may exhibit more problematic behavior and spend more time away from the home, in studies of family functioning following TBI, it is the presence of young children in the home that has been found to be more burdensome (Moore et al., 1993). As noted by Douglas and Spellacy (1996), young children may create more demands on the caregiving relative

while older children approaching adulthood may provide practical assistance. At present, this is an empirical question yet to be evaluated.

In describing the types of behaviors likely to be most troublesome to family members – impaired social awareness, impulsivity and anger outbursts, dependency, an inability to learn from experience, apathy, silliness, and heightened reactivity, among others – Lezak (1988, p.113) notes that "these problems can be quite subtle, making it difficult for psychologically naïve and typically unprepared family members to appreciate what it is in the patients' behavior that is so unsettling or irritating, particularly when much of what they do conforms to the families' past experiences with them." One can imagine that this situation becomes all the more difficult for a child trying to make sense of a present but changed parent. The additional burden of feeling "left out in the cold" (Hardgrove, 1991) or being given limited information about their parent's injury could exacerbate the impact of these symptoms. In a study of 30 British children, Tonin, Daisley, and Wheatley (1996) noted that children's understanding of their parent's brain injury, including ideas about its causes, effects and likely prognosis, varied according to developmental phase. In general, children were poorly informed about their parent's injuries. While some children may show resiliency in the face of such challenges, and an innate ability for adaptation, the confusion of adjusting to such a changed parent with limited information provided by others could have negative ramifications.

Urbach and colleagues (Urbach, 1989; Urbach, Sonenklar, & Culbert, 1994) take a more developmental approach to conceptualizing the impact of a parent's brain injury on a child highlighting that the child's psychosocial response will integrate a number of factors including the parent's outcome, the child's developmental stage, and adaptive

capacities of the family system. He identifies a broad spectrum of possible outcomes (e.g., death of a parent, the "functional death" of a parent in a persistent vegetative state, separation from a parent due to hospitalization or divorce) but perhaps most relevant to the current discussion is dealing with a "changed" parent and changed home circumstances. With a parent who returns home after an injury, Urbach (1989) describes the adjustment of the child as having to deal with "a different parent in the same body." This description is echoed by first-hand reports of living with a parent with a brain injury (e.g., Butera-Prinzi & Perlesz, 2004; Hardgrove, 1991) and mirrors that used by Lezak (1988). Home circumstances may include a drop in family income or standard of living, changes in routines such as child care, meal preparation, and homework as well as increased burden and responsibility, all factors commonly identified by other researchers and clinicians (e.g., Butera-Prinzi & Perlesz, 2004; Daisley & Webster, 2008; Lezak, 1988). Urbach and colleagues (1994) describe a variety of potentially persistent and severe symptoms for children including depression, suicidality, school failure, destructive behavior, eating disorders, and prolonged psychosomatic illnesses and provide general clinical recommendations for assessment. On a positive note, case studies of at least three children with parental brain injury suggest that these children respond well to standard therapeutic modalities (Urbach & Culbert, 1991).

Based on findings from children of parents with psychiatric disorders, Urbach and Culbert (1991) describe potential characteristics of resiliency including relatively higher intelligence, the ability to objectify parental disturbance, greater creative aptitudes, a capacity to reach out to adults, and "innate ego strength." Favorable background

circumstances may include parent's problem occurring later in the child's development, the emotional availability of a healthy parent, and higher socioeconomic status.

A study by Butera-Prinzi and Perlesz (2004) in Australia qualitatively and quantitatively assessed four children (ages 9-12; *M* = 11.25 years) who were participating in a multiple family group therapy program and whose fathers' had ABI (cerebral hemorrhage, tumor resection, and aneurism). Based on clinical descriptions from staff, each father had cognitive problems and displayed verbal and physical aggression. Fathers were between 2 and 4 years post-injury. Over the course of a children's group spanning a 6-month period, issues raised paralleled those noted through clinical experience including grief and a sense of loss, understanding and adjustment to the psychological and physical changes in their injured parent, family changes and stressors including competition for their mothers' attention, the role of support networks, and the positive aspects that remained as part of their families' everyday lives. Parental behaviors identified as most troublesome included apathy and physical and verbal abuse, primarily on the part of the fathers with ABI. Interestingly, all the children reported that prior to the research interviews, they had not been asked by anyone about levels of conflict, fighting, abuse, or violence in the home.

As part of the same study, all children and their parents completed the Behaviour Assessment System for Children (BASC; Reynolds & Kamphaus, 1992) questionnaires pre-treatment. Overall, BASC results demonstrated that the children's level of symptoms were not clinically significant, though a closer inspection of the individual profiles indicated some heightened scale scores reaching clinical significance. In comparison to a normative sample, individual scale elevations identified some of the children as 'at risk'

for a variety of problems including anxiety, depression, hyperactivity, feelings of inadequacy, having atypical thoughts, over-compliance, and experiencing difficulties at school and in their relationships with their parents and peers.

Factors reported by the children to lead to more positive coping included the availability of a support person(s) at the time of crisis, a consistent significant figure (e.g., mothers, grandmothers), their ability to share their feelings with friends and family once they had overcome shame and embarrassment, and maintaining relationships and activities outside the family.

Across qualitative studies, personal descriptions, and clinical opinion, several themes emerge about the impact of a parent's brain injury on children in the home. Firstly is the idea of living with a parent who is somehow "changed" but still present. Descriptions of mourning for the 'real parent' are common. Several behavioral consequences of the injury on the part of the affected parent are repeatedly indicated to be most troublesome to children; most especially anger and irritability but also decreased energy and apathy, "childishness," depression, and rapid mood swings. On the logistical side, changes in the home around routine and increased responsibility are often noted along with a reduction in time for play and recreation. Competition for the mother's attention is often highlighted, commonly in direct relation to the attention paid to the injured father or to increased demands more generally on the part of the uninjured parent. Isolation and a reluctance to bring friends into the home are common. The high rate of marital separation or dissolution commonly cited in the brain injured population (e.g., Tate, Lulham, Broe, Strettles, & Pfaff, 1989; Thomsen, 1984; but for competing statistics see Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007) further complicates the picture

by introducing a host of potential problems (or a resolution of problems) for the child that are beyond the scope of the current discussion but are frequently noted in clinical and qualitative studies. Some children (e.g., Butera-Prinzi & Perlesz, 2004) have focused on the positive aspects of the injury including greater availability of the parent with a brain injury. Resiliency along with positive personal growth from facing such difficult circumstances are frequently noted.

With the common description of the clinical needs of this population, the question remains as to whether these needs are being met therapeutically in clinical practice. The answer appears to be that there are small pockets of activity focused on incorporating children in the recovery process but that in most areas, child needs are often neglected. In a recent study of rehabilitation staff in the United Kingdom (Webster & Daisley, 2007) it was found that only a small percentage (19% or 50 of a sample of 263 service providers) reported carrying out work with child relatives. This work may have included education and the provision of information, supportive counselling, the facilitation of coping and adjustment, facilitating maintenance of the child's relationship with the injured family member, and the teaching of specific techniques. 'Work' could have encompassed both direct and indirect contact with the child. Access to training, resources, and support predicted those who carried out such work specifically with children. Individual and workplace attitudes towards work with child relatives also influenced their inclusion in care. Besides the group previously mentioned in Australia, and in addition to individual clinicians, there are groups in the UK (e.g., Daisley & Webster, 1999, 2008), Canada (e.g., Ducharme, 2003), and the US (e.g., Cavallo & Kay, 2005; McLaughlin, 1992) focused on specifically addressing the needs of these children.

However, despite the wealth of clinical information suggesting that these children represent an "at risk" group, with limited empirical data to support these claims it is likely that such projects will run into difficulty with funding and support. It seems that a more appropriate starting point would be the gathering of empirical evidence to support (or refute) clinical observations.

Empirical Evidence

While the impact of brain injury on children has been discussed and reviewed in the clinical literature for decades and recent qualitative evaluations have looked at its impact in small samples, at the time of preparation of the current project only two published empirical studies focused directly on the impact of parental brain injury on children and these both focused on the effects of TBI specifically. These studies are widely cited as providing evidence that parental TBI has a detrimental effect on children. However, on closer inspection each study has significant limitations that impact the generalizability of results. Neither of these relatively small studies was likely intended to serve as a definitive example of the impact of parental brain injury on children, but instead as a starting point for future research. But, as they are the only empirical studies to date, they are often put forth as definitive statements. As these studies represent the entirety of empirical data on children's psychosocial adjustment following parental brain injury, it seems useful to review them at some length. Of note, more recent additions to the empirical dataset are included below in the section entitled "More recent empirical evidence."

Pessar and colleagues (1993). In 1993, Pessar, Coad, Linn, and Willer evaluated 24 families in which one parent had suffered a TBI, primarily fathers (16 injured fathers,

8 injured mothers). Families were recruited for participation with the requirements that they had a child who was born before the parent's injury and still lived at home at the time of the study. Fifty-two children (26 boys, 26 girls), some of whom were siblings, were represented by the 24 families who participated. Ages of the children ranged from 2 to 23 years old (M = 12.6, SD = 5.6). Average time since the injury was 46 months (SD = 19.6, range 16 to 84 months).

Information was obtained from injured individuals and their spouses, both of whom completed independent questionnaires. However, the bulk of information (all but one symptom checklist) was completed by the uninjured parent. Importantly, the children themselves did not provide any information.

Questionnaires included a Child Information Form (CIF); a Behavior Rating Scale (BRS); the Symptom Checklist-90-Revised (SCL-90-R), a commonly used self-report checklist of psychiatric distress; and the Health and Activity Limitation Survey (HLAS) which was used to obtain motor and sensory disability ratings for the affected individual. All of these items were completed by the uninjured spouse with the parent with a brain injury completing only the SCL-90-R.

The CIF consisted of 11 questions regarding the parent's perception of change in the child's behavior since the injury and 12 questions about perceived changes in parenting behavior. Each question was rated on a 5-point Likert-type scale and later coded such that scores on each item ranged from -2 (much more frequent negative behavior) to +2 (much more frequent positive behavior *or* much less frequent negative behavior). Using principal components analyses, these 23 items were further subdivided into factors with three factors reflecting child behavior (5, 3, and 3 questions each), three

factors reflecting the uninjured parent's view of the *injured* individual's parenting behavior (3, 3, and 2 questions each) and one factor representing the uninjured parent's view of his or her *own* parenting behavior (4 questions). For each of the seven resulting factors, an average score was computed with an average less than -1 being considered a "substantial increase" in that problem area since the injury (e.g., on average, a negative change had occurred on each item in the factor).

While there is some confusion in the reporting of results, it appears that 22 of the 24 uninjured parents retrospectively reported negative changes in their child's behavior since the injury. Most of these parents reported infrequent problems while a smaller subset reported more frequent problems or more severe changes. On average, at the group level, none of the child factors met the criteria of a "substantial increase" in that problem area since the injury ($M_{\text{acting-out behavior}}$ = -.49, *SD* = .56; $M_{\text{emotional problems}}$ = -.28, *SD* = .63), although these criteria would have been met for individual families. The most commonly reported problem area was the child's relationship to the parent with a brain injury ($M_{\text{injured parent relationship}}$ = -.70, *SD* = .71) and there was significant overlap across domains such that families reporting a substantial increase in emotional problems (*n* = 4) or a substantial increase in acting-out behavior (*n* = 5) also reported relationship problems with the injured parent.

Twenty-three of the 24 uninjured parents reported a negative change in at least one parental behavior for the *injured* parent. These included not fulfilling the parental role (e.g., showing interest, being responsible, helping; *M*= -.79, *SD* = .87), negative behavior such as yelling, arguing, and being impatient (*M* = -1.14, *SD* = .74), and reduced positive behavior such as praising and having fun (*M* = -.72, *SD* = .86). Uninjured

parents also rated their own behavior as more problematic than prior to the injury (e.g., feeling overwhelmed, arguing, being impatient, doing less fun activities; M = -.52, SD = .61). So, in the opinion of the uninjured parents, all parenting behaviors assessed had, on average, been negatively impacted by the brain injury, both in themselves and the injured parent.

Results pertaining to the symptom profile of the injured individual (BRS, HALS, SCL-90-R) are only briefly presented at best and its relationship with child behavior is unclear. Depression measures for both parents showed a high rate of depressive symptoms across the sample. Fifteen of 24 injured parents and 17 of 24 uninjured parents scored more than one standard deviation above the mean for gender-adjusted SCL-90-R depression *T*-scores. Whereas depression in the *uninjured* parent showed significant positive correlations with reported acting-out behavior in the children (r = .52) and relationship problems between the child and the injured parent (r = .72), depression scores of the *injured* parents did not correlate significantly with any measure of child behavior. In this sample, then, depression in the *uninjured* parent appeared to have more of an impact on reported child difficulties as compared to depression in the *injured* parent. It is unclear how obtaining the uninjured parent's report of child behavior may have affected the results. It is possible that depression in the uninjured parent is more closely tied to child behavior or it is equally possible that depression in the uninjured parent colors the report of child behavior.

While this study is widely-cited in the broader literature as finding that many families with a parent who has a brain injury evidence negative outcomes for children, a closer analysis of the Pessar group's (1993) results suggests that, while not universal,

there is likely a smaller subset of families who experience significant long-term difficulties following a brain injury, including an impact on the children. In looking at the families in the Pessar et al. (1993) study who do report problems, it is interesting to note that the bulk of disturbances appear to relate more often to the symptoms of the parent with a brain injury and not to more widespread difficulties in terms of children's "acting out" behavior or "emotional problems." For example, disruptions in parenting by the injured parent such as not helping or showing an interest, yelling, arguing, and being impatient were more commonly reported than children having problems in school, disobeying, or having bad dreams. Children were most often negatively impacted in terms of (a) their relationship to the injured parent, perhaps related to symptoms of the injury, and (b) depression in the uninjured, but not the injured parent. Children's relationship to the uninjured parent was not assessed.

While overall not a substantial problem, "acting out" behavior was significantly positively correlated with the injured parent's age (r = .56), age at injury (r = .51), and male gender, (r = .42) as well as depression in the *uninjured* parent (r = .52). Depression in the uninjured parent also correlated significantly with relationship problems between the child and the parent with a brain injury (r = .72). Since these outcomes were reported by the uninjured parent, it is unclear whether depression in the uninjured parent (n = 17 of 24) influenced the relationship between the child and the injured parent or if the uninjured parents' depression impacted the reporting of relationship difficulties. In contrast, self-reported depression of the parent with a brain injury (n = 15 of 24) did not correlate significantly with any of the child's problem areas, as reported by the uninjured parent.

There are several limitations to this study that make the interpretation of results difficult. Perhaps most striking is the use of a primary outcome measure consisting of only 23 total items that was then further sub-divided into seven individual factors. Some of these factors consisted of only three items and in several instances these items do not appear to be either an adequate description of the content area or directly related to one another. For example, the factor labelled "emotional problems" in the child consists of three items: (a) did not go out with friends, (b) had bad dreams, (c) complained of headaches. This seems a meager account of as complicated a construct as "emotional problems." Additionally, in terms of face validity, not going out with friends would not seem to be directly related to having bad dreams, although both could co-occur in a child experiencing emotional difficulties.

An equally important and related issue is the large age range of children assessed. While including a large age range of children may be desirable to increase the generalizability of any results to the broader population as a whole, the inclusion of pre-school aged children makes the interpretation of results difficult. For one, while a challenge at any age to state that problems occurring in the home are likely related to the occurrence of a brain injury in one of the parents, considering the developmental changes of a 2- to 4-year-old clouds this relationship even further. Additionally, the authors do not indicate how items such as "received poor grades" or "were absent from school" were handled in this young group. In fact, some items such as "disobeyed the injured parent" may be developmentally-appropriate for preschool-aged children.

Linked to the issue of age is the retrospective nature of the study. While it can be difficult in general to compare a child or parent's behavior pre- and post-injury, this task

seems all the more difficult when considering the behavior of a child who has aged between four and seven years since the time of the injury. In fact, the authors report a trend such that teenagers in the sample were more likely to have problems than younger children. Among other possible explanations, this could be due to the nature of the questions asked or the increased freedom related to the teen years.

An additional missing piece of information is how families with multiple siblings were handled. Were the parents instructed to think of one particular child when formulating responses or to provide a more general overview of how they think the behavior of their children as a whole had changed since the injury? Each of these instructions could potentially impact results.

There are substantial statistical and methodological issues that also limit the interpretation of results. For one, there is no control group with which to compare typical outcomes on the CIF, the primary outcome measure, so that one is left interpreting means and standard deviations alone. While providing useful descriptive information, it would be helpful to have a comparison group to provide a framework for interpreting results. Additionally, likely due in part to the small sample size along with the small number of items in each domain, there is substantial variability on each factor making interpretation of averages difficult. In fact, since it was noted that there was substantial overlap between families reporting difficulties (e.g., families reporting problems in one domain often reported difficulties in another domain), it may be that a few families in more extreme distress are driving the results. Additionally, although information was obtained regarding the symptomatology of the injured individual, these results are only briefly discussed and it is unclear whether they relate directly to child behavior.

Lastly, as noted previously the focus of the study was primarily on the opinion of the uninjured parent, while the child's own perspective or that of the parent with a brain injury, was not included.

Uysal and colleagues (1998). In 1998, Uysal, Hibbard, Robillard, Pappadopulos, and Jaffe contributed a second empirical evaluation of the effect of brain injury on parents and children. This study, though different in format and objectives, addresses several of the methodological limitations of the earlier study by Pessar and colleagues. Participants included 16 families in which one parent had sustained a TBI and 16 families in which no parent had a TBI, who served as controls. Participants were recruited from larger study samples and were invited to participate if they were parents with children between the ages of 7 and 18 who were currently residing in the home. The TBI participants were self-identified as "disabled" and were all at least two years post-injury (M = 9.3 years, SD = 11.5; range 2-39 years). The majority of injuries were caused by motor vehicle accidents (73%) with being hit by falling or a flying object making up the next portion (20%) and a small percentage representing sports-related injuries (7%). Duration of loss of consciousness (LOC), an indicator of injury severity, varied widely with approximately half of the sample showing an LOC greater than one week (27% 1 to 4 weeks, 27% greater than 1 month), 13% showing an LOC more than a day but less than a week, and 33% ranging from no LOC to less than a day. Whenever possible, both parents were included in two-parent families.

