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**The Assessment of Parent Needs Following Pediatric  
Traumatic Brain Injury**

by

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A Dissertation Submitted in Partial Fulfillment of the  
Requirements for the Degree

**DOCTOR OF PHILOSOPHY**

in the Department of Psychology

We accept this thesis as conforming  
to the required standard

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### **ABSTRACT**

The pediatric version of the Family Needs Questionnaire was administered to parents of children with traumatic brain injuries (TBI, n = 19) a year or more post-injury. Parents of diabetic children (DIAB group, n = 21) and parents of orthopedically injured children (ORTHO group, n = 14) were included as control groups. Parents rated 40 items in terms of their importance and how well these needs have been met. The ORTHO group rated significantly fewer items as important relative to the TBI and DIAB groups (who endorsed a similar number of items). Of those items rated as important, TBI parents' needs were more likely to remain unmet relative to both the DIAB and the ORTHO groups; out of 28 items rated as important, TBI parents report that 19 needs are still unmet. Within the TBI group even for those needs reported as met most items were endorsed by fewer than half of the parents, indicating that a large proportion of the TBI parents still felt those needs were unmet. DIAB and ORTHO parents more consistently reported their needs as met both across items and within groups. Needs most often rated as unmet for TBI parents include the needs for health/medical information, professional support, community support networks, and the need to be involved in their child's care. These results present important findings for TBI rehabilitation professionals. Future studies need to investigate whether TBI parents' needs are unmet because there are no community resources or if the resources available are unused, or not targeting the needs TBI parents feel are most important.

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## Introduction

Family members appear to be the silent and often neglected victims of traumatic brain injury (TBI) (Florian & Katz, 1991). Their fears, concerns, and confusion are frequently overlooked by the medical field, because the head injured patient is seen as the primary client. Nonetheless, evidence has repeatedly shown that parents of children with TBI typically experience intense feelings of grief, loss, guilt, and helplessness when dealing with their child's initial injury and subsequent neurobehavioral sequelae (Acorn, 1993; Brooks, 1991; Cunnings, 1976; DePompei & Williams, 1994; Resnick, 1993; Wade, Drotar, Taylor & Stancin, 1995). As a result of the parents' emotional losses and the changes in the child's behavior, caretakers of brain injured patients have been shown to experience an overwhelming sense of subjective burden (e.g., Hu, Wesson, Kenney, Chipman & Spence, 1993; Kreutzer, Gervasio & Comclair, 1994; Perrot, Taylor & Montes, 1991). It is of further significance that these profound feelings of burden have been shown to persist for as long as 15 years post injury (Thompson, 1985).

Recent studies have shown that supporting parents following a child's brain injury may not only help *them* to cope with these difficulties, but may also enhance the success of the child's recovery as well (e.g., Elliot & Smith, 1985; McClelland, 1988; Wade et al., 1995; Yeates et al., 1997). Conversely, it has been shown that a chaotic family environment is strongly associated with poor recovery of behavioral and adaptive functioning in children. In fact, family environment may even have a larger impact on recovery of function than the severity of the injury (Kreutzer, Marwitz, & Kepler, 1992; Max et al., 1997; Rivara et al., 1993; Rivara et al., 1994; Rivara et al., 1996; Taylor, et

al., 1999; Yeates, et al. , 1997). These studies suggest that cohesive family functioning may decrease the impact of injury severity, while chaotic families may exaggerate the effects of the injury.

This literature, coupled with the preponderance of studies documenting parents' emotional stress and confusion following TBI (e.g., Lezak, 1986; Livingston & Brooks, 1988; Serio, Kreutzer & Gervasio, 1995; Solomon & Scherzer, 1991; Taylor et al., 1995), has led to strong urgings to monitor family adaptation to TBI, and to begin to develop clinical intervention programs to help parents cope with their child's injury (Max et al., 1999; Perlesz, Kinsella, & Crowe 1999; Yeates et al., 1997). Due to a lack of empirical investigations into the specific needs of family members, those support groups which have been started by rehabilitation centers and head injury associations have primarily been designed based on descriptive literature or theories about the emotional and practical difficulties this population might face (e.g., Acorn, 1993; Brown & McCormick, 1988; DePompei & Williams, 1994; Elliot & Smith, 1985; Foster & Carlson-Green, 1993). Although these groups are clearly well intentioned (and may even meet with some success), some authors (e.g., Waaland, Burns, & Cockrell, 1993) have criticized that this kind of program development often results in a "hit-and-miss" approach to treatment and is not well suited to consistently meet participants' needs.

Only one study has systematically examined and compared what type of psychosocial intervention may be most effective for this population (Singer et al., 1994). Their results were striking in that they were counterintuitive to what the literature might

suggest as being the best treatment for this population. More specifically, the authors of this study compared two different types of support groups for parents of children with TBI. One group focused on coping skills and stress management training, while the other group was designed (as most published support groups have been) to provide information and supportive therapy for issues that are commonly reported by this population.

Surprisingly, the results indicated that the informational support group actually *increased* the parents' anxiety and depressive symptoms. The stress management group (which was not predicted to have been as useful) was the most successful of the two groups, and resulted in significantly decreased anxiety and depressive symptoms. This study clearly indicated that effective intervention methods cannot be designed based solely on the medical community's perspective of family needs, and without further investigation of the efficacy of the treatment. It is essential to develop an understanding of specific priorities and needs *from the parents' perspective*.

There have been a handful of such studies which have examined the subjective endorsement of family "needs" following TBI (e.g., Engli & Kirsivali-Farmer, 1993; Junque, Bruna & Mataro, 1997; Kreutzer, Serio & Berquist, 1994; Maus-Clum & Ryan, 1981; Waaland et al., 1993). However, the majority of these have focused on either an adult patient population, or on the *acute* period of recovery for pediatric patients and their families. As noted above, parents most frequently continue to experience significant emotional and adaptation difficulties well past the acute stages of recovery. Therefore, it would appear that the parents' needs persist beyond the time when they have access to

rehabilitation staff. It is quite possible that providing parents with well-developed clinical interventions specifically designed to address their concerns will improve their feelings of helplessness and overall subjective burden, but in order to implement such interventions an investigation into self-reported needs is necessary. The purpose of this dissertation is to establish this information by examining the needs of parents with TBI children who are in the post-acute stages of recovery (i.e., one year or more post-injury). It is anticipated that this information will help provide the necessary data to guide development of empirically based support groups which can best meet the needs of this population.

### **Understanding the Cognitive and Behavioral Changes in Pediatric TBI**

In order to provide a sound basis for the purposes and goals of this research, and a stronger understanding for parents' emotional reactions, it is useful to begin by documenting the common cognitive, behavioral, and psychosocial consequences seen in children following TBI. Although this information is not directly relevant to the self-reported needs of *parents*, it is important to remember that it is the changes in the *child* that leads to the family's cycle of emotional upheavals and an increasing need for professional intervention. Consequently, this review establishes a basis for the description of families' typical emotional reactions, changes in psychological functioning, and reports of subjective burden during the rehabilitation of a TBI patient.

### **Cognitive Sequelae in Pediatric TBI**

There is significant debate regarding the relationship between severity of brain injury and subsequent neurocognitive sequelae. Some authors argue that there is a dose-dependent relationship between severity of brain injury and cognitive deficits, (Anderson et al., 1997; Brown, Chadwick, Shaffer, Rutter & Traub, 1981; Jaffe et al., 1992, Jaffe et al., 1993; Kinsella et al., 1997), such that children with mild injuries show minimal if any cognitive deficits (e.g., Asarnow, Satz, Light, Lewis, & Neumann 1991; Bijur, Haslum, & Golding, 1990; Prior, Kinsella, Sawyer, Bryan & Anderson, 1994) while children with severe injuries are more significantly impaired (e.g., Asarnow et al., 1991; Eiben et al., 1984; Prior et al., 1994; Rivara et al., 1993). However, there are others (e.g., Boll, 1983; Casey, Ludwig & McCormick, 1986; Donders, 1993; Gronwall, Wrightson, & McGinn, 1997; Jaffe et al., 1992) who argue that mild head injuries can have a substantial impact on cognitive functioning. There has also been substantial debate regarding the consequences of moderate brain injury as some authors have found minimal cognitive deficits in these children (Perrot et al., 1991), while others show significant and persisting impairments (Donders, 1993; Jaffe et al., 1993; Kinsella et al., 1997). Because there is no agreed upon definition of injury severity, these kinds of discrepancies are frequently seen in the brain injury literature.

Regardless of how one defines the severity of an injury, one of the underlying difficulties in clarifying the relationship between injury severity and subsequent cognitive deficits is that a child's brain is a *developing brain*. Therefore, unlike an adult who's

deficits are clearly observable immediately after an injury, a child may actually *grow into* his or her deficits, even if they appeared to have made a satisfactory recovery immediately following the injury. This paradoxical effect occurs because once the child's brain is damaged, it may not develop in a normal fashion. Consequently, the child fails to acquire new, age-appropriate skills because the brain structures have been damaged and are, therefore, not capable of developing to the point of supporting these functions (Crafton & Eslinger, 1991; Mateer & Williams, 1991; Oddy, 1993; Waaland & Kreutzer, 1988). An example of this paradox was recently demonstrated by Gronwall, et al., (1997). When they tested pre-school aged children with mild head injuries their results showed that there were no significant differences between controls and brain injured children when testing was performed within 48 hours after the injury. However, when children were tested again at four and eight months post-injury the head injured children were shown to perform significantly poorer than controls on visual memory and visual closure tasks. Given this tendency to develop deficits over time it is highly likely that new and ongoing struggles will be in store for the child and consequently, for his or her parents. This is an especially important factor when considering the long-term coping of parents; although some parents (and their child) may appear to adjust well initially, as the child grows into new deficits, the parents may experience more difficulties coping with the intellectual limitations of their child.

Despite the controversy regarding the relationship between severity of TBI and subsequent deficits, there is still substantial evidence indicating that children with

moderate and severe brain injuries do exhibit deficits in psychometric intelligence, cognitive functioning and academic achievement.<sup>1</sup> Furthermore, the inconsistencies within the mild TBI literature suggests that even these children may be at risk for developing cognitive deficits. Although no child exhibits the exact same pattern of cognitive impairment, the most commonly cited symptoms include distractibility, impulsivity, poor decision making, and failure to shift from one activity to another (Deaton, 1987). Children with TBI also have difficulties with speeded motor tests, measures of visual-motor and visual-spatial functioning, and speed of information processing (Chadwick, Rutter, Shaffer, & ShROUT, 1981; Jaffe et al., 1992; Jaffe et al., 1993; Lord-Maes & Obrzut, 1996). Memory impairments and decreased attention have also been identified as some of the most common sequelae in pediatric brain injury (Dennis et al., 1995; Jaffe et al., 1992; Jaffe et al., 1993; Levin & Eisenberg, 1979; Lord-Maes & Obrzut, 1996).