Children ranged in age from 8 to 18 years with no age difference between groups ($M_{\text{TBI family}}$ = 14.3 years, SD = 2.6; M_{control} = 13.3 years, SD = 3.4). Eighteen children represented the 16 families with TBI. Fourteen of these 18 children were born before the

TBI occurred (average age of these 14 children at time of parental TBI = 8.21 years, *SD* = 2.83; range 5 years to 14 years). Twenty-six children represented families without parental TBI leading to a grand total of 44 children.

To assess children's behavior, parents completed a modified version of the Children's Problems Checklist (CPC) where they rated their child's behavior across a variety of domains such as emotion, self-concept, peers and play, school, language/thinking, behavior, habits, and health on a 3-point scale (no problem, problem, important problem). Parents also completed the Behavior Rating Profile, Second Edition (BRP-2), a 30-item scale assessing a child's behavior at home.

As evaluating parenting skills and the effects of parental TBI on levels of depression for all family members were primary objectives of the study, measures of depression, family stress, and parenting were also completed by parents.

Children completed two self-report measures of behavior: (a) the Behavior Rating Profile, second edition (BRP-2), a 60-item true/false questionnaire assessing behavior at home, school, and with peers; and (b) the Children's Depression Inventory (CDI). Children also completed measures assessing their perception of parenting skills within the family.

Results suggest that children of parents with a brain injury did not have a greater frequency of behavioral problems than children of parents with no disability. These conclusions were based on a series of individual *t*-test comparisons of 11 measures from the parent-completed CPC and one overall score from the BRP-2 completed by parents. Ratings of parents with brain injury and their spouses were assessed separately. From the child's perspective, three subscales from the BRP-2 (home, school, peers) were assessed.

While this study has several strong methodological features, including the inclusion of a control group, it still has limitations that impact the generalizability of results. For one, the measure of the child's perspective sounds somewhat limited. Consisting of only 60 true/false items that were collapsed into three outcome scores, the BRP-2 may not have had sufficient variability as to capture subtle differences between groups. When combined with a small sample size of only 18 children, it is not surprising to find nonsignificant results. Additionally, as the BRP-2 appears to be focused on the child's behaviors, it is unclear what type of impact the brain injury may have had on the child's inner, emotional life.

As this is the only empirical study to date reporting the child's perspective and as there is a wealth of clinical data suggesting that these children do represent an "at risk" group, it seems that one, small empirical evaluation would be insufficient for supporting or refuting a claim that these children have more difficulties in psychosocial functioning than is typical. On the one measure of emotional functioning given, the Children's Depression Inventory, while not depressed based on a cutoff score, the group as a whole did show more depressive symptomatology than the control group. It is possible that there was a more pervasive impact of parental brain injury either in a subset of individuals or on aspects of psychological functioning not assessed in the study.

Lastly, as the primary focus of the project was on parenting skills, the symptomatology of the brain injury itself, outside of general injury descriptors, is not directly addressed.

Other empirical evidence. In addition to the two published studies described above, there have been three unpublished doctoral dissertations looking at similar issues.

Unfortunately, as the results are unpublished and two of the studies were completed overseas (the United Kingdom), only limited information is available.

In a doctoral dissertation at the University of Michigan, Hansell (1990) compared 17 school-aged children of men who had survived a severe closed head injury with 14 children of men who had incurred a physical disability as a result of a spinal cord injury. Children were assessed using standard measures of competence and behavior, although the measure used is unavailable. A semi-structured interview was administered to qualitatively explore the children's experience of their fathers' injuries. Statistical analyses suggested no significant differences between the two groups on mothers', teachers' and self-ratings of competence and behavior, though mothers in both groups rated their children as less competent than normative groups. In within-group analyses, child and family factors such as: (a) the gender of the child, (b) the degree of the family's change in socioeconomic status following the injury, and (c) the father's level of depression were all found to be better predictors of the child's adjustment than the type of injury incurred. Interview data suggested that children with head-injured fathers were most bothered by their father's irritability and that both groups described their fathers' disabilities as negatively impacting peer relationships.

In another unpublished doctoral dissertation, Smiton (2005) at Oxford University attempted to apply the transactional model of stress and coping as a framework for investigating adjustment in children following the brain injury of a parent. The focus of the study lay primarily on the coping strategies employed by these children and how these coping strategies varied according to demographic variables, though it is unclear what these demographic variables entailed. Coping strategy, injury characteristics, and

demographic variables were examined as predictors of child adjustment. Forty families and 40 children between the ages of 8 and 18 participated in the study. As a group, the children were found to be "at risk" for adjustment difficulties and showed significantly more emotional symptoms than a normative sample. However, all the children were able to report positive outcomes from the injury and were found to demonstrate "posttraumatic growth" as a group. Time since injury was found to be the biggest predictor of adjustment difficulties with difficulties increasing over time.

Although referenced in other works (e.g., Daisley and Webster, 2008), direct information regarding an additional dissertation (Daisley, 2002) is unavailable.

More recent empirical evidence. Subsequent to the current project being reviewed and in progress, several studies came forward to help expand our understanding of this often neglected group.

In one set of studies, Danish researchers evaluated a group of 35 families with parental ABI and reported their findings in a series of papers (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011; Kieffer-Kristensen & Teasdale, 2011; Kieffer-Kristensen, Siersma, & Teasdale, 2013). Their sample included 18 injured fathers and 17 injured mothers with an average age of 46 (SD = 6.2) for the injured parent and 45.6 (SD = 5.9) for the uninjured parent. Types of injuries included stroke (60%), TBI (26%) and 'others' identified as tumors and infections (14%). Time since diagnosis was reported to be 3.7 years (SD = 1.7) and all were thought to be moderate to severe injuries. Within the sample, 37% of the patients and 89% of their spouses were currently employed. Inclusion criteria included only dual-parent households and those patients who resided in the same household as prior to the injury. No individuals in the sample had other

chronic, terminal, or psychiatric illness, assumingly at present or in the past though this is not noted by the authors.

Their child sample included 13 boys and 22 girls between the ages of 7 and 14 with an average age of 11.0 (*SD* = 2.3). Only a single child from each family was enrolled. In multiple-child homes, the enrolled individual was chosen at random (e.g., the child with the closest forthcoming birthday). Excluding a questionnaire that was sent to the child's teacher, families completed all paper-and-pencil questionnaires during a home visit by the primary author (RKK).

In their initial project (Kieffer-Kristensen et al., 2011), they report findings looking at the post-traumatic stress symptoms in children affected by ABI, behavioral and emotional problems in these children, as well as the correlation between these two sets of data. Measures included: 1) the Danish version of The Children's Revised Impact of Event Scale (CRIES-13), a 13-item child-friendly self-report questionnaire commonly used to screen children at risk for PTSD; 2) the Beck Youth Inventory (BYI), a self-report scale designed to identify current emotional states across five subscales including self-concept, depression, and anxiety; and 3) a Danish translation and standardization of the Child Behaviour Check List (CBCL) completed by parents and the related Teacher Report Form (TRF), both thought to be fairly comprehensive measures of common emotional and behavioural problems in children. Results were compared both to a control sample consisting of 20 children whose parents were diagnosed with diabetes as well as normative data.

Findings suggest significant post-traumatic stress symptoms in the ABI group with 46% of the children falling above a recommended clinical cut-off (CRIES $\geq$ 30) as

compared to 10% in the control sample. Effect sizes were large on the total score (Cohen's *d* = 1.2) and across subscales of intrusion, avoidance, and arousal (Cohen's *d* = 1.2, 0.9, and 0.8, respectively) as compared to controls.

While the authors contend that these results suggest a large subset of children meeting criteria for probable post-traumatic stress disorder (PTSD), this is a bit of a leap. Firstly, the cutoff score used in the study has been shown to correctly classify only 75-83% of children in a validation sample (Perrin, Meiser-Stedman, & Smith, 2005). Secondly, the instrument used does not include a measure of the functional impact of the reported symptomatology and as the original authors contend, one cannot make a clinical diagnosis from scores on the self-completed scales alone. While it is likely that such a high level of distress would be tied to functional impairment, we cannot make that assumption without additional information (e.g., a clinical interview). It is possible that these children often think about the brain injury but that it does not cause them distress. As the questionnaire has only 13 total items, it is also possible it picks up distress that could be better classified with an alternate diagnosis (e.g., depression, another anxiety disorder). Lastly, for clarification purposes, while the children were asked to complete the form "with respect to the parental injury" it is unclear whether they conceptualized this as meaning the initial injury itself or the current outcome. It is also worth noting that the scale is slightly skewed towards distress with responses at the top of the scale being given a higher weight (e.g., 'none' = 0, 'rarely' = 1, 'sometimes' = 3, 'a lot' = 5). For example, a response of 'sometimes' on 10 of the 13 items would classify a child as clinically distressed.

While the classification of 46% of the sample as exhibiting traumatic symptomatology seems a bit high, especially given that studies of children exposed to severe trauma (e.g., war, natural disaster, human rights violations) suggest that only 20 to 30% of these children go on to develop PTSD (Perrin et al., 2005), the authors contend that these rates are similar to what is seen in other studies on child adjustment to significant familial illness (e.g., 29% of a sample of adolescents adjusting to parental cancer demonstrated a high degree of post-traumatic stress symptoms; 32% of healthy siblings of pediatric cancer patients were found to meet criteria of PTSD). It may be that the chronic form of the stressor leads to a higher rate of persistent symptomatology or, conversely, that the measure is tapping an element of distress common in these populations.

However, despite its limitations, the CRIES-13 data appears to picking up on some clear distress in this sample. The authors argue that due to the often event-specific nature of childhood traumatic stress such that emotions diminish over time in their daily lives but are quickly reactivated through events and reminders, these children may be particularly vulnerable to trauma-specific symptoms, such as those measured by scales of post-traumatic stress, rather than to generalized anxiety and depression scales. This is supported by the finding of average scores on self-report measures of self-concept (avg T = 50.31, SD = 8.73), anxiety (avg T = 49.86, SD = 8.36), and depression (avg T = 49.66, SD = 8.91). In contrast, results from the CBCL completed by parents suggest elevations on all the constructs assessed (externalizing and internalizing subscales, total score) as compared to the normative sample but not controls; similarly, results from teachers suggest higher scores on the internalizing subscale as compared to the normative sample

but not controls. Effect sizes ranged from small to moderate (Cohen's d = 0.27 to 0.50) though the clinical impact of these findings are difficult to ascertain since each mean falls within one standard deviation of the mean of the normative sample. Moderately-sized correlations (r = 0.25-0.34) were found between some of the CRIES-13 scores (avoidance, arousal, total score) and some of the parental CBCL scores (internalizing, total score). Similarly, self-reported anxiety and depression on the BYI, while average overall, also showed moderate positive correlations (r = 0.26-0.38) with some of the CRIES-13 scores (intrusion, arousal, total score) suggesting that the CRIES scores are clearly tapping some level of general distress.

A follow-up study further explored the impact of injury and family factors (e.g., parenting stress, marital relationship) on child psychosocial functioning in this sample. In a 2013 study, Kieffer-Kristensen and colleagues attempted to clarify injury and family characteristics that may contribute to psychological problems in the children including injury characteristics (e.g., type of injury, localization), demographic information (e.g., gender of the affected parent, child's gender), and family variables such as parenting stress, dyadic adjustment, and the symptom profile of both the healthy (e.g., depression, anxiety, aggression) and the injured parent (global impact of brain injury, depression). Child outcome was dichotomized into "affected" versus "not affected" based on scores on each of two measures (CRIES-13, CBCL) which were then analyzed separately. Results suggest that of the 24 variables assessed, only the levels of parental stress as reported by the uninjured parent were related to child psychosocial functioning on these dichotomized variables such that higher levels of stress, distress, or impairment in parent-child interactions were related to higher levels of child psychosocial problems.

Interestingly, results suggest that injury characteristics, including general outcome on a rating of brain injury symptoms, depression in either parent, and marital satisfaction were not related to child psychosocial function, as one may suspect. This is surprising not only given the suspected relationships between these variables and child psychosocial functioning but also given results from a prior study suggesting relatively high rates of marital dissatisfaction and unhappiness in this sample (Kieffer-Kristensen & Teasdale, 2011). However, spouses in this sample did not show high levels of depressive symptomatology as compared to a normative sample; different results may occur in a sample with a higher level of depressive symptomatology overall. It is worth noting that a prior study (Kieffer-Kristensen & Teasdale, 2011) suggests that spouses reported only moderate levels of general parenting stress that was no different from controls in families with parental diabetes. Instead, it was the ABI patients in the sample who reported higher overall levels of parenting stress, but this stress was not directly related to child psychosocial functioning. Limitations of this project include that the authors do not provide an explanation for dichotomizing the child psychosocial measures and it is unclear how this dichotomy may have impacted the results (e.g., further accentuating a small effect). As results were analyzed using nonparametric procedures, it would also be useful to know what the median scores were across the samples, as compared to the reported means. Additionally, as this is the first analysis of its type further replication in a larger cohort is warranted. Similarly, as the sample was made up of a majority of stroke patients (60%), it is unclear how these findings would generalize to other populations.

A group in England set out to examine the experiences of adolescent offspring following parental ABI and the role of supportive relationships in their coping (Moreno-Lopez, Holttum, & Oddy, 2011). As support systems have been found to moderate adult relatives' life satisfaction following ABI and have been described as an important determinant of postinjury family adjustment, the authors posited that this effect may trickle down to adolescent offspring. Nine adolescents (6 girls, 3 boys) between the ages of 13 and 20 were recruited for participation (M = 16.7 years). Siblings were included and children represented six separate families. Parental ABI was classified as severe requiring post-traumatic amnesia of more than a week for those with TBI (5 of the 6 families) and severe memory impairment along with psychosocial deficits for nontraumatic injuries (1 nontraumatic subarachnoid hemorrhage). Average time post-injury was 2.5 years (range 1 to 4 years). Families represented a community-based sample with little history of contact with mental health services.

Using an analysis grounded in theory, the authors created a proposed model of adaptation following ABI based on interview data from the adolescent participants. Categories in the final model included wanting to protect the family from further stress, attempting to provide a sense of "normality" to their lives, and renegotiating peer relationships. A higher-order category included reevaluating life and self. Key findings included generally positive outcomes with the majority of participants reporting that their families were more united and worked better together than prior to the injury. Emotion-focused coping strategies such as avoidance, positive reframing, humor, and catharsis (e.g., art and writing) were evidenced and friends were identified as an essential source of

emotional support. Themes detected in other studies, such as the rapid maturation due to added responsibilities post-ABI, were apparent.

Strengths of this study included the novel approach, the rigorous qualitative procedures used along with the feedback from adolescents regarding the model itself. Though primarily TBI fathers, the sample represented a diverse group in terms of gender, nature and degree of injury, and socioeconomic status and results would likely be directly applicable in clinical settings. Limitations include the relatively small sample size (though the authors argue that the sample size was theoretically driven) along with a limited discussion of the interplay between peer relations and coping.

Impact of Parental Chronic Illness on Children

Living with a parent with a brain injury has at times been compared to living with a parent affected by chronic illness. While beyond the scope of the current discussion, it is worth noting some key features of this large body of literature that may be relevant to the current discussion. Firstly, such studies have generally been conducted on one disease process (e.g., multiple sclerosis, cancer, HIV) making comparisons across groups difficult (e.g., children of parental chronic illness). Where different disease processes have been compared, it appears that the ability to cope increases with age (Steck et al., 2007). Additionally, how the parents cope can be the best predictor of how the children cope (Steck et al., 2007; Thastum, Johansen, Gubba, Olesen, & Romer, 2008). A key feature in positive coping when facing many such illnesses involves breaking the silence and talking about the condition with children at age appropriate levels (Longfield & Warnick, 2009; Mutch, 2005). Lesser understood diseases, such as chronic fatigue syndrome, may provide parallels to the brain-injury community by being able to relate to

a poorly-understood but debilitating process that impacts the entire family. Themes such as social withdrawal and shame, the parental illness playing a pivotal role in family life, living in a changed world, shifts in roles and responsibilities, financial strain, and conflicts regarding the actual severity of the illness are likely not unfamiliar to families living with a brain-injured parent (Donalek, 2009).

Impact of Parental Mental Illness on Children

Further complicating the matter, it has been known for some time that parental mental illness can impact children. Whether this effect is through a genetic predisposition or environmental influence, mental illness tends to occur along family lines. There is no one-to-one ratio, however, such that the type of mental illness in the parent predicts the type of problem that may occur in the child. Instead, there is a spectrum such that children with parents who have mood disorders may have an increased tendency to suffer from a mood disorder at some point in their lives and children whose parents have anxiety disorders may have an increased tendency to suffer from some type of anxiety disorder at some point. These lines are quite gray, however, and more generally speaking a mental disorder in a parent may lead to an increased risk of any (often related) mental disorder in a child. The transmission of such disorders is often conceptualized from a biopsychosocial perspective such that underlying biology may predispose an individual to a certain condition, but environmental factors must play a role for that underlying predisposition to progress to a mental illness (Fowles, 2001; Rhee, Feigon, Bar, Hadeishi, & Waldman, 2001).