Investigations focusing on intellectual functioning have noted that children with TBI tend to display a diffuse impairment in IQ during the acute stages of recovery (Chadwick et al., 1981; Farmer & Peterson, 1995; Filley, Cranberg, Alexander & Hart, 1987; Rivara et al., 1994). Although there are some indications that this improves with time post-injury (Chadwick et al., 1981; Filley et al., 1987), Costeff, Groswasser, Landman and Brenner (1985) warn that even when children do show recovery on intellectual measures, their psychometric IQ scores seems to improve more than their

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<sup>1</sup>For a comprehensive review of the literature on the cognitive deficits in pediatric TBI, please see Dennis,

actual learning capacity does. This is based on the finding that while the children in their study did increase their scores on intelligence tests, their academic performance continued to be impaired 2 years post-injury. Other authors have confirmed that children with moderate and severe brain injuries often display significant deficits in academic functioning well after their injury, despite average IQ scores (Ewing-Cobbs & Fletcher, 1990; Lord-Maes & Obrzut, 1996; Perrot et al., 1991). Furthermore, it has been shown that children with even mild brain injuries acquired during preschool have significantly more difficulty learning to read than children who sustain injuries to other parts of the body (Gronwall et al., 1997).

Although there are only a handful of studies that have examined long-term consequences of pediatric brain injury, those studies indicate that children may continue to exhibit cognitive deficits for years after their injury (Perrot et al., 1991; Rivara et al., 1993) even as long as twenty-three years post injury (Klonoff, Clark & Klonoff, 1993). This is consistent with literature on the adult head injury population where deficits have been shown to persist well past 10 years (Thomsen, 1985). Although some of these impairments may improve over time, these studies suggest that most children with TBI's rarely return to an estimated pre-morbid level of functioning. Consequently, parents must learn to accept and adapt to the changes in their child, and therefore, the expectations they had for the child's eventual achievements.

### **Behavioral and Psychosocial Sequelae in Pediatric TBI**

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Wilkinson, Koski & Humphreys, 1995; Ewing-Cobbs, Fletcher & Levin, 1986; Oddy, 1993 and 1984.

A review of the literature suggests that children are also at significant risk for behavioral changes and psychosocial difficulties following TBI. Although cognitive sequelae are easier to document, and may have significant effects on the child's academic and functional independence, changes in personality have also been shown to be a long-term handicap (e.g., Bragg, Klockars, & Beringer, 1992; Coster, Haley & Baryza, 1994; Klonoff, Low & Clark, 1977; Lehr, 1990; Thompson, 1985) both for the child and for the parents. The course of these symptoms tends to be more variable than cognitive sequelae and is not as closely tied with the severity of injury. In fact, behavioral changes following pediatric TBI appear to be due to a combination of factors which include severity, pre-injury behavior, and family functioning (Max et al., 1997; McGuire & Rothenberg, 1986; Rivara et al., 1992; Rivara et al., 1994).

Changes in behavior and personality are consistently seen in children with severe brain injury (e.g., Asarnow et al., 1991; Coster et al., 1994; Papero, Prigatano, Snyder & Johnson, 1993; Wade et al., 1995), but there has been some debate about the psychosocial consequences of children with *mild* TBI. Although many authors have documented behavioral changes in this population (Asarnow, et al., 1991; Rivara et al., 1993), others have not (Casey et al., 1986; Prior et al., 1994). Some argue that children with certain personality characteristics (e.g., hyperactivity or impulsivity) are at greater risk for *mild* TBI's, and therefore, any behavioral symptoms seen in this population are in essence pre-morbid characteristics (Bijur et al., 1990; Brown & McCormick, 1988; Rivara et al.,

1994)<sup>2</sup>. However, studies which have screened out children with pre-injury difficulties have still shown changes in psychosocial functioning following mild TBI (Asarnow et al., 1991; Fletcher, Ewing-Cobbs, Francis & Levin, 1990; Pelco, Sawyer, Duffield, Prior & Kinsella, 1992). Consequently it appears that all children with TBI's are susceptible to the development of new behavioral difficulties regardless of the severity of their injury or any pre-morbid characteristics.

As indicated above, family functioning has also been shown to be an important predictor for a child's adaptive and behavioral outcome. Rivara et al. (1993, 1994, and 1996) studied the families of 94 children with TBI. Families were interviewed within three weeks of the child's injury in order to provide a picture of the family's cohesion and function before the accident. Follow-up evaluations occurred at 3 and 12 months post-injury. Their results indicated that families with high levels of cohesion, positive relationships and flexibility were significantly correlated with good behavioral functioning in the child one year following their accident. Conversely, children from rigid and poorly functioning families had worse outcomes one year post-injury. It should be emphasized that these papers also confirmed that severity of injury still plays a key role in a child's long-term prognosis. Thus, even a child from a highly functioning family could demonstrate significant behavioral difficulties if they sustain a severe head injury.

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<sup>2</sup> Children with severe brain injuries do not appear to have a greater incidence of pre-morbid difficulties than are normally seen in the population (Bijur et al., 1990; Donders, 1992). Therefore, any changes in behavior are generally considered to be a consequence of the head injury.

The common behavioral sequelae of pediatric TBI include changes in emotional control, activity level, interpersonal social skills, and (perhaps as a consequence of these deficits) decreased adaptive functioning (Bragg, Brown & Berninger, 1992; Costeff, Groswasser, Landman & Brenner; Leher, 1990; Papero et al., 1993). The child's cognitive sequelae also play a key role in behavioral difficulties since decreased attention, and perseverative thinking can greatly impair a child's interpersonal skills; these kinds of impairments reduce the child's ability to engage in age-appropriate play and to interact with his or her peers in a socially acceptable manner. Furthermore, children with TBI's may have profound difficulty learning from their mistakes making inappropriate social behaviors difficult to extinguish (Deaton, 1987; Lezak, 1988).

Typical changes in emotional functioning include increased agitation, irritability, poor anger control, and decreased frustration tolerance. These children may also exhibit profound mood swings which include periods of calm followed by periods of crying, screaming and intense temper tantrums. Conversely, some children exhibit a significant decrease in emotions and become apathetic, socially withdrawn and display poor motivation or difficulties initiating new activities. Like the changes in emotional functioning, activity levels can either increase or decrease following pediatric TBI. Some children exhibit a notable increase in activity such that they become impulsive, restless, and hyperactive; these children often fulfill the behavioral requirements for an attention deficit disorder because of the intensity of these symptoms. Other children become hypoactive and display a reduced initiative for engaging in activities. The manifestations

of these changes in emotional functioning and activity level often result in behavioral difficulties such as extreme attention seeking behavior, increased acting out, aggressive behavior and destructiveness (Filley et al., 1987; Fletcher et al., 1990; Livingston & McCabe, 1990; Rivara et al., 1994; Wade et al., 1995).

In addition to the behavioral and emotional changes noted above, these children often fail to develop (or lose previously established) interpersonal social skills, which again contributes to difficulties in family coping during the post-rehabilitation period (Oddy, 1993; Waaland & Kreutzer, 1988). More specifically, TBI children have significant difficulties responding appropriately to social cues (especially subtle signs such as body language), and have difficulty monitoring their own behavior for inappropriate actions or statements (Deaton, 1987; Lezak, 1988). These children are often socially disinhibited so that even if they “know” their actions are wrong, they have difficulty preventing themselves from engaging in them (Lehr, 1990; McGuire & Rothenberg, 1986). Uninjured children typically develop the capacity to understand the perspectives of others and put the needs of others ahead of their own. Children with TBI’s, however, either fail to develop this awareness or revert back into a more egocentric frame of mind (Oddy, 1993). As a consequence of these psychosocial impairments, children with TBI’s typically lose their friends over time and eventually become socially isolated from their peers (Costeff et al., 1985; Filley et al., 1987; Lehr, 1990)

A review of the literature exploring the long-term effects of pediatric TBI suggests that many of these changes persist for an extended period of time. In one of the earliest prospective studies of children with TBI, Thomson (1984) demonstrated that children continued to have changes in personality and emotional functioning as long as 10-15 years after the injury. Consequently, he concluded that these changes are permanent and he noted that these sequelae tend to present the most serious problems for children in adaptive functioning. Although there are no recent studies which have examined children's behavioral and psychosocial recovery so long after their injury, several other authors have found similar trends in persisting behavioral difficulties between one and five years post injury (Asarnow et al., 1991; Bragg et al., 1992, Fletcher et al., 1990; Klonoff et al., 1977; Papero et al., 1993; Perrot et al., 1991).

Some authors in the adult literature have shown that caregivers also indicate an increasing rate of personality change in the patient over the first year of recovery (Brooks & McKinlay, 1983; McKinlay, Brooks, Bond, Martinage & Marshall, 1981). A recent study in the literature on pediatric TBI has shown similar consequences in the younger population (Coster et al., 1994). No study has been able to clearly elucidate why these symptoms appear to develop after the acute stages of recovery. Coster et al. suggest that it may be due to the parents' growing ability to acknowledge the patient's symptoms (as their initial denial resolves). It may also be a consequence of the child becoming frustrated with his or her new deficits. Regardless of the cause, Brooks and McKinlay noticed that even though the symptomatology increased over time, the pattern of deficits

could usually be measured within the first three months of recovery. Thus, these are not necessarily new deficits, but an exaggeration of earlier identifiable symptoms. This increase in the report of behavioral changes does mirror the results examining burden. Thus, it is possible that increases in self-reported burden may parallel the parents' awareness or complaints of behavioral changes in their child.

To complicate matters, however, it appears that children can grow into behavioral and psychosocial deficits much in the same manner as they grow into cognitive impairments. This delayed appearance of symptoms related to TBI can make it difficult for parents to understand the causes of their child's problems; often the head injury is not thought of as a possible contributing factor since the child appeared to make a reasonable recovery (or had not shown these difficulties during the earlier stages of rehabilitation). Consequently, unexpected behavioral difficulties may be misattributed (e.g., as motivational problems), making it even more difficult for parents to cope.

In summary, children are susceptible to developing a wide array of behavioral and psychosocial impairments following TBI. These behaviors may occur immediately after the injury and intensify over time, or they may appear after a period of apparent recovery. As a consequence of these changes, children often have a difficult time making and keeping friends, and become socially isolated. In addition to the cognitive deficits which may improve somewhat overtime, these behavioral changes may create permanent disabilities in children and seem to represent the most difficult changes for parents to cope with following the injury.