For purposes of the current discussion, perhaps the most relevant influences are those of parental depression on children. Affective disorders are some of the most

prevalent psychiatric conditions in the United States with a one-year prevalence rate of around 10% and a lifetime prevalence rate of approximately 6% for a major depressive episode. While genetics likely play a role in the familial transmission of depression, life events most often precede depression and in some cases precipitate episodes. Events most often linked to depression include those characterized as long-term or ongoing. Childhood depression has been linked both to genetics and psychosocial factors such as having parents with affective disorders; having parents who are more negative, critical, detached, punitive, angry, and psychologically abusive; poorer communication and decreased warmth in the home; and problematic familial relationships. (Hammen & Rudolph, 1996; Rehm, Wagner, & Ivens-Tyndal, 2001)

With the high rates of depression reported both in individuals with brain injury (Seel, Macciocchi, & Kreutzer, 2010) and caregivers (Brooks, 1991) along with the findings by Pessar's group (1993) that depression in the uninjured parent relates to child outcome, it is important to consider the impact parental depression can have on children, even in the absence of brain injury.

Summary & Goals for the Current Project

Evidence from research on caregivers, clinical and qualitative studies of children, preliminary quantitative evaluation, and research on other parental chronic illnesses all suggest that children living with a parent who has a brain injury may experience consequences in terms of their psychosocial functioning. Still other findings suggest a certain degree of resiliency and strength. To date, there is limited empirical evidence available to inform our understanding of this reportedly "at risk" group.

The goals of the current project are a preliminary look at a small group of children of parents with brain injury to ascertain whether differences in the group as a whole can be detected in areas suggested in previous research to be most vulnerable (e.g., depression, anxiety, parental relationships, school behavior). While it is tempting to say that a large-scale study is required to look at the various factors that may or may not impact child outcome, at this point in time, large-scale investigation seems premature. With only a handful of empirical studies to date, research on the impact of parental injury on children is still in its infancy. Prior to large-scale evaluations, the field would benefit from additional hypothesis gathering in smaller-sized samples.

Goals of the current project include the following:

1) The primary goal of this study is to explore the impact of ABI on children living in the home. Firstly, I aim to determine if these children as a group fundamentally differ from age-related normative information available for the general population. As little is known regarding the possible outcome of this evaluation, both quantitative and qualitative measures will be employed such that the current study will serve a hypothesis-generating purpose. As prior research has focused solely on parental report, child self-report will be a key element of the current study.
2) A secondary goal includes determining whether findings from prior research hold in a new sample (e.g., the impact of the parental relationship on these children, the influence of demographic and environmental factors). I plan to report and explore the impact of the

injured parents' neurobehavioral profile, especially in terms of the emotional and behavioral changes reported to be most salient to caregivers of individuals with ABI. I also hope to report and explore the impact of clinical depression in either parent as prior reports have been mixed regarding its impact on child psychosocial functioning in this population (e.g., Kieffer-Kristensen et al., 2013; Pessar et al., 1993).

METHODS

Participants

Participants included families with children between the ages of 8 and 18 in which a parent living in the home had suffered a brain injury (e.g., TBI, stroke). Recruitment materials included letters and emails to national support group chapters (US and Canada) and postings to online resources directed at individuals with brain injuries. Participants were recruited in person at local events in Texas sponsored by the Brain Injury Association of America. Flyers were posted in various rehabilitation centers and physicians working with individuals with brain injury were informed about the project and provided with materials to distribute to any interested parties. All qualified participants who had been seen since 2008 at a local brain injury rehabilitation facility (Mentis Neurorehabilitation, Houston, Texas) were contacted by staff and informed of the project. Study materials and procedures were approved by the Human Research Ethics Board at the University of Victoria and informed consent, or assent for younger children, was obtained from all participants.

In total, seven families completed all study materials including ten children (ages 9-18 years; M_{age} = 13.08, SD = 2.6; 6 males, 4 females), seven parents with a brain injury (4 fathers, 3 mothers), and five parents without a brain injury (1 father, 4 mothers). Detailed demographic information is provided in Table 1. In two single parent households, a close friend (2 females) provided an alternate perspective on the neurobehavioral symptoms of the individual with a brain injury.

Table 1. Demographic information.

	PBI	nPBI	Informant	Child
Age	42.56 years (8.5)	45.54 years (11.6)		13.08 years (2.6)
Minimum	32	33		9
Maximum	52	63		18
Gender	4 males, 3 female	1 male, 4 female	2 female	6 males, 4 female
Age at Injury	35.71 years (11.9)			9.75 (2.8)[a]
Minimum	15			4[a]
Maximum	49			14

Note. Numbers provided are mean (*SD)*; age information is provided in years; age information was not collected for non-parent informants; PBI = parent with brain injury; nPBI = non-brain injured parent.

a. Mean and minimum provided only for children who were alive at the time of the injury (n = 9).

Mode of injury among study participants included five TBIs (four motor vehicle accidents, one fall), one stroke, and one motor vehicle accident complicated by multiple associated strokes. Based on reported injury characteristics summarized in Table 2 including duration of loss of consciousness, post-traumatic amnesia, and retrograde amnesia, all participants with TBIs would be classified as having had moderate to severe injuries (e.g., American Congress of Rehabilitation Medicine guidelines). Classification of stroke severity tends to rely on outcome either immediately following the event or over the longer term (Kelly-Hayes et al., 1998). Although no detailed neurological exam was available for study participants, reported outcome data (described in more detail in the Results section) suggests that each of the two stroke victims would be classified as having had severe injuries (e.g., severe deficits in at least one functional domain). All seven participants with a brain injury were in the more chronic stages of recovery (see Table 2). Excluding one individual who had acquired his injury in adolescence and was 28 years post-injury, average time post-injury was 3.3 years (*SD* = .79) with a range from 2.1 to 4.1 years. Type of injury, level of injury severity, and time post-injury all suggest that the current sample is consistent with those individuals who would be seen in post-acute brain injury rehabilitation programs (e.g., Adams, Sherer, Struchen, & Nick, 2004;

Malec & Basford, 1996), though there were more females in the current sample than is typical (42.9%).

Table 2. Injury characteristics.

Family #	Time Post-Injury (years)	Mode of Injury	Duration LOC	Duration PTA	Retrograde Amnesia
1	28.0	MVA	> 24 hours	> 7 days	> 2 months
2	4.1	Fall	>30 min but < 24 hours	≤ 1 week	1 hr
3	4.0	MVA & stroke	> 24 hours	> 7 days	> 1 month
4	2.1	MVA	> 24 hours	> 7 days	1 week
5	3.5	MVA	≤ 30 min	> 7 days	1 week
6	3.7	Stroke	No LOC	No PTA	N/A
7	2.6	MVA	Unknown (GCS = 7)	> 7 days	2-3 weeks

Note. LOC = loss of consciousness; PTA = post-traumatic amnesia; MVA = motor vehicle accident; GCS = Glasgow Coma Scale score, as reported by person with brain injury.

Prior History of Mental Illness or Significant Health Concerns

A summary of mental health and general health history is provided in Table 3. All family members were screened for a history of severe mental illness (e.g., schizophrenia) prior to participation. One participant with a brain injury reported a premorbid history of depression and one child participant had a premorbid history of a mood disturbance; both individuals were treated with psychotherapy and these histories were not considered grounds for exclusion. Since the brain injury, one participant reported symptoms of anxiety and panic that were being treated with medication and another reported a history of post-traumatic stress disorder and depression that were treated with combined psychotherapy and medication management. Symptoms for each individual had resolved at the time of study enrollment.

Table 3. Mental health & general health history.

	Premorbid	Post-Injury	Current
Mental Health History			
PBI	Depression Heavy drinking Drug use	Anxiety PTSD & depression	--
nPBI	--	--	--
Child	Mood disorder	--	ADHD
Health History			
PBI	--	Seizure disorder	--
nPBI	Cancer	--	--
Child	--	--	--
Grandparent(s)	--	Cancer Heart problems Alzheimer's Disease Death	Ongoing health problems

Note. PBI = parent with brain injury; nPBI = non-brain injured parent

No child enrolled in the study had a history of a learning disability. One child had a history of Attention-Deficit/Hyperactivity Disorder (ADHD) and was being treated with medication at the time of study participation.

In terms of substance use, one participant with a brain injury reported a premorbid history of recreational drug use as well as a drug-related premorbid seizure. One other participant with a brain injury reported a premorbid history of heavy drinking per NIH criteria (US Department of Health and Human Services, 2007) but denied substance use since the injury. All families denied any history of more severe substance abuse problems or treatment.

All participants denied a personal history of severe health problems (e.g., cancer, HIV, heart attack). In one family, a grandparent living in the household had ongoing health problems related to diabetes and the mother had a remote history (10 years prior) of cancer that was successfully treated surgically. In four of the six remaining families, at least one grandparent had faced a severe health crisis (e.g., cancer, heart problems) and two families had faced the death of at least one grandparent. In one family, a grandparent living out of state had recently passed away from Alzheimer's disease. In addition to the premorbid drug-related seizure history noted above, one participant with a brain injury reported a history of seizure activity following the injury that was well-managed with medication. No other neurologic disorders in immediate family members were reported.

Measures

Child Psychosocial Functioning and Adjustment

Behavior Assessment System for Children, Second Edition (BASC-2)

The BASC-2 is a comprehensive, multidimensional measure of child psychosocial function assessing numerous behavioral and emotional domains (Reynolds & Kamphaus, 2004). Considered a "system" of assessment, the BASC-2 includes a variety of measures for children of different ages and for differing clinical needs. For the purposes of the current study, the Self-Report of Personality (SRP) and the Parent Rating Scale (PRS) were used.

Normative data are available for both clinical samples and the general population. For purposes of the current study, general population norms were used which are based on large, representative samples reflective of the 2001 US Census population figures. Each form includes validity indexes designed to assess specific patterns of response, such

as inattention or overinflation of negative symptoms. Normative groups within the age ranges in question consist of ages 8-11, 12-14, and 15-18 for both the SRP and the PRS. When necessary for descriptive purposes, scores were classified as recommended by the test developers (e.g., *T*-score $\geq$ 70 = Clinically significant, 60-69 = At risk, 41-59 = Average, 31-40 = Low, $\leq$ 30 = Very low; Reynolds & Kamphaus, 2004, p. 16). Following this convention, scores in the 'at risk' range either indicate problems that, while requiring treatment, may not be severe enough to warrant a formal diagnosis or, identify potential or developing problems that should be monitored. Scores in the 'clinically significant' range identify a high level of maladaptive behavior or, conversely, an absence of adaptive behavior (Reynolds & Kamphaus, 2004).

SRP. The SRP is a self-report inventory that queries a variety of emotions and perceptions across multiple domains. Responses take one of two forms: the first part of the record form consists of statements requiring a 'true' or 'false' response; the second part of the form consists of statements with a 4-point frequency rating scale ranging from 'never' to 'almost always.' Taking approximately 20-30 minutes to complete, the SRP is written at a 3rd grade reading level. For purposes of the current study, there were two versions used representing different age groups: one version covered children ages 8 to 11, another covered adolescents ages 12 to 21. Except for two additional scales on the adolescent version (sensation seeking, somatization), there is substantial overlap between the constructs assessed across age groups. Due to developmental differences, there is some variability of item content.

Internal consistency estimates range from moderate (coefficient alpha = .68 to .71 for Self-Reliance) to high (coefficient alpha = .84 to .88 for Depression) across scales and

age groups. Median coefficient alphas across scales are .80, .83, and .81 for age groups 8-11, 12-14, and 15-18, respectively. Although slightly lower than estimates for the PRS, these values still suggest good reliability. With an interval of 13 to 66 days, test-retest reliability was weaker but still adequate with a median adjusted reliability (per Cohen, Cohen, West, & Aiken, 2003) across scales of .71 for the child version and .75 for the adolescent version. Confirmatory factors analysis and intercorrelations between scales support the factor structure of the SRP and reflect current understanding of behavioral dimensions.

To assess concurrent validity, the SRP has been compared to other commonly-used self-report inventories. As similarly comprehensive self-report measures are limited for children under 12 years of age, the child SRP was compared to the Children's Depression Inventory (CDI; Kovacs, 1992) and the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 2000). The adolescent version was also compared to these measures as well as the ASEBA Youth Self-Report (Achenbach & Rescorla, 2001) and the Conners-Wells' Adolescent Self-Report Scale (CASS; Conners, 1997).

Correlations between the depression scale of the SRP and the total score on the CDI were surprisingly low ($r_{adjusted} = .29$) on the child version but high ($r_{adjusted} = .69$) on the adolescent version. As the item content of the depression scale of the SRP is quite similar at both child and adolescent levels (only 1 item different on the child version), the reason for these correlational differences is unclear. Reynolds and Kamphaus (2004) suggest that the response format of the CDI requiring the child to select a statement from a group of three similar statements may have been confusing for younger children, but

since the CDI has been used successfully in a wide variety of child samples, this seems unlikely. As the pattern of correlation across scales was slightly different between the two versions, it is possible that the inventories are capturing slightly different constructs in the two age groups. In contrast, the total anxiety score on the RCMAS was correlated with the anxiety scale on both the child ($r_{adjusted}$ = .60) and adolescent ($r_{adjusted}$ = .49) versions of the SRP, although both were also equally correlated with the SRP social stress scale ($r_{adjusted}$ = .62 and .51 for child and adolescent versions, respectively).

On the adolescent version, conceptually similar scales generally show moderate to high correlations on both the ASEBA Youth Self-Report and the CASS (for specifics, see Reynolds & Kamphaus, 2004, pp. 213-218).

For the purposes of the current study, primary outcome measures consisted of the 10 emotional/behavioral scales and the four adaptive scales that are consistent across the two versions (see Table 4).

Table 4. Outcome measures.

Measure		Scale/Scores		
Child Psychosocial Functioning				
Uninjured Parent	BASC-2 PRS	Emotional/Behavioral Scales		Adaptive
		• Hyperactivity • Aggression • Anxiety • Depression	• Somatization • Atypicality • Withdrawal • Attention Problems	• Adaptability • Social Skills • Activities of Daily Living • Functional Communication
Child	BASC-2 SRP	Emotional/Behavioral Scales		Adaptive
		• Attitude to School • Attitude to Teachers • Atypicality • Locus of Control • Social Stress	• Anxiety • Depression • Sense of Inadequacy • Attention Problems • Hyperactivity	• Relations with Parents • Interpersonal Relations • Self-Esteem • Self-Reliance
Qualitative Measures		• Incomplete Sentences • Parental Relationship • General Descriptors (Child, Parent)		
Parental Neurobehavioral Profile				
Uninjured Parent	NFI	• Depression • Somatic • Memory/Attention		• Communication • Aggression • Motor
	HIBS	• Emotional Regulation		• Behavioral Regulation
	M2PI	• Total score, Categorical ranking		
Injured Parent	NFI	• Depression • Somatic • Memory/Attention		• Communication • Aggression • Motor
	M2PI	• Total score, Categorical ranking		
Other Environmental & Contextual Factors				
		• Employment status		• Perceived financial strain
Parental Depression				
Uninjured Parent	PHQ-9	• Total Score		
Injured Parent	PHQ-9	• Total Score		

PRS. The PRS provides a comprehensive measure of a child's adaptive and problem behaviors in community and home settings. Taking approximately 10 to 20 minutes to complete, it is written at a 4th grade reading level and consists of descriptions of behaviors that the respondent rates on a 4-point Likert-type scale of frequency ranging from 'never' to 'almost always.' For the purposes of the current study, two versions were used representing different age groups: one version covered children ages 6 to 11 and another covered adolescents ages 12 to 21. Except for two additional scales on the adolescent version (conduct problems, leadership) there is substantial overlap between the constructs assessed on the two versions. Due to developmental differences across age groups, there is some variability of item content on some scales (e.g., anxiety) but not others (e.g., attention problems).

Internal consistency estimates are generally good across scales and age groups with coefficient alphas ranging from .72 to .76 at the low end (Activities of Daily Living) to .87 to .88 at the high end (Attention Problems). Median coefficient alphas across scales are .86, .85, and .85 for age groups 8-11, 12-14, and 15-18, respectively. Test-retest reliability was also good within an interval of nine to 70 days with a median adjusted reliability (per Cohen et al., 2003) across scales of .84 for the child version and .81 for the adolescent version. Interrater reliability estimates were a bit lower but still adequate with median adjusted reliability estimates across scales of .69 for the child version and .77 for the adolescent. Confirmatory factor analysis supports the factor structure of the PRS. The relationship between scales and composite scores (internalizing problems, externalizing problems, adaptive skills) supports the validity of the underlying scales as measuring related constructs (e.g., hyperactivity and aggression

hang together as externalizing problems vs. anxiety, depression, and atypicality hang together as internalizing problems).

As an indication of concurrent validity, the PRS has been compared to other commonly-used instruments designed to provide a parent's opinion of child behavior. These include the Child Behavior Checklist (CBCL) of the Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2001), the Conners' Parent Rating Scale, Revised (CPRS-R; Conners, 1997), and the Behavior Rating Inventory of Executive Functioning (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000). As suspected, similarly named composites and scales tend to show moderate to high correlations between measures (for a full description, see Reynolds & Kamphaus, 2004, pp. 179-184). There is some tendency for the correlations between similarly named scales to be higher in the child sample than in the adolescent sample. Additionally, the PRS measure of anxiety centering on general nervousness, fear, and worry appears to tap a slightly different construct than that of the CBCL (r = .34 for the $PRS_{adolescent}$) and the CPRS-R (r = .41 for the PRS_{child}, r = .35 for the $PRS_{adolescent}$).

For the purposes of the current study, primary outcome measures consisted of the eight emotional/behavioral scales and the four adaptive scales that are consistent across the two versions (see Table 4).

PRS vs. SRP. As with many child self-report measures (see Achenbach, McConaughy, & Howell, 1987 for a meta-analysis), there is only a moderate relationship at best between PRS and SRP scores, even on overlapping clinical scales. This overlap is a bit stronger on the adolescent version (correlations on similar clinical scales range from .30-.46) than on the child version (correlations on similar clinical scales range from .19-

.44). These findings suggest that each measure, while correlated, provides distinct information regarding the child's psychosocial functioning.