### **Emotional Reactions of Parents to Pediatric TBI**

Despite the substantial amount of research regarding the effects of TBI on families with *adult* patients, few authors have investigated the unique emotional reactions of parents following *pediatric* TBI. Consequently, this review will incorporate both the relevant adult literature as well as those studies focusing on children with TBI's, in order to provide a comprehensive description of the family's reaction to head injury. Parental responses to pediatric TBI have been conceptualized in three different, but not necessarily independent ways; all three approaches highlight the parents' typical emotional reactions, however, they emphasize different frameworks. On the one hand, some authors have simply listed and/or described a series of common parental reactions (e.g., Acorn, 1993; Jarman & Stone, 1989; Lezak, 1978; Sachs, 1991), while others have developed models depicting stages of coping and adjustment (Grovesman & Brown, 1985; Lezak, 1986; Martin, 1988; Spanbock, 1987). The third approach emphasizes the burden parents experience as a consequence of the child's initial injury and subsequent neurobehavioral sequelae (e.g., Brooks, Campsie, Symington, Beattie & McKinlay, 1986 and 1987; Florian & Katz, 1991; McKinlay et al., 1981). As burden typically reflects psychological distress (e.g., depression and/or anxiety) it is closely tied to the emotional reactions parents display throughout the recovery of their child's injury.

Regardless of the approach taken, most authors would agree that parents experience a wide range of emotional changes and adaptations throughout the rehabilitation process of their child. Whether the patient is a child or an adult, parents typically experience

feelings of helplessness, denial, anger and guilt. As the patient begins to recover and the family becomes aware of the remaining cognitive and behavioral changes following the injury deficits family members also begin to grieve the loss of the child as he or she once was. Over time, many family members also become socially isolated as they become involved in the increased care-taking needs of the child and as the child's behavior often makes it difficult to bring him into social situations. These various reactions and their implications are important to clarify to better understand the needs of parents as they cope with their child's TBI.

The most commonly reported reaction to a child's injury during the acute period is denial (Brooks, 1991; DePompei & Williams, 1994; Lehr, 1990; Martin, 1988; Romano, 1974). Few families at this point in time are able to see beyond the physical injuries and are unable to anticipate behavioral and psychological changes. Furthermore, when families are told that the patient will "recover" they expect that the prognosis will extend to the patient's cognitive and behavioral functioning (Eisner & Kreutzer, 1989; Lezak, 1986). Thus, it often appears as though the family simply does not hear or understand the unwanted negative news provided by the medical staff (Brooks, 1991). Instead, they cling to their child's progress and fervently believe that their child will completely recover. Even when they do acknowledge difficult or unusual behaviors in their child (e.g., temper outbursts without apparent triggers), they may rationalize that it is because their child is in pain or they may remember that "he always did have a temper" (Brooks, 1991; Groveman & Brown, 1985; Martin, 1988; Romano, 1974).

When denial occurs in the acute stages of the injury, it is an important and very effective coping mechanism (DePompei & Williams, 1994; Martin, 1988). These parents are often exhausted, stretched to their emotional and physical limits, and may not be able to absorb any more bad news. Consequently, they are in fact unable to accept the prognosis provided by the medical staff (Brooks, 1991). This denial period can give the family time to build up their defenses and adapt to change so that they can eventually face their child's deficits more effectively (DePompei & Williams, 1994). Trying to rush families through this process by insisting they acknowledge their child's deficits is generally ineffective and angers the family instead of helping them. If the family remains in denial for too long, however, it can significantly impair rehabilitation efforts, because family members and clinical staff cannot agree on treatment goals (Durgin, 1989; Florian, Katz & Lahav, 1989; McKinlay & Hickox, 1988). It can also lead to feelings of anger and guilt within the family members, especially if the denial is due to a limited understanding of the consequences of TBI. For example, relatives may become angry if they feel that their child's behavior is intentional (Florian et al., 1989). Consequently, denial in the early stages of the child's recovery is an essential defense mechanism which helps families to adjust to their child's difficulties, but prolonged denial can hinder the child's rehabilitation and the family's ability to adapt and function effectively.

As parents begin to acknowledge the changes in their child and accept the permanency of his or her deficits they begin to grieve for the child they once knew. There is sadness at the loss of both the child's pre-injury personality and at the thoughts

of what might have been. The grieving process tends to be episodic rather than a single phase the parents must work through, because each time the child fails to accomplish typical lifetime milestones (e.g., graduating from high school or getting married) the parents are again reminded of what their child may never have. This grief for a “living child” is often associated with feelings of guilt because many parents believe they should be grateful that their child is alive (DePompei & Williams, 1994; Jarman & Stone, 1989; Martin, 1988). As a result, parents often feel the need to hide their grief which can lead to feelings of isolation and loneliness (Lezak, 1986; Spanbock, 1987).

Guilt associated with grieving is commonly seen with family members of both adult and pediatric patients with TBI's. Parents of injured children, however, also tend to feel immense guilt about the accident itself. Often they believe that they could have or *should have* prevented their child's injury since it is their “duty” to protect their child (Lehr, 1990). Although in some cases, parents may have in fact contributed to the accident, most parents could not have done anything to prevent their child's injury. Nonetheless, they live with profound and enduring feelings of guilt and regret. To make up for “failing” their child, parents may become overprotective in order to prevent any further harm from occurring to them. Overprotectiveness can also arise when parents become fearful of the possibility of another injury occurring or when a post-injury medical complications occur (e.g., if a seizure disorder develops), (Brooks, 1991; Brown & McCormick, 1988; Oddy, 1993).

Other problems unique to the families of pediatric TBI include the realization that their child may never reach independence (Lezak, 1988). Thus, parents must face an extended parenthood and the need to learn how to deal with new behavioral difficulties. Because the child's personality and behavior generally changes following an TBI, the parents' usual way of dealing with their child may no longer be effective (Sachs, 1991). The need to come up with new interventions and disciplinary actions coupled with the parents' desire to be overprotective can produce a significant amount of strain between the parents. Consequently, as one might imagine, marital difficulties and divorce are common within these families, as parents frequently differ in their response to these new parenting demands (Harris, Schwaitberg, Seman & Herman, 1989; Lezak, 1987).

Because of the child's changes in personality and behavior, parents often feel helpless and frustrated. They may be worried about their child engaging in embarrassing behavior while in public or have less available free time, and consequently they begin to withdraw from social engagements. Over time these families become more and more socially isolated, partly because it is impossible to predict what the child may do, and partly because parents begin to feel that no one else can possibly understand what they are going through (Acom, 1993; Kozloff, 1987; Lezak 1987; Sachs, 1991). As noted above, the child also loses their friends over time and begins to become dependent upon their family not only for support and care-taking, but also to serve as their only social network. This in turn can lead to an increase in parents' sense of burden as their children

become increasingly reliant upon them for entertainment as well as for care-taking and parenting.

### The Stages of Adapting to Pediatric TBI

Several authors (Lezak, 1986; Groveman & Brown, 1985; Martin, 1988; Spanbock, 1987) have incorporated the emotional reactions described above into a series of developmental stages describing the adjustment to pediatric TBI (for a comprehensive review of these stages see Rape, Bush, & Slavin, 1992). These stages represent the parents' growing ability to understand their child's injury and its repercussions. Most of the authors agree that people do not rigidly progress from one stage to the next, though some propose that resolution of earlier stages are essential to deal with the problems of later stages (e.g., Groveman & Brown, 1985). Parents may, therefore, cope with their child's injury at different paces or even different orders. Furthermore, there is some allowance for parents to regress to previous stages, especially when presented with striking reminders of their child's losses.

Despite some slightly different theoretical backgrounds and unique terminology, all of these models describe a relatively similar process of coping. Briefly, the models suggest that parents first go through a period of denial and unrealistic expectations (as described above). Over time they begin to acknowledge their child's deficits which leads to a period of emotional turmoil, anger, grief, and mourning. Eventually the parents begin to accept the changes in their child and learn to adapt to them. Those parents who

reach and resolve the final stages of these models learn to appreciate their child as he or she is and able to let go of their sorrow for the child who used to be.

Lehr (1990) offers a different approach to describing the “stages of coping” by emphasizing the major transition periods that parents must cope with following a child’s TBI. For example, she notes that the first period of transition occurs immediately following a child’s injury. This period is often characterized by disorganization and family crisis, and is driven by the frantic fears about whether their child will even survive. Once the child is stable, parents must begin the transition of discharging the child from the hospital and taking him/her home. Although this can be a period of relief (as the child has survived the initial injury and often has made significant physical recovery) parents are often not adequately prepared to deal with their child’s needs. Furthermore, the reality of the child’s long standing cognitive and behavioral sequelae cannot really be understood or accepted by the family until the child returns home. Consequently, parents may not be adequately prepared to deal with or understand the delayed effects of head injury, which can lead to overwhelming feelings of confusion and helplessness. Lehr also emphasizes that the anniversary date of the injury and the achievement of lifetime milestones by other relatives represent other periods of “transition” which can also renew feelings of grief, loss, and helplessness.

Regardless of the approach taken, all authors agree that coping with a child’s TBI is a difficult and enduring process. It often involves intense feelings of fear, denial, grief, loss, and feelings of helplessness and/or confusion. Unfortunately, the need to adequately

care for their child's physical needs and to accept and understand the subsequent neurobehavioral changes can also place a significant amount of strain on the parents themselves. This latter difficulty, which is often depicted as family "burden," is described in more detail in the following section.

### Subjective Family Burden after TBI

Subjective burden typically refers to the degree of strain or distress parents experience as a consequence of their child's injury and neurobehavioral sequelae (Brooks et al., 1986). Consequently, it can be measured by examining the parents' social, emotional, and psychological reactions to their child's injuries (Livingston & Brooks, 1988). Many authors also believe that burden is reflected by decreased family functioning and poor parent-child relationships, as these tend to suffer when the parent (and other relatives) becomes overwhelmed or is no longer able to cope effectively with the patient's TBI (e.g., Hu et al., 1993; Kreutzer, et al., 1994; Perrot et al., 1991). Because burden is a subjective experience, direct measures have been difficult to ascertain. Consequently, many studies have relied on measures of mood, anxiety and family functioning to *estimate* the degree of burden. Others, have depended upon self-report by asking relatives to rate their degree of burden on a 7-point likert scale (Livingston & Brooks, 1988).

One of the earliest studies to examine caretaker burden of TBI patients was performed by Oddy, Humphrey and Uttley (1978). They interviewed the relatives of 54

adult patients with severe closed head injury within a month of the patient's accident. Relatives were re-assessed at 6 and 12 months post-injury. Their results showed that relatives demonstrated significant levels of distress during the first month post-injury. Notably, levels of stress were associated with the relatives' perception of the patient's personality changes, while physical deficits or severity of head injury did not correlate with reported feelings of burden. By sixth months post-injury the degree of stress leveled off, but there were no further changes at 12 months. Therefore, this study suggested that the most difficult time for families is the period immediately following the injury, and that over the ensuing months families begin to effectively cope with and adjust to their relative's TBI.