Drawbacks and limitations. The primary limitation related to the use of the BASC-2 in the current study is the age split resulting in two measures across the age range in question (ages 8 to 18). Of primary concern is the difference in structure such that the number and type of scales differ between the child and adolescent versions (e.g., there are two additional scales on the adolescent version that are not found on the child version). However, it is worth noting that scales selected for analysis in the current study *do* show stability of constructs across age ranges, if not specific item content. Composite scores, which are unique across age groups, were not included in analyses.

While selection of overlapping constructs across age group reduces some of the differences between the measures, there remains the significant limitation of differing item content on some scales. It is worth noting, however, that many of the differences in item content actually reflect reasonable developmental change in the presentation of specific behaviors or emotion states across age. For example, the anxiety scale of the SRP varies slightly between the child and adolescent versions such that the child version includes three statements that are not included on the adolescent version. Similarly, the adolescent version includes three statements that are not included on the child version. One could argue that anxiety can present itself differently across ages and that these subtle changes may reflect those differences. This is supported by the fact that item content for each age group was assessed using factor analysis. Statistically, the differences in item content represent differences in self-report between the child and adolescent versions. What is most important is looking at the constructs in question in a

manner that is developmentally-appropriate to the age group in question. It is possible that item content differences across age actually capitalize on the instrument's ability to tap the construct in question. Additionally, it is worth noting that the number of similarities between the scales far outweighs the differences. On the same SRP Anxiety scale, for example, the child and adolescent versions share 10 of 13 items.

Assets. While differences between child and adolescent versions make the BASC-2 less than ideal, it has several features that support its use to capture child psychosocial function in the current study.

For one, it provides a comprehensive measure of child psychosocial function on one instrument. This means not only that the test development and administration procedures are consistent across scales but also that the normative groups are similarly selected and relatively consistent, a strong attribute when compared to selecting separate measures for each construct in question (e.g., one measure for depression, one for anxiety, etc). The consistency of the normative group across domains allows for more direct comparisons between scales (e.g., since the normative group is the same, one can look more directly at the pattern of responses across scales) as well as more informed comparisons between child and parent report. Additionally, the BASC-2 normative sample is large (normative groups in question range from 800 to 1500 respondents) and representative of the US census in terms of geographic and ethnic make-up.

Secondly, to the best of my knowledge, the BASC-2 is the only such comprehensive measure that includes a self-report across the entire proposed age span (ages 8 to 18). In looking at child psychosocial function, I would argue that child self-

report is a critical element. While parent report provides one view into the inner life of the child, the child's own self-report can provide a richer, more complete view.

An additional reason for the selection of the BASC-2 is its inclusion of measures of adaptive functioning, including a scale assessing the parental relationship which has been reported to be instrumental in influencing psychosocial outcomes in this group (Ducharme, 2003; Pessar et al., 1993). Some have noted that when looking at changes post-brain injury, especially in caregiving samples, researchers have a tendency to focus on negative outcomes to the exclusion of positive outcomes. The inclusion of measures of adaptive functioning allowed for the possibility of looking at both positive and negative outcomes.

Qualitative Measures

In order to gain additional insight into the perspective of the children enrolled in this project, more qualitative measures of child functioning were included.

Incomplete sentences. Children completed a series of open-ended sentences commonly-used in clinical practice. Instructions prompted them to finish each sentence as quickly as possible and write down the first thing that comes to mind. Sentences included items such as "I like…", "I am best when…" "I feel bad when…" "If my mother only would…" "My greatest worry…" Themes identified in each individual's responses were first coded independently. Common themes across individuals were then identified by comparing coded responses and collapsing, as needed (e.g., themes of 'happiness' and 'desire for happiness' were collapsed together into a single category). In addition to overarching themes, individual responses to items related to fear ('My greatest fear…'), worry ('My greatest worry…'), and coping ('If no one helps me…')

were also coded. Notable responses that did not fit into one of the above categories but would commonly be reported in clinical practice were recorded and coded.

Parental relationship. While the BASC-2 SRP includes a measure of the parental relationship, questions group together both parents (e.g., parents, mother and father). As previous research (Pessar et al., 1993) suggests that the relationship with one or the other parent may impact child psychosocial functioning independently, the same 11 questions were asked again with 'parents' replaced by 'mother' on one form and 'father' on the other. Questions were rated on the same Likert-type scale (one true/false item) included in the BASC-2. Items were grouped such that the first set of questions related to one parent while the next set related to the other. The order of administration (e.g., mother first versus father first) was randomized across participants.

General descriptors - Child. Children were asked to provide written responses to some general descriptive questions to gain a better understanding both of their initial experiences at the time of their parent's injury and of their perspective of the impact the injury has had on the family. A sample of the questions asked is provided in Appendix A. In one set of questions, children were asked whether they remember the day their parent was injured and the specific circumstances and emotional response around learning of the injury. They were also asked about their experiences when their parent first returned home from the hospital. Questions included items such as, "How old were you when your dad or mom's brain injury happened?" "Do you remember the day your mom or dad was injured?" and "What was it like for you when your dad or mom first came home after the brain injury?" In a second set of questions, they were asked about changes following the injury (e.g., changes in dad or mom, in the family, in general) and

how they perceive their family in relation to others. Their perspective on positive and negative outcomes was elicited as well as coping strategies for dealing with difficulties. Questions included items such as "What is the biggest change in dad or mom since the brain injury?" "Do you feel like your family is the same or different from other families?" and "Some kids find that there are some good things that have come out of their parent's brain injury. For you, what is the best thing about your dad or mom's injury?" Questions varied from open-ended to structured formats with ample space provided for additional commentary. One question, "How often do you have friends over to the house?" was rated on a 5-point scale including never, not very much, sometimes, often, all the time. Children were also asked whether their parent's brain injury impacted their decision to have friends over and rated their response as yes, no, or sometimes.

General descriptors - Parent. As a means of fleshing out child and parent perspectives regarding the impact the injury has had on the children, one parent was asked to provide written responses to the same set of descriptive questions as the child. Using a theory of mind framework (e.g., Frith & Frith, 1999), in doing so the parents were asked to imagine how each child would respond to these items. Instructions were provided as follows: "This next section is a bit unusual as I want you to put yourself in your child's shoes and imagine how he or she would respond to the following questions. Instead of answering the questions how you would, I want you to take a guess about how you would expect your child to respond. So, using your best guess and without asking your child directly, how do you think your child would respond to the following questions…" Parent and child responses were reviewed for consistency and inconsistency.

Injured Parent Behavioral Profile: Symptoms of the Brain Injury

Neurobehavioral Functioning Inventory (NFI)

"Neurobehavioral problems" have been conceptualized as adverse changes in physical well-being, personality, cognition, and affect that result from neurological dysfunction (see Kreutzer, Seel, & Marwitz, 1999). The NFI was developed to complement psychological and neuropsychological tests by assessing the day-to-day impact of neurologic conditions (Kreutzer et al., 1999). Consisting of 76 descriptors that are rated on a 5-point Likert-type frequency scale ranging from 'never' to 'always,' the NFI describes a wide spectrum of post-injury behaviors and symptoms characteristic of neurological disability and encountered in everyday life. Using factor analysis, the scale has been divided into six "critical items" (e.g., threatens to hurt self) and six factors reflecting major content domains: depression, somatic, memory/attention, communication, aggression, and motor disturbances. Two parallel forms are available for completion by patients or family members. Designed for a 6th grade reading level, the NFI takes approximately 20 to 40 minutes to complete.

With a wide range of ages at time of evaluation (16 to 82 years) and age at time of injury (4 to 81 years), the normative sample of 520 patients and 520 informants covers a variety of individuals. Reflective of the brain-injury community, two-thirds of the patient sample was male and most (80%) were involved in motor vehicle accidents. In terms of racial and ethnic make-up, 77% of the patient sample was Caucasian, 21% was African American, and 2% was of other ethnic backgrounds. Normative information, including *T*-scores and percentiles, are reported by age of informant (ages 17-24, 25-34, 35-44, and

45+) and time the patient was unconscious (less than or equal to 1 hour, more than 1 hour but less than 14 days, greater than or equal to 14 days).

Pearson correlations between subscales indicate a high degree of overlap (r = .44 to .67). As closed head injury is often associated with diffuse cortical dysfunction and a diversity of neurobehavioral problems, the authors argue that these intercorrelations are not unexpected. Results from other studies (Johnston, Shawaryn, Malec, Kreutzer, & Hammond, 2006) suggest that measures of functional outcome post-TBI, like the NFI, assess a unidimensional construct that can be clinically or qualitatively separated into specific domains. Internal consistency estimates are high within subscales with Cronbach's alpha calculations ranging from .86 to .95. Despite issues of self-awareness in the brain injury population (see Prigatano, 2005 for a review), concordance between patient and family member ratings are high. At the individual item level, percent agreement between patient and informant ranges from 48% to 84%. At the factor level, matched-pair t-tests of average frequency ratings revealed no statistical differences between family and patient mean scores for five of the six scales. Only the communication scale showed a difference with family mean scores being significantly less than patient mean scores, but this difference was small in magnitude (M = 1.83 vs. M = 1.99). When injury severity was taken into account, individuals with very severe injuries were found to underrate problems as compared to informants, whereas individuals with mild injuries rated problems as occurring slightly more frequently than family members did. Test-retest reliability has not been assessed.

To assess criterion-related validity, NFI informant results were compared to scores on a series of related neuropsychological tests (e.g., memory, attention, language,

visuoperception, etc.) completed by patients. Only the communication subscale was found to have significant correlations across neuropsychological test performance (r = -.18 to -.34). The memory/attention subscale showed a significant correlation only with the Symbol Digit Modalities Test, Oral Version (r = -.18; Smith, 1973). The memory/attention subscale also correlated with scores on the Wechsler Memory Immediate (r = -.25) and Delayed Memory (r = -.23) subscales, although these correlations did not meet the Bonferroni corrected criteria of $p < .001$. Historically, more ecologically-valid assessment measures, like the NFI, have shown poor correlation with neuropsychological test performance (e.g., Johnston et al., 2006).

Additionally, results of the NFI were compared to five scales from the MMPI-2 found to be sensitive to the effects of brain injury: Hypochondriasis (scale 1), Depression (scale 2), Hysteria (scale 3), Psychasthenia (scale 7), and Schizophrenia (scale 8). Pearson correlations of MMPI-2 scale scores and NFI scores suggest that patients reporting more psychological problems were more frequently described by informants as having neurobehavioral problems. Correlations between scales on each measure followed expected patterns (see Kreutzer et al., 1999, pp. 40-42 for a description).

For descriptive purposes and to capture the severity of each brain-injured participant's neurobehavioral profile, the NFI was completed both by the injured and uninjured parent or informant. Outcome measures include *T*-scores on each of the six subscales for each informant (e.g., injured and uninjured parent). As suggested by the test developers, a mean filling procedure was used for rare instances of missing data (Kreutzer et al., 1999).

Head Injury Behaviour Scale (HIBS)

As noted previously (see 'Impact of Brain Injury on Caregivers and Families' section), of particular importance to primary caregivers of individuals with brain injuries are the behavioral and emotional sequelae of the injury itself. Clinical and qualitative studies suggest that these aspects of injury outcome are also important to children (Butera-Prinzi & Perlesz, 2004; Ducharme, 2003; Hansell, 1990; Lezak, 1988; Pessar et al., 1993). One measure that taps common behavior problems seen following injury is the 20-item HIBS of Godfrey and colleagues (Godfrey, Partridge, Knight, & Bishara, 1993; Godfrey et al., 2003). The HIBS consists of a list of 20 descriptors which are rated as either being a problem or not. For items that are reported as problem behaviors, the amount of distress caused by this behavior is rated on a 4-point scale ranging from 1 to 4. (Another way of conceptualizing the responses are on a 5-point scale of distress ranging from 0, 'not a problem and causes no distress,' to 4, 'a problem and causes severe distress.')

Principal components analysis of responses from caregivers identified two main factors, labeled "emotional regulation" and "behavioral regulation," consisting of 10 items each. Emotional regulation items assess the patient's ability to control his or her emotions. Examples of problem behaviors would include impatience, anger, irritability, or sudden and rapid mood change. Behavioral regulation items assess the patient's ability to control his or her behaviors. Examples of problem behaviors would include lack of motivation or initiative, irresponsibility, or poor decision-making.

Homogeneity of items in each subscale was weak to adequate as assessed by item-total correlations. Correlations were higher for the emotional regulation factor

(median r = .66; range = .49 to .76) as compared to the behavioral regulation factor (median r = .59; range = .47 to .70). In contrast, alpha coefficients were high for both emotional regulation (α = .91) and behavioral regulation (α = .87) factors. Correlation between the subscales (r = .65) was lower than the correlation within subscales suggesting that the two factors assess separate but related constructs. Test-retest reliability estimates suggest that caregivers' ratings were moderately stable over a one-year period (intraclass correlation coefficient r = .68). As evidence of concurrent validity, distress ratings of 66 caregivers were found to correlate (r = .65) with clinician ratings of the severity of problem behaviors on a structured clinical interview (Godfrey et al., 1993).

Normative information is provided for 242 caregivers with a mean age of 43.7 years (SD = 13.5). Caregivers were comprised of 88 parents, 81 spouses, 11 siblings, 34 other relatives, 14 friends, and 13 other acquaintances (e.g., professional caregivers). Injury characteristics of their injured significant other included a mean age of 30.2 years (SD = 12.1), an average of 13.7 days in a coma and 73 days in the hospital. All injured persons were six or more months post-injury (M = 11.3 months, SD = 7.5 months) at the time of rating.

Supporting some findings from the caregiver literature (see above), spouses reported significantly higher levels of distress for the emotional regulation subscale as compared to parents; accordingly, normative information is presented separately for these groups. In contrast, no differences were seen on the behavioral regulation scale which includes the entire normative sample. For consistency in interpreting results on each scale for the current caregiver sample, normative information from only the 81 spouses

was used. Total scores on the emotional regulation and behavioral regulation scales were transformed into *T*-scores for ease of interpretation.

Mayo-Portland Adaptability Inventory-4, Participation Index (M2PI)

The Participation index (M2PI) of the Mayo-Portland Adaptability Inventory-4 (Malec, 2004, 2005; Malec et al., 2003) consists of eight general probes of participation in everyday activities (e.g., social contact, leisure activities, independence in transportation, employment) that are rated on a 5-point scale. As a means of assessing more holistic aspects of injury outcome, such as community integration and independence (e.g., leisure activities, employment), the M2PI was completed either by both parents or, in single parent families, by the injured individual and a close friend. Total scores were converted into *T*-scores based on normative data of 134 individuals with acquired brain injuries seen at a Mayo-Rochester clinic for outpatient brain injury rehabilitation (Malec, 2005). The injured sample was predominantly male (61%) and Caucasian (92%) with at least a high school degree (82%). Average age at time of testing was 38.8 years (*SD* = 13.5 years) and time post-injury varied (mean = 5.3 years, *SD* = 8.4 years; range 1 mo – 43.4 years). Injury type included TBI (65%), CVA (15%), tumor resection (8%), infection (5%) and other injuries (e.g., anoxia, toxin exposure, multiple sclerosis; 7%). Severity of TBI ranged from mild (29%) to moderate (12%) to severe (44%) with some data unavailable (15%). Outcome scores, then, represent performance as compared to other individuals with brain injuries of differing severity (primarily moderate to severe) and etiologies (primarily TBI and CVA) being seen for outpatient rehabilitation. Categorical outcome scores (e.g., typical, severe limitations even as

compared to other people with ABI) were created using recommendations developed by the test developers (e.g., *T*-score below 30 represent relatively good outcomes).

Other Contextual and Environmental Factors

Employment Status

To assess shifts in employment status related to the injury, families were asked who in the family was working both prior to and following the brain injury. Ability to meet current, desired social role (e.g., full-time work, student, childrearing) was ascertained on the M2PI and rated by both the individual with the brain injury and the other parent or informant.

Perceived Financial Strain

The perceived financial strain experienced by the family since the injury was rated on a 5-point Likert-type scale (0 = minimal, 5 = substantial; Moore et al., 1993).

Parental Depression: Patient Health Questionnaire – 9 (PHQ-9)

Parent with a brain injury. Depression is a common occurrence following TBI (Rosenthal, Christensen, & Ross, 1998) and has been reported in the literature to be a factor in the psychosocial outcome of children with parental TBI (Hansell, 1990). Assessment of depression in this population, however, is complicated by the overlap between the neurological sequelae of the injury and the symptomatology of depression. Specifically, features of major depression such as slowed thinking, poor concentration, lability, sleep problems, and decreased energy and activity can often be directly attributable to the injury without the presence of a major depressive episode. However, recent research (see Seel et al., 2010 for a review) suggests not only that depression can be differentially diagnosed in this population, but that there are some relatively successful

screening instruments that can meet these demands. In particular, the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was found to provide a brief and accurate assessment of major depression within a large TBI sample (Fann et al., 2005) and fared better than a variety of other instruments in terms of ruling in and ruling out depression in this population (Seel et al., 2010).

The PHQ-9 is a brief self-report measure consisting of nine items related to the diagnostic criteria of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (*DSM-IV*; American Psychiatric Association, 1994). The individual is asked to rate the frequency of each problem (e.g., "How often have you been bothered by any of the following problems?") over the past 2 weeks on a 4-point scale consisting of 'not at all,' 'several days,' 'more than half the days,' or 'nearly every day.' Each item is assigned a score of 0 'not at all' to 3 'nearly every day' and the total score is summed. Major depression is considered if: 1) five or more of the nine symptom criteria have been present at least more than half the days in the past two weeks and 2) one of the endorsed items is either depressed mood or anhedonia. Based on findings in a large medical sample (580 primary care patients), the following interpretative ranges have been recommended: 5-9 mild depression, 10-14 moderate depression, 15-19 moderately-severe depression, 20-27 severe depression. The PHQ-9 typically takes 2 to 10 minutes to complete.