Oddy et al.'s conclusion that levels of distress are associated with perceived personality changes within the patient has yet to be discredited. In fact, whether relatives have been assessed 3 months or 15 years post-injury, studies have consistently shown that the degree of relatives' burden is most closely associated with the changes in personality and behavior of the patient (e.g., Brooks et al., 1986; Brooks et al., 1987; Cavallo, Kay & Ezrachi, 1992; McKinlay et al., 1981). The only other factor that has been shown to be as critical for predicting family adaptation to pediatric TBI is pre-morbid family functioning (Rivara et al., 1992 & 1993). Since a highly functioning, cohesive and flexible family is more likely to be able to deal with adversity and stressful changes these results make intuitive sense. Their importance lies in the ability to predict which families may need extra assistance in dealing with their child's injury. Nonetheless, as noted

above, even the highest functioning families may have difficulties dealing with the profound behavioral changes a child may experience as a consequence of a *severe* TBI.

Although Oddy et al.'s (1978) conclusions regarding the relationship between personality changes and family burden have withstood the test of time, their finding that subjective burden decreases over the first six months post-injury has met with significant controversy. In fact, the majority of the ensuing investigations (again mostly with adult patients and their families) have shown drastically different results. Overall, there seems to be a trend within the literature which suggests that perceived feelings of distress and burden are lowest during the early stages of recovery and actually increase over time (for a comprehensive review see: Brooks, 1991; Kreutzer et al., 1992; Livingston & Brooks, 1988; Wade et al., 1995). A closer analysis of Oddy et al.'s (1978) paper shows that almost 25% of the subjects did not complete the measure used to determine levels of distress on the two follow-up interviews, therefore the representativeness of his findings are questionable.

A review of the more recent literature indicates that as early as three months post-injury, relatives demonstrate elevated levels of anxiety, depression and overall distress (Kreutzer et al., 1994; Livingston, Brooks & Bond, 1985; McKinlay et al., 1981). Measurements of burden and distress at 6 months are significantly higher (Livingston, 1987; Rivara et al., 1992), and little improvement is seen by one year post-injury (Brooks & McKinlay, 1983; Cavallo et al., 1992; Hu et al., 1993; Livingston, Brooks & Bond, 1985b; Oddy et al., 1978). In fact, some studies have shown that the degree of subjective

burden may increase between the first and fifth years post-injury (Brooks, et al., 1987), and families continue to have difficulties as long as 15 years later (Thompson, 1985).

The practical ramifications of these results are a decreased ability for the family to cope effectively (Brooks et al., 1986; Kreutzer et al., 1994; Rivara et al., 1992). These results have been demonstrated predominately for adult patient populations, and assumptions have been made that findings would be similar for pediatric TBI families. Only a few studies have attempted to verify this by directly focusing on the unique dynamics of the parent-child relationship and overall family functioning following pediatric TBI. For example, Perrot et al., (1991) found that parents experienced increased stress and tension in the relationship with their injured child. In 1995 Taylor et al. confirmed these results and also showed increased rates of parental distress and dysfunctional family environments. Therefore, it appears that the repercussions of a child's injury can affect the parent's psychological functioning, as well as overall family functioning and the relationship between the parent and child.

### **Parents' Self-Reported Needs after Pediatric TBI**

Understanding the changes in a child after TBI certainly has helped to develop the theoretical models depicting the needs of their parents. However, it would be especially useful to determine what the parents themselves report needing, rather than assuming what their needs are. A small handful of investigators have begun to assess self-reported needs of parents rather than merely documenting symptoms of burden, or changes in a

child post-injury. Of further interest, they have also documented how well these needs have been met over time. Overall, families of adult patients appear to report an increasing number of unmet needs as time post-injury increases (Kreutzer et al., 1994; Witol, Sander & Kreutzer, 1996). These findings are consistent with the literature depicting an increase in parents' feelings of subjective burden over time. If findings are similar for pediatric TBI (something not yet investigated), this would be especially important to consider, since intact family functioning appears to play such a critical role in the recovery of the brain injured child (Max et al., 1997; Rivara et al., 1993; Rivara et al., 1994). Consequently, there is a strong need to find the most effective means for understanding the needs of these families and then for developing programs to meet these needs.

Mauss-Clum and Ryan (1981) were the first to empirically investigate the needs of family members caring for a brain-injured relative. They sent questionnaires to the families of adult patients who had been treated for TBI through a rehabilitation unit. Brain injuries had been acquired either through traumatic accidents (17), vascular accidents (9), or dementing disorders(4). Participants were asked to prioritize a list of needs in order to determine what was most important to them during the recovery of their relative. The highest ranked needs included a desire for clear explanations and the discussion of realistic expectations. Also important for these families was the provision of emotional support, and financial and resource counseling. No information was

provided regarding the relationship between cause of injury and subsequent needs, nor was it clear whether time since injury influenced family needs.

Campbell (1988) was also a pioneer investigator into the perceived needs of relatives caring for adult brain-injured patients. He obtained fourteen participants through family support groups run by the National Head Injury Foundation. Each participant was asked to indicate the usefulness (ranked as “not important”, “important”, or “not applicable”) of receiving help in three areas: educational needs, psychological needs, and social needs. All of the participants indicated the need for having questions answered honestly, to learn the effects of head injury, to learn about community support, and to feel there is hope. Other needs ranked highly included the ability to obtain information about financial assistance, to know what the future holds for their relative, and to have emotional support. Time since injury for the relatives of these participants ranged from 6 months to 12 years. Unfortunately, the mean time post-injury was not provided, nor was there any evaluation of whether time since injury influenced the needs of the caregivers.