As described in more detail below, the PHQ-9 shows high internal consistency and test-retest reliability estimates in general medical samples. When compared to the Structured Clinical Interview for the *DSM-IV* (SCID), considered a "gold standard" in the diagnosis of depression, in a sample of 135 adults with TBI the PHQ-9 showed high

sensitivity (.88) and specificity (.90) while providing a positive predictive value of .63, a negative predictive value of .97, a positive likelihood ratio of 8.8, a negative likelihood ratio of .14 and a κ of .67. The area under the PHQ-9 summary score ROC curve is .97 suggesting that the test discriminates well between persons with and without major depression. When compared to a series of screening instruments (Seel et al., 2010), the PHQ-9 performed better than all other scales at ruling in the presence of depression by minimizing false-positive screens. Combined with its excellent ability to rule out the presence of depression in persons with TBI, the PHQ-9 is a strong choice as a depression screening tool. Test-retest reliability of 132 assessments repeated within seven or fewer days was fair with a correlation of .76 for the total score and a κ of .46 (Fann et al., 2005).

Convergent validity in a TBI sample was assessed by comparing performance on the PHQ-9 with other commonly used measures of depression. Correlations were high (.90 with the SCL-20 and .78 with the HAM-D). The PHQ-9 score was also examined in relation to functional impairment (Pearson's coefficient = .59) and general health (Pearson's coefficient = .40) and showed adequate and statistically significant agreement. When compared to a Head Injury Symptom Checklist (HISC) in a subset of 39 subjects, relatively low correlations (.44 to .49) suggest discriminant validity (Fann et al., 2005).

For purposes of the current study, the primary outcome measure for the parent with a brain injury was the total score on the PHQ-9.

Uninjured parent. In addition to serving as a strong screening instrument in the TBI population, the PHQ-9 was originally developed for use in more general populations, including primary care settings, and is therefore an appropriate choice as a depression screening instrument in uninjured parents. As suggested by Pessar and colleagues

(1993), depression in the uninjured parent may play a key role in child psychosocial outcomes in this population.

The PHQ-9 is a module originally developed as part of a larger Patient Health Questionnaire (PHQ) designed to serve as a self-administered instrument to screen for a variety of mental health disorders (see Spitzer et al., 1999). As an independent form, it has been assessed in various samples including 3,000 patients in primary care settings and 3,000 obstetrics-gynecologic patients. Internal reliability estimates are high with a Cronbach's α ranging from .86 to .89. Test-retest reliability within a 48-hour period is also high (.84).

Criterion validity of the PHQ-9 has been assessed by comparing scores to results from a blind phone interview conducted by a mental health professional (PhD clinical psychologist or a senior psychiatric social worker). Based on results from 580 patients and using a cutoff score of $\geq$ 10, sensitivity (.88) and specificity (.88) were high. Positive predictive values ranged from 31% for a cut point of 9 to 51% for a cut point of 15. Positive likelihood ratios also increased with scores, confirming an association between increasing PHQ-9 scores and the likelihood of major depression. ROC analysis showed that the area under the curve for the PHQ-9 in diagnosing major depression was .95, suggesting that the test discriminates well between persons with and without major depression (Kroenke et al., 2001).

A more recent meta-analysis (Gilbody, Richards, Brealey, & Hewitt, 2007) of 14 studies including 5,000 participants across different countries and types of samples (e.g., primary care and community, general medical outpatients, specialized medical services), support previous findings of good diagnostic properties of the PHQ-9 with results

suggesting excellent sensitivity (.92) and strong specificity (.80). As further support of its generalizability, despite variability in settings, properties of the PHQ-9 were generally consistent (for information on 3 outliers, see Gilbody et al., 2007).

Convergent validity was assessed in large samples (3,000 primary care patients; 3,000 ob-gyn patients) by comparing scores on the PHQ-9 with a measure of quality of life (SF-20 Health-related Quality of Life Scales). The observed association between increasing PHQ-9 severity scores and worsening function on all six of the SF-20 scales suggests that the PHQ-9 is tapping a construct related to quality of life. Additionally, this relationship between more severe PHQ-9 scores and worsening function was greatest on the scales shown in previous studies to be most strongly related to depression (e.g., mental health, social, overall, and role functioning) providing further support that the measure is assessing features linked to depression and everyday functioning. Additional measures of construct validity included concordance with self-reported disability days, clinic visits, and the general amount of difficulty patients attribute to their symptoms. Greater levels of depression severity, as rated by the PHQ-9, were associated with an increase in disability days (r = .39), health-care utilization (r = .24) and symptom-related difficulty in activities and relationships (r = .55) (Kroenke et al., 2001).

The similarity of results across various samples suggests that the PHQ-9 findings may be generalizable to outpatients seen in a variety of clinic settings and are likely appropriate for the current study.

Primary outcome measures for the uninjured parent was the total score on the PHQ-9.

Procedure

Approval was obtained from the Human Research Ethics Board of the University of Victoria before implementing any study procedures (Ethics Protocol #12-046). Additionally, the research review committee at a local brain injury rehabilitation center reviewed study materials prior to agreeing to contact former clients regarding the opportunity to participate.

Data from two of the seven families were collected in person. For the remaining families, all data were collected by phone or by mail.

Once contacted by a family expressing interest in the study, information was conveyed regarding what participation would entail (see Appendix B). A brief screening instrument was completed that ensured that families were eligible to participate (e.g., had children living in the home between the ages of 8 and 18 years). If appropriate, consent materials were then reviewed (see Appendix B), information regarding injury characteristics was collected, and the names and ages of family members were gathered.

Testing packets and consent forms were then mailed to participants' homes along with a self-addressed, stamped envelope. A follow-up phone call was made several days later to answer any questions and to collect additional demographic information. Additional phone calls were made, as needed, to answer questions or ensure return of study materials. All study participants were provided with my contact information and I was contacted several times by phone for clarification of study procedures or with questions regarding specific questionnaires. Study materials were completed at the place of the participant's choosing and at their own pace. When necessary, some materials were read aloud to brain injured individuals for completion.

Testing packets were reviewed when returned both to check for completion and regarding the sensitive nature of some of the material collected. For example, responses to items regarding suicidality on the PHQ-9 were checked and child and parent BASC-2 responses were scored. When necessary, responses were reviewed with my faculty supervisor (Mateer) and follow-up was made, as needed. Follow-up phone calls were also made to complete missing data or expand on responses. Regarding attrition, in one family two siblings declined to participate. One additional family withdrew from participation as child materials were incomplete; it was unclear whether the child did not want to participate or if the parent decided to withdraw the child from participation (e.g., parent and significant other materials were completed and returned but not child materials; unable to reach parent for follow-up).

Participation

Child

Each child completed the BASC-2 SRP and a series of qualitative measures. Though each child was allowed to work at their own pace, completing all materials should have taken approximately 30 to 40 minutes. Parents were encouraged to allow their child to complete the study measures in private and all responses were provided in writing. Some children asked the researcher (in person, by phone) clarifying questions on a limited number of items. To the best of my knowledge (e.g., feedback provided by parents and children, handwriting), all children completed study measures independently.

Parent with a brain injury

The parent with a brain injury completed the NFI, PHQ-9, and M2PI. Approximate completion time was estimated between 30 to 40 minutes. In single parent

homes and one additional, the parent with a brain injury also completed the BASC-2 PRS and qualitative questions regarding the child's experience of the parent's brain injury.

Uninjured parent

The uninjured parent completed the BASC-2 PRS, NFI, HIBS, PHQ-9, M2PI, and qualitative questions regarding the child's experience of the parent's brain injury. Approximate completion time was estimated between 1 hour and 1 hour 30 minutes. In single parent homes a friend completed the NFI, HIBS, and M2PI to provide an outside perspective of the affected parent's behavior and outcome.

Compensation

As compensation for the inconvenience related to study participation, each family was entered in a drawing for one of four $25 gift cards to the merchant of their choosing.

RESULTS

Child Psychosocial Functioning and Adjustment

Results from one 12-year-old boy were of questionable validity and were excluded from the following analyses (N = 9). Specifically, results on qualitative measures suggested that he may have completed study procedures even though he was no longer interested in participating in the project. Additionally, one of the validity scales on the BASC-2 (F Index) suggested the use of caution in the interpretation of results.

BASC-2 Results

BASC-2 SRP

Validity indices on the BASC-2 were reviewed for all study participants. Results suggest only two outliers as discussed previously and below. Additional validity indices including those assessing potentially-biased response patterns, the tendency to portray oneself in an excessively positive light (L-index), and positive responses to implausible statements (V-index) were within normal limits for all participants.

One child declined to answer questions regarding body image resulting in no available score for the self-esteem scale (n = 8). One child showed inconsistency in responses to similar item pairs. However, as the pattern of responding was not suspected to bias results, this individual's responses were included in the following analyses. All other validity indicators across participants suggested valid patterns of responding.

Of note, *T*-scores for the adaptive scales (interpersonal relations, parental relationship, self-esteem, self-reliance) were inverted prior to analyses such that higher scores on all scales are indicative of more problematic behavior. Due to the exploratory

nature of these analyses and to preserve power, a p-value of .05 was maintained for all analyses; all tests were two-tailed.

Means and standard deviations for each of the 14 SRP scales of interest are reported in Table 5. Results of the Kolmogorov-Smirnov test suggest that despite the small sample size, only the social stress, $D(9) = .29$, $p < .05$ and sense of inadequacy, $D(9) = .30$, $p < .05$ scales show significantly non-normal distributions. A 1-sample *t*-test was conducted on each scale to determine whether the sample mean differed significantly from the normative mean of 50. Only the sense of inadequacy ($t(8) = -4.06$, $p < .01$) and parental relationship ($t(8) = -2.37$, $p < .05$) scales showed significant differences with each scale showing means significantly *lower* (i.e., better) than would be expected in the general population ($\bar{x}_{\text{inadequacy}} = 43.78$, $SD = 4.6$; $\bar{x}_{\text{parental relations}} = 44.44$, $SD = 7.0$). Sample effect sizes ranged from medium (Cohen's $d_{\text{parental relations}} = .65$) to large (Cohen's $d_{\text{inadequacy}} = .85$). A review of effect sizes for each additional scale (see Table 5) suggests that there may have been one other medium-sized effect (Cohen's $d_{\text{self-reliance}} = .69$) that was not detected due to low power. Similarly to the findings above, this mean was also trending in the direction of being *lower* than would be expected in the general population ($\bar{x}_{\text{self-reliance}} = 43.56$, $SD = 8.8$).

Table 5. BASC-2 SRP results.

Scale	N	Mean	SD	K-S	*t*	Cohen's *d*	Wilcoxon *W*	Wilcoxon *Z*
Attitude to School	9	47.67	11.1	0.27	-0.63	-0.22		
Attitude to Teachers	9	48.00	6.7	0.12	-0.89	-0.24		
Atypicality	9	50.56	8.9	0.21	0.19	0.06		
Locus of Control	9	45.56	8.1	0.27	-1.65	-0.49		
Social Stress	9	50.33	10.6	***0.29****	0.09	0.03	18	-0.53
Anxiety	9	52.00	8.5	0.24	0.70	0.22		
Depression	9	48.33	6.6	0.19	-0.76	-0.20		
Sense of Inadequacy	9	43.78	4.6	***0.30****	***-4.05****	***-0.85***[a]	***1.00****	***-2.57****
Attention Problems	9	49.00	9.6	0.22	-0.31	-0.10		
Hyperactivity	9	51.44	9.5	0.17	0.46	0.15		
Relations with Parents	9	44.44	7.0	0.20	***-2.37****	***-0.65***[a]		
Interpersonal Relations	9	46.89	7.4	0.27	-1.27	-0.36		
Self-Esteem	8	47.50	10.2	0.22	-0.69	-0.25		
Self-Reliance	9	43.56	8.8	0.22	-2.21	***-0.69***[a]		

Note. K-S = Kolmogorov-Smirnov test statistic with Lilliefors correction; * indicates significance at $p < .05$

a. Medium to large effect sizes.

While the *t*-test is generally robust to violations of assumptions of normality, Moore and McCabe (2006) have suggested a "rule of thumb" that if the sample size is less than 15, then you should not use a 1-sample *t*-test if data are clearly skewed or if outliers are present. Those scales violating assumptions of normality were then re-analyzed using a nonparametric 1-sample Wilcoxon signed rank test. Results suggest that the sense of inadequacy scale ($W(9) = 1.00$, $Z = -2.57$, $p = .01$) but not the social stress scale ($W(9) = 18$, $Z = -.53$, $p > .05$) has a median that differs significantly from 50. Again, the median on the sense of inadequacy scale is *lower* than would be expected in the general population ($median_{inadequacy} = 44$).

As the BASC-2 is a commonly used measure in clinical practice, a second way of interpreting results would be to look at the number of children showing scale elevations in the 'at risk' or 'clinically-elevated' range (as described above, *T*-score $\geq$ 70 =

Clinically significant, 60-69 = At risk). In clinical practice these elevations may identify behaviors that warrant further investigation and/or require treatment. Based on this commonly-used metric, five of the nine children studied showed elevations on at least one scale. Four children reported at least one scale in the 'at risk' range and three children showed at least one elevation in the 'clinically significant' range (see Table 6). From a clinical perspective, these results are somewhat difficult to interpret as one score in the 'at risk' or 'clinically significant' range may or may not be of importance. Instead, clinicians often look for converging evidence to support hypotheses generated from tests like the BASC-2. As a means of balancing the finding of scale elevations, it is worth noting that eight of the nine children in the sample also demonstrated scores 1 standard deviation *below* the mean on at least one scale (see Table 6).

Table 6. Scale elevations and depressions on BASC-2 SRP.

Sbjt	'At risk'[a]	'Clinically elevated'[b]	Recommendations[c]	'Low'[d]
3	--	--	No	3 Locus of control Parental relationship Interpersonal relations
6	3 Atypicality Social stress Anxiety	2 Hyperactivity Self-esteem	Yes	3 Attitude to school Attitude to teachers Self-reliance
9	1 Anxiety	--	Yes	1 Self-reliance
12	--	--	No	4 Attitude to school Locus of control Inadequacy Attention problems
15	4 Atypicality Depression Attentional problems Interpersonal relations	1 Social stress	No	--
20	--	1 Attitude to school	No	2 Inadequacy Self-reliance
21	1 Self-reliance	--	No	1 Locus of control
25	--	--	No	2 Parental relationship Self-esteem
26	--	--	No	6 Attitude to teachers Locus of control Attention problems Parental relationship Self-esteem Self-reliance

a. *T*-scores 60-69 (1 *SD* above the mean)
b. *T*-scores $\geq$70 (2 *SD*'s above the mean)
c. Recommendations made for further assessment
d. *T*-scores 31-40 (1 *SD* below the mean)

While the information gathered for the current project was intended for research purposes and by no means represents a comprehensive clinical evaluation, the use of clinical instruments provided some limited insight into the behavioral profile of participants. For two children in the sample, the information gathered was deemed of

sufficient clinical significance that recommendations were made for families to seek more comprehensive evaluations and support.

BASC-2 PRS

Results are reported from the entire sample (N = 10). Forms were generally completed by the child's mother (8 of 10) and the non-brain injured parent (6 of 10). Validity indicators including those designed to assess potential response biases, inconsistency, and the tendency to portray one's child in an excessively negative light (F-index) all suggested valid patterns of responding across participants. Similarly to the SRP analysis, *T*-scores for the adaptive scales (adaptability, social skills, activities of daily living, functional communication) were inverted prior to analyses such that higher scores on all scales are indicative of more problematic behavior. Due to the exploratory nature of these analyses and to preserve power, a p-value of .05 was maintained for all analyses; all tests were two-tailed.

Means and standard deviations for each of the 12 PRS scales of interest are provided in Table 7. Results of the Kolmogorov-Smirnov test suggest that only the hyperactivity, $D(10) = .27$, $p < .05$, and aggression, $D(10) = .27$, $p < .05$, scales show significantly non-normal distributions. A 1-sample *t*-test was conducted to determine whether the sample mean on each scale differed significantly from the normative mean of 50. Only the aggression ($t(9) = -2.67$, $p < .05$ and social skills ($t(9) = -2.94$, $p < .05$) scales showed significant differences with each scale again showing significantly *less problems* than would be expected in the general population ($\overline{x}_{\text{aggression}} = 43.4$, $SD = 7.8$; $\overline{x}_{\text{social skills}} = 42.2$, $SD = 8.4$). Effect sizes ranged from medium (Cohen's $d_{\text{aggression}} = .74$) to large (Cohen's $d_{\text{social skills}} = .85$). A review of effect sizes for each scale (see Table 7)

suggests that there may have been one other medium-size effect (Cohen's $d = .53_{withdrawal}$) that was not detected due to low power. Similarly, this mean was also trending in the direction of being *lower* than would be expected in the general population ($\bar{x}_{withdrawal}$ = 45.5, *SD* = 6.9).

Table 7. BASC-2 PRS results.

Scale	N	Mean	SD	K-S	*t*	Cohen's *d*	Wilcoxon *W*	Wilcoxon *Z*
Hyperactivity	10	46.00	13.1	***0.27****	-0.96	-0.35	13.00	-1.48
Aggression	10	43.40	7.8	***0.27****	***-2.67****	***-0.74***[a]	***6.00****	***-2.23****
Anxiety	10	49.40	11.1	0.21	-0.17	-0.06		
Depression	10	48.30	9.0	0.14	-0.60	-0.18		
Somatization	10	54.70	15.3	0.24	0.97	0.37		
Atypicality	10	46.80	6.0	0.19	-1.70	-0.40		
Withdrawal	10	45.50	6.9	0.19	-2.08	***-0.53***[a]		
Attention Problems	10	46.40	8.7	0.20	-1.31	-0.39		
Adaptability	10	47.10	10.8	0.16	-0.85	-0.28		
Social Skills	10	42.20	8.4	0.16	***-2.94****	***-0.85***[a]		
Activities of Daily Living	10	49.00	9.4	0.16	-0.34	-0.10		
Functional Communication	10	46.50	7.3	0.17	-1.51	-0.40		

Note. K-S = Kolmogorov-Smirnov test statistic with Lilliefors correction; * indicates significance at $p < .05$

a. Medium to large effect sizes.

Scales violating assumptions of normality were then re-analyzed using the 1-sample Wilcoxon signed rank test. Results suggest that the aggression (W(10) = 6.00, Z = -2.23, $p < .05$) but not the hyperactivity scale (W(10) = 13.00, Z = -1.48, $p < .05$) has a median score that is significantly less than 50 ($median_{aggression}$ = 40.0).

Three of the 10 children were rated by parents as falling in the 'at risk' or 'clinically-elevated' range on at least one scale. Two children were rated as 'at risk' and three were rated in the 'clinically significant' range (see Table 8). In the context of other information gathered from families, none of these scale elevations were deemed of sufficient evidence as to warrant recommendations for clinical follow-up. Similarly to

the SRP results, seven of the 10 children were also rated as exceptionally low on at least one scale (see Table 8).

Table 8. Scale elevations and depressions on BASC-2 PRS.

Sbjt	'At risk'[a]	'Clinically elevated'[b]	Rec's[c]	'Low'[d]
3	--	--	No	3 Aggression Social skills Functional communication
6	--	--	No	--
9	--	--	No	7 Hyperactivity Aggression Somatization Withdrawal Adaptability Social skills Activities of daily living
12	--	1 Anxiety	No	1 Social skills
15	--	--	No	--
20	--	--	No	2 Aggression Social skills
21	1 Withdrawal	1 Somatization	No	1 Hyperactivity
22	5 Depression Somatization Attention problems Adaptability Activities of daily living	1 Hyperactivity		--
25	--	--	No	6 Hyperactivity Aggression Anxiety Depression Attention problems Adaptability
26	--	--	No	9 Hyperactivity Aggression Anxiety Adaptability Social skills Depression Attention problems Activities of daily living Functional communication

a. *T*-scores 60-69 (1 *SD* above the mean)
b. *T*-scores $\geq$70 (2 *SD*'s above the mean)
c. Recommendations made for further assessment
d. *T*-scores 31-40 (1 *SD* below the mean)

Qualitative Measures

Incomplete Sentences

Up to six themes were reported for each individual child. Overall themes and their frequencies are reported in Table 9. Common themes across respondents were generally positive and included happiness or a desire for happiness, love of family, and like of school. Other themes reported that would be common in childhood included being bullied, worry about school or performance, and the importance of family. Perhaps less common themes included regret or sadness about the brain injury, hurt and pain, or fear of a family member being hurt.

Table 9. Incomplete Sentences themes.

Theme[a]	Frequency[b]
Happiness/desire for happiness	4
Love of family (and significant other)	3
Liking school	3
Regret or sadness about the brain injury	2
Being bullied	2
Worry about school/performance	2
Dislike of school or teachers	2
Sports	2
Generalized worry or anxiety	1
Importance of family	1
Strained relationship with a family member	1
Needing help (from family)	1
Fear of family member being hurt	1
Hurt, pain	1
Escape (school, adulthood)	1
Disappointment/fear of disappointing	1
Liking friends/support from friends	1
Misunderstood	1
Being good	1
God/religion	1
Girls have it easier	1
Singing	1
Communism	1
Total	**35**

a. For these purposes, a "theme" is meant to imply only a commonly occurring topic within an individual child's responses.
b. Frequency refers to the number of children who identified this common topic within their responses.

Table 10 provides thematic responses for other notable items within the measure, including those related to fear and worry. Two children in the sample identified their greatest fear as death or the loss of a loved one (e.g., My greatest fear… "is losing the people I love", "is my dad dying while I'm away at college."). Other fears included the fear of failure, academics or academic failure, and fears of bugs or the dark. Themes of

death and loss as well as academic failure were also evidenced when children were asked about their greatest worry. In fact, worry about death, the loss of a loved one, or parents' well-being was the most commonly reported concern ($n = 4$). Again, fear of having an accident was noted as a worry, as well.

Table 10. Incomplete Sentences themes for fear, worry, and notable responses.

Theme	Frequency
Greatest Fear	
Death/losing a loved one	2
Failure	1
Academics/academic failure	1
Religious reference (e.g., God)	1
To become my (non BI) parent	1
Bugs	1
The dark	1
Sawed in half by a magician	1
Total	**9**
Greatest Worry	
Death/losing a loved one/worry about parents well-being	4
Academics/academic failure	2
Having an accident	1
Losing control	1
Going into a black hole in space	1
Total	**9**
Other Notable Responses	
Positive self-esteem	2
Fear of repeating of what happened to parent	2
Money concerns	1
Questioning why a loved one is sick (non-brain injury)	1
Questioning why the injury happened (brain injury)	1
Wanting parent back to normal	1
Wanting to help parent with brain injury	1
Fear of having an accident or hurting oneself	1
Sad for others in a similar situation	1
Temper of person with brain injury	1
Being alone/abandonment	1
Others don't believe in me	1
Dislike of school	1
Disappointment	1
Total	**16**

Other notable responses demonstrated both themes of positive self-regard (e.g., I'm good at… "being me") as well as fears and concerns related to the parent's injury (e.g., I hope I'll never… "have to go through the things I had to go through when my dad was in the hospital"). Again, at least one individual expressed fear of being hurt (I hope I'll never… "hurt myself badly").

One could conceptualize two categories of common themes emerging from the data, then. On one hand, themes of strength and resiliency emerged (e.g., positive self-regard, love for family, like of school, a desire for happiness). On the other hand, fears of death or the loss of a loved one as well as fears and concerns related to both the parent's injury and the child's own well-being were salient, as well. Academic fears along with a fear of failure also stood out as common themes both across the measure and among respondents.

An examination of coping strategies evidenced in responses (see Table 11) suggests both active (n = 5) and passive (n = 3) coping styles within the sample. (One response provided a somewhat ambiguous response that could be coded as either active or passive depending on the interpretation.)

Table 11. Coping strategies as evidenced on Incomplete Sentences task

Subject	If no one helps me…	Active/Passive Coping
3	"I feel lost."	Passive
6	"I sometimes do bad."	Passive/Active
9	"I can't do well."	Passive
12	"I try even harder."	Active
15	"I help myself."	Active
20	"I can do it on my own."	Active
21	"I figure it out."	Active
25	"then I have nobody to disappoint."	Passive
26	"I can usually figure it out myself."	Active

Parental Relationship

Except for two brothers who are estranged from their uninjured father, all study participants indicated that they get along well with each parent. Ratings of the relationship with each parent was relatively high ($\overline{x}_{mother}$ = 36.11 of 40 possible points, *SD* = 6.2; $\overline{x}_{father}$ = 30.78 of 40 possible points, *SD* = 8.6) though analyses were limited due to the small sample size.

General Descriptors – Child

At the time of their parents' injury, eight children in the current sample (N = 9) ranged in age from 4 to 14 years old with a mean of 9.85 (*SD* = 3.0) years. One child (participant 3) was born more than a decade following the parent's injury. With the obvious exception of this child (participant 3), all but the youngest child at the time of injury (age 4) remember when their parents were injured and 6 of the 8 children in question remember the parent's hospitalization.

No child was present during any of the traumatic injuries. Two siblings were present when they found their father after his stroke and one child participant called 911 for their mother. For the children whose parents had traumatic injuries, most were told of the accident by close family or friends, either after having received a phone call relaying the news or when the child was supposed to be picked up from school. In one family, a child vividly remembers being present when his father received a phone call from the police notifying him of his mother's accident and remembers accompanying his father to the hospital when the extent of his mother's injuries were unknown; he is the only child in the sample who reported still being bothered by memories of the initial injury.

Children described feeling nervous, shocked, emotional, or worried when learning of the parent's injury; at least two children recalled praying at the time. When the parent returned home, typically after more than a month away, children recall feeling happy and nervous. One child described the situation as "very awkward" another as "stressful but relieving." A 10-year-old boy described it as "a good learning experience for me" as he learned how to do more around the house. Children in single parent homes recall helping the parent take care of everyday tasks like walking, bathing, or dressing. One child described it being difficult to see her parent in pain; others recall continued "temper issues" or fatigue.

When asked to describe the biggest changes in the injured parent post-injury, children described sequelae such as chronic pain, physical limitations, speech impairments, memory problems, and issues with temper. Others described their parent as "act[ing] differently" or saw the biggest change in the parent as the "ability to function as 'adult' self sufficiently." Not all children described negative sequelae. Others described the parent as nicer, happier, and "just a totally different person." From the children's perspective, the biggest changes in the family and in general post-injury included not being able to do as much as before. Children described changes in the uninjured parent's stress level, a rise in marital conflict, or shifts in family dynamics in general. One child described the "loss of dad [pre-injury]" and the replacement with "new dad." Other children described being happier, grateful, having more contact with grandparents, and enjoying each moment together more than before. One child described understanding better "how much my [parent] does for me."

Nearly all the children in the sample described their families as different from other families. Some children specifically referenced the injury stating that "my [parent] is injured and I worry about what my life will be like in the future" or "my [parent] has a brain injury and most families don't know how that feels." Others described being closer, more content, and more aware of each others' needs, "we don't seem to have as many arguments." One child described his family as being "able to keep its peace through the chaos." The only child who implied that his family is similar to other families stated that they're "pretty much the same, minus a sportsy father."

When asked to describe positive changes that had come about as a result of the brain injury, children described being grateful, thankful that things were not worse, and more in touch with God. Children described feeling closer as a family and having more time with the parent with a brain injury. One child indicated that "[mommy/daddy] hugs me more." When asked to describe more negative changes that had come about as a result of the injury, several children referenced the injury itself with more than one child expressing nostalgia for the way it was before, "thinking about the way things used to be, before [the] accident." Children also described their injured parent's physical, cognitive, and emotional changes (e.g., forgetting, arguing, yelling, mistrust, mood swings, physical limitations) as problematic. One child noted that it was difficult having more responsibility as a result of the injury and another described marital conflict. When asked about coping strategies for dealing with the difficulties that arise as a result of the injury, children described walking away, talking to the uninjured parent to try and resolve conflict, focusing on the positive, using positive self-talk (e.g., I say to myself

"everything is going to be ok") and physically helping the parent with disability. One child described a strategy of avoidance, "I just try not to think about it."

As previous clinical and qualitative studies suggest that children may be hesitant to have others at their home due to the parent's brain injury, children were asked how often they have friends over to their house. Frequency of responses to a 5-point Likert-type scale varied from 'not very often' ($n = 4$) to 'sometimes' ($n = 3$) to 'often' ($n = 2$) with no children responding 'never' or 'always' ($\overline{x} = 1.78$, $SD = .8$). When asked whether the parent's injury influences their decision to have friends to the house, four children responded 'sometimes' while the remaining five children indicated that the parent's brain injury did not influence their decision. No child indicated that the parents' injury consistently kept them from having friends to the house.

General Descriptors – Parent

Forms were generally completed by the child's mother (7 of 9) and were completed by either the brain injured (4) or non-brain injured parent (5). No striking deviations were noted when comparing child and parent responses to general descriptive questions regarding the impact of the injury on the child. At times parents seemed to focus on slightly different aspects of the situation than the child (e.g., What is the biggest change in mom/dad since the injury? Parent: doesn't play as much, Child: forgets a lot, hand hurts, gets mad easier) or assume more sophisticated understanding than the child expressed (e.g., What is the biggest change in general since the injury? Parent: we do not take one another for granted ever anymore, Child: his voice is lighter and he can't run). As a general rule, parent and child responses tended to agree in terms of major content; at times parents mirrored what the child was thinking (e.g., What is the worst thing about

the injury? Parent: accepting how my [parent] is now, Child: thinking about the way things used to be, before [the] accident"; or, What is the biggest change in the family since the injury? Parent: mom and dad hard to get along, Child: mom and dad don't get along as well as they used to).

Injured Parent Behavioral Profile: Symptoms of the Brain Injury

NFI

As compared to other individuals of similar age and injury severity (based on time unconscious), both participants with a brain injury themselves and informants alike reported typical rates of depressive symptoms ($\overline{x}_{PBI}$ = 48.29, *SD* = 11.8; $\overline{x}_{inform}$ = 48.00, *SD* = 10.8), somatic complaints ($\overline{x}_{PBI}$ = 48.29, *SD* = 11.7; $\overline{x}_{inform}$ = 48.29, *SD* = 10.3), memory and attention problems ($\overline{x}_{PBI}$ = 49.43, *SD* = 12.2; $\overline{x}_{inform}$ = 48.86, *SD* = 10.0), communication difficulties ($\overline{x}_{PBI}$ = 49.29, *SD* = 11.9; $\overline{x}_{inform}$ = 52.14, *SD* = 12.2), problems with aggression ($\overline{x}_{PBI}$ = 48.4, *SD* = 10.4; $\overline{x}_{inform}$ = 48.43, *SD* = 10.2), and motor impairments ($\overline{x}_{PBI}$ = 47.43, *SD* = 9.9; $\overline{x}_{inform}$ = 47.14, *SD* = 9.7). It is important to remember that these results do not suggest that these individuals were not having problems, only that as a group their behavior is comparable to others of the same age with similar injuries.

Following conventions put forward by the test developer, extreme scores were identified that fell more than 1.5 standard deviations above or below the mean for that particular scale. At the individual level, four extreme scores were identified, even as compared to other individuals with brain injuries of similar severity. One participant reported tremendous difficulty with depressive symptoms (>1.5 *SD* above the mean) and

managing aggressive behaviors (>1.5 *SD* above the mean). His wife agreed that he had difficulty managing his aggression (>1.5 *SD* above the mean). Another spouse reported that her husband had significant communication difficulties (>1.5 *SD* above the mean) and he agreed that they were a notable problem (>2/3 of a *SD* above the mean).

One brain injured individual (family 5) described himself as having had an exceptionally and unusually positive outcome, given his injury severity. This is reflected in very low ratings of problematic behavior both by himself (5 of 6 scales >1.5 *SD* below the mean) and his wife (4 of 6 scales > 1.5 *SD* below the mean). One informant rated a brain injured participant's memory and attentional problems as minimal (>1.5 *SD* below the mean), though the individual herself conceptualized her own problems as typical given her injury (*T*-score = 57). As this informant was a friend and not a spouse, it is possible that he/she was not as familiar with the person's limitations as someone living in the home would be.

In summary, results of the NFI ratings suggest that the sample as a whole was experiencing an expected level of problematic behavior, given injury severities. Two individuals were experiencing extreme difficulties (depressive symptoms, aggression management problems, communication impairment) while one other individual had an exceptionally positive outcome.

HIBS

As rated by informants, the emotional regulation of the sample of individuals with a brain injury showed significant variability ($\overline{x}$ = 42.27, *SD* = 14.8; range 27 to 68). As compared to other individuals with brain injury, only one person in the sample would be classified as having pronounced difficulty (>1.5 *SD* above the mean). In contrast, three

participants would be classified as having less problems with emotional regulation than is typical (<1.5 *SD* below the mean).

Ratings of behavioral regulation also showed significant variability ($\overline{x}$ = 40.77, *SD* = 12.7; range 24-53). Two individuals in the sample would be classified as having less problems with behavioral regulation than is typical for individuals with brain injury (<1.5 *SD* below the mean). No individuals were considered to have severe problems (>1.5 *SD* above the mean). It is worth noting that as compared to a larger sample of 242 informants, these ratings appear to slightly underestimate difficulties. Regardless of normative sample, however, all scores at the upper end of the range would be classified as average.

In total, the sample demonstrated limited difficulty with emotional and behavioral regulation as compared to other individuals with brain injury. Only one person exhibited extreme difficulty with emotional regulation; no participants demonstrated unusual difficulty with behavioral regulation. Again, this is not to say that some participants were not experiencing problems, only that the extent of problematic behavior was considered typical as compared to other individuals with brain injuries.

M2PI

Consistent with findings on other measures, the ability of individuals with a brain injury to participate in everyday aspects of life (e.g., social activities, activities of daily living, employment) showed considerable variability. Excluding one missing set of data (family 2, informant), all participants with a brain injury and informants agreed on the overall level of functioning. In summary, as compared to patients being seen for outpatient rehabilitation, two individuals in the sample showed relatively good outcomes

(family 5, 7; *T*-score <30) and two showed more severe limitations, even as compared to others with brain injuries (family 3, 6; *T*-score >60). Three individuals in the sample demonstrated standard limitations that ranged from mild to moderate (family 2, 4; *T*-score 40-49) or moderate to severe (family 1; *T*-score 50-59) impairments. Reports of employment and employability are included below; it is worth noting that the sample included two individuals (family 3, 6) who required nearly 24-hour per day supervision and could only be left home alone for short periods of time due to safety risks or physical impairments.

Other Contextual and Environmental Factors

Employment

Data on employment status is provided in Table 12. Premorbidly, all of the individuals with a brain injury were employed ($n = 6$) except in one case where the injury occurred during adolescence. In four families both parents were working prior to the injury; in two single-parent households the person with the brain injury was the primary breadwinner.

Table 12. Employment status.

	PBI	nPBI
Premorbidly		
Employed full-time	6[a]	4
Injury during adolescence	1	
Postmorbidly		
Employed full-time	3[a]	3
Full-time student	1	
Unemployed/unemployable	3	2

Note. PBI = Person with brain injury; nPBI = Non-brain injured parent

a. Includes 2 single parent families

Postmorbidly, four of the seven participants with a brain injury were involved in constructive activities outside the home, including two single parents who were employed full-time. In terms of desired social role, the remaining three participants with a brain injury considered themselves unemployed or unemployable. In those families where neither parent was working either due to caregiving demands or the impact of a recent economic downturn, families were supported through disability or military benefits.

Perceived Financial Strain

Perceived financial strain since the injury varied by family. On a 5-point Likert-type scale, families reported an average financial strain of 3.1 (*SD* = 1.8; see Table 13). All but one family reported at least some financial strain with two families reporting substantial strain.

Table 13. Perceived financial strain.

Family	Rating[a]
1	5
2	5
3	0
4	2
5	3
6	4
7	3

a. Scale of 0 (minimal) to 5 (substantial)

Parental Depression

PHQ-9

Parent with a brain injury. Three of the seven parents with brain injury denied symptoms of depression at the time of testing (PHQ-9 = 0). Four individuals reported mild (*n* = 3; PHQ-9 = 9) to moderately severe (*n* = 1; PHQ-9 = 18) depressive symptomatology. As items on the PHQ-9 are linked to DSM-IV criteria, an alternate way of conceptualizing scores involves identifying whether a diagnosis of depression may be

considered (e.g., 5 or more symptoms reported at least ½ the days over the past 2-week period with one of the symptoms being either depressed mood or anhedonia). Based on these criteria, only one individual would potentially qualify for a diagnosis of a major depressive episode.

Uninjured parent. Two of the uninjured parents reported minimal (*n* = 1; PHQ-9 = 3) to no depressive symptoms (*n* = 1; PHQ-9 = 0) at the time of testing. The remaining three parents reported mild (*n* = 1; PHQ-9 = 6) to moderately severe (*n* = 2; PHQ-9 = 16, 17) levels of depressive symptomatology. In two of the cases, a diagnosis of a major depressive episode may be warranted.

DISCUSSION

The primary goal of the current project was to explore the impact of parental brain injury on children living in the home and determine whether, as a group, these children appear to be at risk for emotional or behavioral problems.

Child Psychosocial Functioning and Adjustment

BASC-2 SRP and PRS

The BASC-2 provides a quantitative analysis supporting one of the primary goals of the study, namely to identify whether the children of parents with ABI fundamentally differ from normative data on age-matched children in the general population. Both self-report measures and parental assessment suggest that, as a group, the children in the current sample did not evidence significant problems across a variety of emotional and behavioral domains assessed. In fact, the only statistically significant results across both measures suggest particular resiliency in this sample with lower than average rates of inadequacy and aggression and stronger than average parental relationships and social skills. Due to the relatively small sample size, there were likely additional effects within the sample that were not detected through statistical analysis including stronger than average self-reliance and lower than average levels of social withdrawal. Effect sizes ranged from medium to large representing, on average, a five to eight point decrement as compared to a normative sample. As the BASC-2 was primarily developed to assess problem behaviors, item-level analysis suggests that floor effects may have impacted some effect sizes (e.g., aggression scale).

While statistically significant and representing moderate to large effect sizes, there are no clear benchmarks for assessing whether these differences represent a

clinically meaningful shift at the group level. One potential delineating factor would be if the differences represented a change to a distinct clinical classification level (e.g., the equivalent of one standard deviation from the mean) but none of the results meet that requirement. The fact that we would anticipate a certain degree of measurement error further obscures the results. Additionally, despite moderate to large effect sizes, multiple factors bring into question the replicability or generalizability of the current results. These include regression to the mean, low reliability of some of the scales of interest (e.g., SRP self-reliance), and potential changes in standard deviations with the addition of more participants (e.g., *SD* for sense of inadequacy was relatively low in the current sample) which could in turn potentially impact resulting effect sizes.

At the individual level, five of the nine children in the current sample identified themselves as falling in the 'at risk' or 'clinically significant' range on at least one scale. Parents rated three of the 10 children as falling within these ranges, not necessarily in agreement with self-report. As noted previously, due to the large number of analyses across multiple scales (e.g., 14 SRP measures per individual) the odds of at least one measure falling in the elevated range merely by chance is quite high, somewhere along the magnitude of 90%, such that it is difficult to interpret the clinical implications of these findings. Perhaps a better way of looking at the data is considering those individuals whose responses rose to the level of clinical concern when examined more holistically. Using this criterion, two of the nine children assessed displayed some level of clinical distress that warranted recommendations for further evaluation and/or support. Given the base rate of psychological problems in the general population (e.g., 9-22% of children and 18-22% of adolescents have significant emotional or behavioral problems at

any given time; Frick & Silverthorn, 2001) these findings are likely consistent with what would be found in any similarly-aged sample.

In comparison to a prior study of four children whose fathers had ABI (Butera-Prinzi & Perlesz, 2004) in which participants completed an earlier version of the questionnaire (BASC) some important similarities and differences emerge. Though not analyzed statistically, each of the four children in this earlier study showed at risk levels of symptomatology in areas including anxiety, depression, hyperactivity, inadequacy, atypical thoughts, and overcompliance. They also evidenced trouble in school as well as in relationships with parents and peers. On first glance, then, it appears that this prior sample was experiencing more psychological distress. However, it is worth noting that only two of the four children demonstrated clinical elevations on any scale; one child evidenced distress on only one of the nearly 30 scales assessed; and only one of the four children demonstrated distress across a variety of domains, primarily as rated by his parent. It seems, then, that similarly to the current sample, most of the children were not evidencing wide-sweeping distress on quantitative measures. While one of the four children in the sample appears to evidence some of the resiliency detected in the current sample, consistent signs of resiliency were not apparent as were seen in the present evaluation. An important distinction, however, between the two samples is that the earlier study included individuals enrolling in a family therapy program whereby the current study focused on members of the general community of individuals with brain-injuries. It is possible that the clinic-referred sample was demonstrating less resiliency. As the ages of the two samples appear relatively comparable (M = 11.25 vs. 13.12), it is unlikely that the increased stress inherent in caring for younger children noted in the

literature (e.g., Douglas & Spellacy, 1996; Moore et al., 1993) played a role in influencing the discrepancy of results. However, the slightly older age of the current sample may suggest that these children have been able to take on additional responsibilities around the home which could support (or conversely undermine) resiliency. Alternately, the slight age increase may suggest a greater capacity to understand the parent's injury. At this point, any conclusions regarding the impact of age in the current sample are speculative.

Additional considerations are raised by more recent work by Kieffer-Kristensen and colleagues (2011) who suggest that the impact of parental ABI may be more apparent on measures of post-traumatic stress as compared to more comprehensive measures of general psychosocial functioning. From that perspective, it is possible that the measures used in the current study were not sufficiently sensitive as to capture distress.

Qualitative Measures

Incomplete Sentences

Themes detected on a sentence completion task included those frequently seen in childhood and adolescence (e.g., being bullied, family relationships, concerns regarding academic performance) and those that emerged as particularly salient given the current sample. For example, mirroring findings on more quantitative measures, common themes emerged reflecting aspects of strength and resiliency (e.g., positive self-regard, love for family, like of school, a desire for happiness). On the opposite side of the spectrum, themes related to fear of death or loss, concern regarding the parent's injury, or fear regarding the child's own well-being also emerged. While clearly relevant to the current sample, it is unclear how common such themes are in the general child and

adolescent population, though death and danger-related fears are consistently among those most commonly reported from early childhood through late adolescence (Gullone, 1999).

Despite the commonality of death and danger-related fears, given the sudden, life-altering impact of a brain injury it is not surprising that themes included fear of death, loss, or injury, even in this potentially resilient sample, or that feelings such as regret, sadness, hurt, and pain were expressed. These findings likely mirror themes detected in a sample of adolescents coping with parental ABI (Moreno-Lopez et al., 2011) where researchers identified processes of re-evaluation of life and self as well as a desire to protect the family from further stress. One could argue that these children have experienced a loved one's 'worst case scenario' by facing a life-threatening situation involving long-lasting and pronounced changes. It is not surprising, then, that these children reflect continued fears regarding the well-being of their parents and themselves along with feelings of sadness, regret, hurt, and pain. While seemingly self-evident on reflection, these finding would likely be of interest to clinicians working with families of those with ABI as it would provide an avenue to address parental fears regarding the impact of the injury on their children. For instance, clinicians may want to recommend that parents acknowledge the fear associated with the injury in a developmentally appropriate manner and emphasize the likelihood of a recurrence. For example, even though the parent acquired a brain injury this does not mean that it is a typical occurrence and it is unlikely that the child will ever be injured in a similar way. Alternately, clinicians may want to support families in discussing the regret, sadness, hurt, and pain that accompanies a brain injury and affects the entire family, including the children.

Coping styles evidenced on sentence completion included both active and passive strategies. While several responses displayed active, self-sufficient coping (e.g., "I can do it on my own") more passive strategies were also apparent (e.g., If no one helps me…"I feel lost"). No clear patterns emerged linking coping style to the experience of distress or resiliency, likely due to small sample sizes and limited data.

Parental Relationship

Unfortunately, quantitative analyses of the parental relationship were limited by small sample sizes such that comparisons to prior research are difficult. This was further complicated by the inclusion of single parent families (n = 2), both of which reported little to no contact with the uninjured parent. In general, however, ratings of the parental relationship in the current sample were high for each parent and stronger than average overall. It is possible that the strength of these relationships is linked to the resiliency detected in the sample. Conversely, it is equally possible that the resiliency in the sample leads to stronger than average parental relationships.

Prior research on the parental relationship post ABI has focused primarily on the relationship between the child and the parent with a brain injury suggesting that interactions may be problematic or challenging due to the effects of the injury (e.g., Ducharme, 2003; Moreno-Lopez et al., 2011; Pessar et al., 1993). Anecdotally, some families in the current sample reported distinct challenges in the relationship with the injured parent (e.g., memory deficits were troublesome, physical or speech impairments negatively impacted the relationship) whereby other families reported renewed strength in the bond between a child and the parent with ABI (e.g., nicer, calmer, appreciate that person more). An often neglected dyad, however, includes the uninjured parent and

child. As research on the impact of ABI on these important caregivers suggests, the term "uninjured" in no way implies "unaffected." In fact, these caregivers often evidence high rates of stress, distress, anxiety, depression, and burden, in addition to social isolation and financial hardship (see 'Impact of Brain Injury on Caregivers and Families' section). In the context of the current discussion, one wonders the impact that this ongoing stress has not only on the caregivers themselves but on their relationships with their children. In a situation where parents are doing their best to cope with the myriad of changes in their own lives, one can imagine that their emotional availability to their children could potentially be compromised. Add to this the emotional toll of the injury (e.g., ambiguous loss, redefining roles and expectations) along with higher than average rates of anxiety and depression commonly found in the caregiver population and one can infer a potential impact on the children living in the home. While preliminary, prior research suggesting that the symptoms of the uninjured parent link most directly to child behavior (e.g., Kieffer-Kristensen et al., 2013; Pessar et al., 1993) may indicate that these children are even more sensitive to changes in their uninjured caregiver. Discussed in more detail below, results from the current study suggest that at least in this sample, children are aware of the impact and increased demands placed on the uninjured parent. One could imagine a situation where a child feels unable to express his or her needs in a family situation that is already stressed. That being said, results from the current study also suggest that even with a host of challenges within the family system, negative child outcomes or negatively-impacted relationships are not a given. Further exploration in this area that includes both parent-child dyads is warranted. A better understanding of the relational factors that influence child outcome could provide potential avenues for

intervention, when needed, and could help identify protective factors that could benefit other families.

General Descriptors

Children in the current sample were approximately 9 to 10 years of age at the time of the parental brain injury with a broad age range at time of injury overall (4 to 14 years old; one participant was born over a decade following her parent's injury). Though none were present for the injury itself, two siblings were involved in finding their father post-stroke and contacting emergency personnel. Nearly all of the children in the sample remember learning of the injury and have memories related to the initial hospital stay. However, while most of the children remember the early events surrounding the injury only one child reported residual difficulty with these memories. In combination with the quantitative outcome demonstrated on the BASC-2, these findings suggest that only one of the eight participants alive at the time of the injury appear to be experiencing any significant residual effects of the initial trauma. It is possible that the short duration of the initial event along with distal proximity helps protect children from more long-lasting consequences related to the initial trauma (e.g., 4th ed.; text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

These findings differ somewhat from those of Kieffer-Kristensen and colleagues (2011) whose sample of 35 children of parental ABI (60% stroke, 26%TBI, 14% other) reported a high rate of post-traumatic symptomatology. While not formulated as linking directly to the initial injury and instead conceptualized as capturing general, ongoing traumatic stress related to the parent's ABI, these results seem uniquely different from the findings in the current sample. It may be that the current sample was too small to capture

the distress; or, that this sample was not experiencing similar levels of distress; or, that the measures used in the current study were not sufficiently sensitive as to capture the distress. Regardless, as these authors conceptualize the trauma as involving an ongoing process of reactivation that is not necessarily tied to early experiences following the initial injury, it is difficult to relate their results directly to those of the current project.

Moving on chronologically from the initial injury to the parent's return home, during this transitional phase child emotional responses likely mirror that experienced by caregivers. Specifically, this sample of children reported feeling both happy and nervous. As the uninjured parent may be a bit more involved in the initial hospitalization and treatment (e.g., many inpatient units and some rehabilitation facilities limit visits from children), it is likely that these children are even less sure of what to expect on their parents' arrival home. An important observation within the current sample included the report of children from single parent families who indicated that they recall helping parents with basic activities of daily living (e.g., bathing, dressing, walking). This finding is of note to clinicians as it may suggest that additional support may be required during the transition home for single-parent households.

Similarly, once home children appear to report awareness of parental symptomatology in a way that echoes what is reported in the caregiver literature both in terms of awareness of deficits (e.g., physical, cognitive, and behavioral changes) as well as the report of positive aspects of change in the parent with a brain injury (e.g., nicer, happier, a different person). Similar to prior studies, this sample included reports of losing "preinjury dad" while adjusting to a replacement with a "new dad."

Insight was not limited to impairments on the part of the parent with a brain injury. For example, children in the current sample noted broader changes within the family including an increase in the uninjured parent's stress level, a rise in marital conflict, and general shifts in the family dynamic. Nearly all the children in the current sample described their families as different from most noting both positive and negative changes associated with the injury (e.g., unsure of the future due to the parent's injury, more time to spend with the injured parent) or differences more broadly (e.g., closer as a family, more in touch with God, more sensitive to each other's needs than most families). Many identified some of the biggest changes in the family as related to not being as active as before (e.g., 'We can't go to as many places [as before]'). Ongoing challenges included the physical, cognitive, and behavioral consequences of the injury as well as nostalgia for life prior to the injury, increased responsibility, and marital conflict. In terms of positive outcomes, children described being happier, grateful, more appreciative, more content, and more in touch with extended family following the injury. General agreement was seen between parent (primarily mothers) and child responses suggesting that these parents were aware of the experiences of and issues facing their children.

When asked about having friends to the house, the current sample reported limited socialization within the home with only two of the nine children reporting that they often had other children to their house. This is consistent with reports from clinical observation and qualitative research suggesting isolation in this population and a reluctance to bring friends home. However, the sample was split when asked whether it was their parent's injury that limited their desire to bring friends home. While no child indicated that their parent's injury consistently kept them from having friends to the

house, four indicated that it sometimes impacted their decision and five indicated that it did not. Of the four who indicated that the parent's brain injury sometimes impacted their socialization pattern, it is unclear whether this is logistical (e.g., not enough room in the house, impractical), an emotional response (e.g., embarrassment, shame, fear), or related to some other factor (e.g., transportation).

While broad conclusions are somewhat limited by the small sample size, these findings as a whole demonstrate keen awareness on the part of the children into the changes related to the parent's injury. Potential clinical implications include encouraging families to discuss changes, symptomatology, and coping strategies directly with children in the home. For example, while many parents may have the impulse to shield their children from the injured parent's deficits, the children in the present study, of variable age at the time of injury, are expressing sufficient awareness as to warrant an open dialogue (though this finding may not hold for an overall younger cohort of children). While potentially limited early following injury by the commonly held desire of many caregivers and survivors of wanting to "get back to normal" on their return from treatment, this may have increased relevance over time and may be more likely to occur with initial encouragement from treatment staff. Of additional relevance to clinicians is the finding that many children in the current sample reported limitations related to not being able to do as much as a family as before, paralleling self-report of individuals with ABI (e.g., four of five people living with stroke reported feeling limited in carrying out activities that they previously enjoyed; Public Health Canada, 2009). This finding emphasizes the need to include family activities in treatment planning, as appropriate,

and provides additional support for an emphasis on mobility and community integration commonly seen in post-acute brain injury rehabilitation programs.

Injured Parent Behavioral Profile: Symptoms of the Brain Injury

With participants approximately 3 years post-injury, all were in the more chronic stages of recovery. Frequency of type of injury (primarily MVA) and level of severity (moderate to severe injuries) suggest that the current sample is similar to the population commonly seen for post-acute rehabilitation, though most treatment is typically provided in the first two years post-injury. While still a minority at 43% of the sample, there were more females with ABI in the sample than is typical based on standard rates of injury.

Self and informant ratings suggest that, in general, the current sample demonstrates a level of symptomatology that is consistent with other individuals suffering comparable injuries (NFI). At the individual level, however, outcomes are more varied. For example, a commonly-used outcome measure assessing participation in everyday aspects of life (e.g., social activities, activities of daily living, employment) suggests a diverse sample with outcomes ranging from good (n = 2) to typical (n = 3) to severely impaired (n = 2) as compared to individuals with a brain injury being seen for outpatient rehabilitation. While one could argue that the diversity of outcomes may have obscured results in the current study, due to the exploratory nature of this project it seemed important to include a sample that was representative of the general brain-injury community. At present, there remains limited empirical evidence to suggest that the children of individuals with a brain injury at one outcome level should be different than the children of individuals with a brain injury at another, further supporting the use of a more general sample. If effects are not detected in this heterogeneous sample, it seems

reasonable then to generate hypotheses related to which children may be more affected by parental outcome (e.g., is it the children of parents who have more significant neurobehavioral problems who demonstrate more difficulties?). That being said, the current sample did include at least three individuals with extreme problems and/or limitations (NFI, M2PI) even as related to other individuals with brain injury. With a larger sample size, it may have been possible to address questions regarding the relationship between parental neurobehavioral profile and child psychosocial functioning within the existing framework.

Perhaps more significant is the finding that as rated by informants, only one of the seven participants with a brain injury evidenced pronounced difficulty with either emotional or behavioral regulation as compared to other individuals with brain injury. This is not to say that the sample did not evidence dysfunction, only that this dysfunction was not extreme. Additionally, though, three of the seven demonstrated *less* problems with emotional regulation than would be expected and two demonstrated minimal problems with behavioral regulation. Unfortunately, this finding is based on only one measure with questionable psychometric properties (e.g., there were some discrepancies noted in the reporting of normative information) such that it is difficult to determine how much weight to give to this one specific result. As clinical and qualitative studies suggest that the behavioral and emotional sequelae are of particular importance to primary caregivers and children, it may be desirable in future research to specifically select for individuals at differing levels of emotional and behavioral disinhibition to determine whether that factor differentially impacts child psychosocial function.

Other Contextual and Environmental Factors

Employment and Perceived Financial Strain

As is commonly seen in individuals with ABI, post-injury shifts in employment status and financial strain were apparent. While essentially all of the injured individuals were working prior to their ABI (e.g., all were employed except one whose injury occurred in adolescence), a substantial minority (43%) were unemployed or unemployable post-injury. In terms of perceived financial strain, a key moderator of quality of life identified in previous research of families following TBI (Moore et al., 1993), a moderate level of strain was seen overall with all but one of the seven families reporting at least some financial strain and two reporting substantial strain. All in all these finding support that the current sample was experiencing typical environmental stressors reported in the literature to impact outcome and family functioning.

Parental Depression

As depression has consistently been identified as an issue both for individuals with brain injury (Ouimet et al., 2001; Seel et al., 2010) and caregivers alike (Perlesz, et al., 1999) and has been shown to have a direct impact on child psychosocial functioning (for a brief review see Barlow, Smailagic, Huband, Roloff, & Bennett, 2012), an assessment of parental depression was included in the current analysis. Based on scores on the PHQ-9, seven of the twelve parents in the sample (58%) reported experiencing some degree of mood disturbance at the time of testing ranging from mild (n = 4; 3 injured, 1 uninjured) to moderately severe (n = 3; 1 injured, 2 uninjured). In contrast, five parents (42%; 3 injured, 2 uninjured) denied any substantive depressive

symptomatology. In all, three of the twelve parents in the sample (25%; 1 injured, 2 uninjured) may have been experiencing a major depressive episode at the time of testing.

These findings are interesting for two reasons. For one, they suggest that, like other families coping with ABI, many of these parents were experiencing at least some degree of distress at the time of testing with at least a quarter of the sample evidencing clinically significant levels of mood disturbance. Additionally, they raise the interesting question as to why more distress was not evidenced in a child sample of parents with mood disturbances. For one, as there is not a one-to-one ratio of parental depression and child distress and as only a quarter of the sample was significantly affected by depressive symptoms at the time of testing, it may be by chance that these children remained unaffected. Or, it may be that the effects would be more evident over a longer time frame. An intriguing alternate hypothesis is put forth by a recent model (Keller & Gottlieb, 2012) suggesting that the impact of parental depression can be moderated through parenting skills and child coping strategies. Perhaps the same coping strategies that are helping protect these children from the vulnerabilities of their parent's brain injury are also protecting them from the impact of their parents' resulting depressive symptomatology.

Overall Summary of Results

While limited by a small sample size, this exploratory study provided important insight into the lives of a commonly neglected group. For one, quantitative findings provide converging evidence to support that these children are not demonstrating fundamental clinical distress as a group. As a whole, these results may provide solace for families in knowing that the occurrence of an ABI does not imply inevitable long-lasting

and significant clinical distress in their children. While preliminary results of the current study suggest some degree of resiliency within the sample, the replicability and generalizability of these findings are somewhat questionable due to factors such as measurement error. The clinical significance of these findings (e.g., average differences less than one standard deviation from the mean) is also difficult to determine. However, that is not to say that they do not warrant further investigation. In addition to the inherent instability of some of the current quantitative findings, other factors that would likely impact results in a different sample include the referral source (e.g., clinically-referred sample as compared to a general community sample), potential longstanding traumatic effects of the initial injury and hospitalization experience that was not evidenced in this sample, and increased behavioral or emotional problems in the parent with a brain injury. As more recent research suggests that the symptoms of the uninjured parent may be key to child psychosocial functioning (Kieffer-Kristensen et al., 2013), we may also have obtained different results in a sample with uninjured parents experiencing increased distress, though anecdotal reports along with mental health histories suggest a high degree of parental stress in the current sample. Regardless of the limitations of the current study, however, results suggest that, at a minimum, the children in this sample are no different from other typically developing youth. While some children evidenced distress at the individual level, this is likely comparable to base rates in the general population. As noted previously, some may argue that the measures used in the current study were not sufficiently sensitive as to detect distress. However, if general distress on commonly-used clinical measures is not detected in this group, it raises the question as to

how pervasive these difficulties are (for a counter-argument see Kieffer-Kristensen et al., 2011).

Information regarding outcome including the symptom profile of the injured parent provide a context in which to interpret the findings on child psychosocial measures. Results of these analyses suggest that the current sample was typical of the more general brain-injury community in terms of type of injury, injury severity, time post-injury and outcome with some showing relatively good outcomes (n = 1), some showing a typical level of recovery fraught with physical, cognitive, emotional, and behavioral problems (n = 3) and some showing relatively poor outcomes, even as compared to others with ABI (n = 3). Similar to the broader brain-injury community, this sample showed disruption in employment, financial strain, and a significant rate of depressive symptomatology. While slightly higher than is typical in standard groups of persons with brain injury, females with a brain injury in the sample still made up a minority. For many reasons above and beyond the brain injury including histories of mental illness, current marital conflict, death or illness in a close family member, these children are at risk for emotional and behavioral problems. The fact that quantitative analyses suggest that they are similar to or even more resilient than most typically developing children is rather remarkable.

Qualitative analyses provide a wealth of information that may be informative to families and clinicians alike and suggest specific avenues for future study. For example, common fears expressed around death, loss, and injury suggest that these children could use more reassurance that the traumatic event is unlikely to recur or, alternately, that the family is taking steps to reduce the chance of a reoccurrence. Although this may be

reflective of a common fear expressed by many children in the general population, it seems all the more salient given the close-up view of the 'worst case scenario' afforded by the parents' injuries. Providing coping strategies for addressing these anxieties may help stave off potential future problems (e.g., limiting strategies of avoidance).

A second important point that emerged involved the reliance in single-parent households on children for support in completing activities of daily living. Further study is likely warranted examining the differing coping strategies and outcome in single-parent households. Clinicians would likely benefit from increased awareness of the impact on young children during the transition home post-treatment in this vulnerable group.

The fact that several children in the sample identified a critical change post-injury as not being able to do as many things as before seems to highlight the continued focus on and importance of improving participation and community reintegration during the course of rehabilitative treatment. Even small improvements have the chance of improving not only the life of the person with the brain injury but the entire family system.

Lastly, children in the current sample evidenced keen awareness of both the injured parent's deficits as well as more general changes within the family system (e.g., increased stress in the uninjured parent, marital conflict, a shift in family dynamics). These findings suggest that children cannot be shielded from the aftermath of a brain injury. Instead, clinicians may want to encourage families to open a dialogue about the impact and effects the brain injury has had both on the parent with the injury and the family as a whole. Grounding such discussions with the positive changes associated with

the injury can be a helpful way of balancing feelings of sadness and loss with hope and optimism. Additionally, the finding that children appear acutely aware of the changes both within their parents and the family system as a whole suggest that at least some families would likely benefit from a space to process this adjustment. Family therapy may be beneficial in some cases or the inclusion of a separate group for children in online or in person support formats (e.g., community support groups). In addition to the findings on quantitative measures, the ability of these children to identify a variety of positive aspects of the injury (e.g., more appreciative, more grateful, closer as a family) again highlights the resiliency inherent in these children and their families. The fact that similar themes were noted in a study of adolescents of parental ABI (Moreno-Lopez et al., 2011) suggests that this resiliency may stretch beyond the current sample.

Challenges

Over the course of the current project there were several challenges that emerged in working with this population that seem noteworthy. As the original goal of the study was to explore the impact of parental brain injury in a typical sample of individuals with a brain injury, a wide net was cast to obtain access to this population. While the endeavor was embraced by clinicians and families alike, finding suitable and willing participants was more than challenging. Support groups and rehabilitation facilities were hesitant to advertise the project without an established personal relationship. Further complicating the matter, gaining direct access to the population is difficult. For example, most individuals in the chronic phases of recovery will have discharged from rehabilitation facilities and may see clinicians only infrequently. Recruitment was again complicated by looking for a subset of a clinical sample, a bit of a needle in a haystack

dilemma. For those individuals who expressed interest in participating, several did not qualify due to the child's age (e.g., many families with adult children expressed interest in participating). And the challenges I faced do not seem unique. The Danish group conducting similar work (e.g., Kieffer-Kristensen et al., 2011) had to scour the records of five separate brain injury rehabilitation facilities to find 105 eligible participants. Of those, only 35 (33%) were eligible and willing to participate. These challenges highlight the need for large, multicenter collaborations, such as the TBI Model Systems network, though even those collaborations are not without their limitations (e.g., staffing, organizing and sharing data); or the building of relationships between researchers and family support networks (e.g., Brain Injury Association of America). In the current study social media along with referrals from trusted clinicians seemed to be the best way of connecting with potential participants.

A second issue that arose relates to the ethical implications inherent in conducting clinical research. Clinical researchers are forced to balance the research focus on the current evaluation with the clinical implications of findings. For example, when families are found evidencing a certain degree of distress, the role of researcher is unique from that of a clinician and instead becomes one of referral and support. As I feel it is important to consider the clinical ramifications of study findings, work in this particular sample also raises the interesting dilemma of what to do with results. For example, within the post-acute brain-injury community, the child is not typically the focus of treatment. While clinicians can recommend further treatment in community settings, many families find such support prohibitive either due to financial or time constraints. While families can, at times, be included in more comprehensive rehabilitative programs,

it is difficult to determine how much inclusion is appropriate. Additionally, as indicated by the Webster and Daisley study (2007), the comfort of staff in working with children will also impact who is included. While these issues may vary based on the country of origin, they seem important for researchers to consider in an ongoing manner.

Lastly, while it is tempting to base broad clinical recommendations on the findings to date, empirical evidence is still severely limited in this group and any clinical recommendations can only be made sparingly and with specific caveats. While appealing to ensure treatment for all potentially-affected individuals, it is still premature at this point to recommend that children need to be involved in assessment and treatment of parental ABI. Current research suggests interesting hypotheses to be considered by clinicians at their discretion.

Future Directions

As one would hope from an exploratory study such as this one, the current project seems to raise more questions than it answers. Perhaps the first avenue to pursue in future work would be to determine whether results hold either in a larger sample or in a different group of children with parents who have suffered an ABI. Based on findings in clinical, qualitative, and quantitative studies suggesting that the emotional and behavioral changes in the injured parent and depression or stress in the uninjured parent can be the most salient, it would be interesting to determine empirically whether the behavioral profile of the injured parent and/or affective profile of the uninjured parent are able to predict child psychosocial functioning.

Other questions raised by the current findings include whether the fears identified on a sentence completion task are similar or different than other children. While many

children in the general population express similar fears, it would be informative to know whether the rate and quality of these fears are similar to or different in these children. While the current study briefly touched on potential coping strategies, it would be useful to delve further into this domain, as was apparently addressed in a prior unpublished dissertation (Smiton, 2005), and to determine whether these strategies are linked to psychosocial outcome. For example, similarly to a model of the familial transmission of depression, it may be that coping strategies in these children help protect them from the effects of the parental brain injury. As noted, more information is warranted on the similarities and differences between single parent households affected by ABI and the implications of a young child serving as caregiver to an impaired parent. Since several children noted a primary change as a shift in the family's ability to enjoy leisure activities, further exploration into the current limits in the family (e.g., what is the primary factor limiting families activity level?) could help inform treatment strategies. For instance, is it the physical, financial, cognitive, emotional, or caregiving consequences of the injury that seem to interfere most with active community participation? Lastly, this study also highlighted several aspects of resiliency that are worth exploring. How have these children been able to 'weather the storm'? What strategies seem to be most effective in supporting favorable outcomes? Research into the answers to the questions could provide an avenue for treatment that focuses on strength and resiliency as compared to impairment.

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Appendix A

General Descriptive Questions

These next questions ask about *what it was like for you when your dad or mom first had their brain injury* and *what is has been like for your family since*. Please circle or write in your response.

1) How old were you when your dad or mom's brain injury happened?
2) Do you remember the day your dad or mom was injured?
3) Were you there when your dad or mom was injured?
4) Do you remember when they were in the hospital right after the injury?
5) If you weren't there when your dad or mom was injured, how did you find out about it? Who told you? What did they tell you? What was that like for you?
6) What was it like for you when your dad or mom first came home after their brain injury?
7) Do you still think about when it first happened?

Now I'm going to ask questions about what is has been like for you since the injury.

8) Do you remember your dad or mom before the brain injury?
    a. What is the biggest change **in dad or mom** since the brain injury?
    b. What is the biggest change **in your family** since the brain injury?
    c. What is the biggest change **in general** since the brain injury?
9) Do you feel like your family is the same or different from other families? If it's different, how is it different?
10) Some kids find there are some good things that have come out of their parent's brain injury. For you, what is the best thing about your dad or mom's injury?
11) Some kids find that dealing with their parent's brain injury can be tough at times. For you, what is the worst thing about dad or mom's injury?
    a. What do you typically do when that happens? How do you deal with it?

Appendix B

Study Recruitment Materials

In person or by Telephone: Direct Recruitment

"I am a graduate student at the University of Victoria in British Columbia, Canada, and I am currently conducting a research project as part of the degree requirements to obtain my PhD in Neuropsychology. I am interested in learning more about the experiences of families, and particularly children, when a parent suffers a brain injury. Some people have said that these children are likely stronger and more resilient than other kids because they've had to face difficulties from an early age; others have said that these kids are more likely to have problems down the line, say with things like anxiety or depression, because of their early experiences. But the bottom line is that we really don't know much about these kids and I would like to learn more about them. I think that knowing more about them can help improve the way we treat people with brain injuries and their families. For example, if we knew that these kids were just like other children we could tell parents not to worry which may help them feel better and take one more stress off their plate. If we knew these kids were at risk of having specific types of problems, we could intervene early and see if there were things we could do to help prevent problems down the line.

Participation of families like yours is important as it builds our understanding of what it is like living with a brain injury on a day-to-day basis. As I said, it may help improve care for future generations by having a better understanding of what to expect so that we can be better equipped to help families like yours.

Let me tell you a bit about what participation would involve. If you'd like to help out with the project, what I would have you do is complete a series of questionnaires that will be mailed to your home. The questionnaires are rather extensive and will ask about how your child is doing at home and at school; they will ask about your and your child's thoughts, feelings, and behaviors; and about your family's perception of the impact the injury has had. Obviously, these can be potentially sensitive subjects to discuss so I want you to know up front that your information will be kept private and will only be seen by myself, my supervisor, and study personnel. When results of the study are analyzed, your responses will be grouped with others and you will not be identified.

If you are interested, you, [the person with the brain injury/your partner/fellow caregiver] and your child will all have to agree to participate. If there is more than one child in the home who would like to participate, that is fine, too. Completing the questionnaires would likely take about 1 hour for your child, 30-40 minutes for the parent with a brain injury and about 1 to 1½ hours for the other parent or caregiver. At the end of the study, your family will be entered in a drawing for one of four $25 gift cards to compensate you for your time and inconvenience.

Just to reiterate, this is not anything that you have to do. If you get started on the project and decide that it's not for you, that is ok as well. As long as your family completes some of the study measures, you will be entered in the drawing. Does this sound like something you may be interested in? Can I answer any questions about the project for you?"

Script for Consent

"I will be sending you consent forms along with the testing packets. There will be one for you, one for your spouse/partner/fellow caregiver and one for your child. Please read through them and let me know if you have any questions.

There are a few important things for you to know and I wanted to point those out to you. [As I mentioned to you previously,] the questionnaires are rather extensive and will ask about how your child is doing at home and at school; about your and your child's thoughts, feelings, and behaviors; and about your family's perception of the impact the injury has had.

There are some possible risks to participating in this project. Some people may find answering so many questions to be stressful. Or, they may feel anxious or sad while reflecting on their family's situation. To help minimize these risks, you will be able to complete the questionnaires at your own pace so that you can take a break, if you need to.

Additionally, you or any of your family members can decide at any point that you are no longer interested in participating and that would be fine; there are no penalties or consequences to you if you decide to withdraw from the project. If while completing the questionnaires you feel like you've identified an area where your family could use some assistance, I can help you find local resources or point you in the direction of people who may be able to provide support.

As a way to compensate you for any inconvenience, your family will be entered in a drawing for one of four $25 gift cards. As long as you complete some of the study measures, your family will be entered in the drawing.

All the information you provide me will be kept confidential and only myself, my supervisor, and any study personnel will have access. When I present the data, your information will be grouped with other peoples' and you will not be identified. There are a couple limits to this confidentiality, though, that I want you to be aware of:

1) As you'll see on the consent forms, I have an ethical obligation to report any suspected child abuse. So if, over the course of your participation you indicate to me that there is a child at risk of being harmed in some way, such as through physical or emotional abuse, I have an ethical obligation to report that to the proper authorities.

2) If you were referred to this study by a treatment specialist, that person will know that you were referred but will not know whether or not you choose to enroll so your decision to enroll will in no way impact your access to care or the care you are provided.

Additionally, I really want your child to be able to be open and honest with me. If possible, it would be great if your child's responses could be kept confidential. This means providing them with a space to complete the questionnaires by themselves, in private.
During the course of the project, your data will be kept in a locked storage cabinet and any electronic files will be protected by a password. At the end of the project, data that includes your identifying information will be destroyed. Electronic databases that do not include your identifying information will be kept until results are shared in the form of my dissertation, journal publications, and presentations at scholarly conferences.

If you have any questions, there is contact information for myself and my supervisor on the forms as well as the contact information for our Human Research Ethics Office in case you have any questions or concerns.

Any questions about the study, the process, or things we have talked about?"