Although both of these studies clearly contributed to the understanding of the needs of this population, they were limited by small sample sizes, unclear differentiation of the impact of time post-injury, and other methodological issues. For example, both studies provided questionnaires which emphasized only the acute stages of the patient’s recovery. Furthermore, neither study attempted to examine their questionnaire’s validity, reliability, or sensitivity to the unique aspects of brain injury. Furthermore, they did not attempt to

ascertain how well these needs had been fulfilled, which is essential to know when devising intervention methods. In order to address these concerns, Kreutzer (1988) developed the Family Needs Questionnaire. This measure was specifically designed to reflect the full spectrum of family needs across an *adult* patient's recovery time, and to evaluate how well these needs have been met. Since its development, the Family Needs Questionnaire has also been shown to have adequate reliability and validity for the family members of TBI patients (Kreutzer, Serio & Berquist, 1994; Serio, Kreutzer & Witol, 1997).

Consistent with previous research, studies which have used the Family Needs Questionnaire have shown that relatives continuously emphasize the need to obtain honest, clear medical information about the patient (Kreutzer et al., 1994; Serio et al., 1997; Witol, et al., 1996). By one to two years post injury 80 - 100% of the subjects reported their needs for medical information as being met or partly met (Kreutzer et al., 1994; Witol et al., 1996). Despite such a high rate of fulfilled *medical needs*, relatives generally reported an increased number of unmet needs as time post-injury increased. Specific unmet needs typically addressed psychological issues, emotional support, a need for practical information regarding the management of the injured relative's behavior, and needs related to fears about the future and preparing for the worse. Other investigators (e.g., Junque et al., 1997) have also found similar results, regardless of the measures they used.

In 1993, Waaland et al., modified the Family Needs Questionnaire to make the content more appropriate for a pediatric TBI population. They then used this measure to compare the needs of high- and low-income families soon after their child's injury (within one year following the injury or recovery from coma). Surprisingly, they found no difference in the expressed needs of parents based on family income; both groups emphasized the need for clear information, involvement in therapy decisions and understanding from professionals and teachers. As with the adult studies, most parents rated these needs as being met. This sample generally devalued personal needs, family support and concerns regarding the patient. However, it is crucial to point out, that the adult studies also found a lack of emphasis on these factors during the acute stages of the patient's recovery. It was only as time progressed that these became important and/or unmet needs for family members (Kreutzer et al., 1994; Witol et al., 1996). Consequently, Waaland et al.'s findings can not be assumed to accurately reflect the needs of parents during the latter periods of their child's rehabilitation.

Unfortunately, to the author's knowledge, there have been no studies investigating the needs of parents during this latter stages of a child's recovery. This is a striking finding considering this is such a critical period of time for this population (given the decreased access to rehabilitation professionals), and especially because the adult studies have suggested that parents' unmet needs may increase overtime. Although it may be easy to automatically apply these findings to the families of pediatric patients, it is important to note that by definition the needs of caregivers of adults (even if they are

adult *children*) may differ from the needs of parents caring for their youth. For example, parents of pediatric patients will have to cope with pressures related to their education, developmental milestones, and lost potential (DePompei & Williams, 1994; Jarman & Stone, 1989; Lezak, 1988). These differences may result in a unique constellation of needs which may be crucial for improving the parents' adaptation to their child's injury and its neurobehavioral consequences. These specific needs should be empirically determined so as to develop the most useful intervention program for parents of TBI children.

In summary, family members report an increased number of unfulfilled needs as time post-injury increases. These needs also closely parallel their reports of increased burden and emotional distress. Unfortunately, as time post-injury increases, families become less involved with rehabilitation facilities and have few options to have these needs met.. Psycho-educational support groups may be a possible solution to this dilemma, as they may provide a forum for providing parents with the means to fulfill their needs. However, before an empirically based support group can be developed for the parents of TBI children during the post-recovery recovery period, the parents' needs should first be determined. The proposed study attempted to evaluate this population's needs using Waaland et al.'s (1993) revised Family Needs Questionnaire to determine what are the most important needs during the post-recovery period and how well have they been met.

### **Summary and Predictions of the Present Study**

The literature clearly indicates that parents of brain-injured children experience significant distress in response to their child's initial injuries and subsequent sequelae. Parents typically undergo a series of emotions including denial, grief, guilt, and feelings of helplessness as they learn to accept and deal with their child's injuries. Although parents who have children with acquired physical disabilities report decreased feelings of burden and distress during the first year post injury, parents of children with TBI consistently report increasing levels of distress, anxiety and depression (Florian et al., 1989; Wade, et al., 1995). It is of further concern that these parents continue to report high levels of burden for as long as fifteen years after their child's injury. This is a distressing finding especially since it has been shown that the child's functional outcome is directly tied to the cohesiveness of the family and its ability to deal with the stressors following such an injury.

Some authors have begun to investigate self-reported needs of the caretakers of TBI patients. During the acute period of the patient's treatment, relatives often report a high need for honest, clear medical information, and expectations for the patient's prognosis. By the first or second year post-injury these needs have been generally met. However, as time increases post-injury, relatives of adult patients report an increased amount of unmet emotional and psychological needs. To date, there have been no studies which have investigated the needs of parents of TBI children beyond the acute stages of recovery.

Many professionals who work with these families have made clinical observations that support groups may be a practical and useful way to offer these parents the support and education they may need to accommodate to their child's injuries. The post-recovery period (12 months or later post-injury) appears to be the ideal time to offer such resources as this is when parents begin to report increased feelings of burden, anxiety and turmoil. However, the lack of a clear understanding of these parents' needs may hinder the development of any support services; without a clear awareness of what parents may feel they need to cope with their child's injuries, one runs the risk of providing inefficient treatment.

This dissertation endeavored to evaluate what parents of TBI children report needing from support services and how well these needs are being met. In order to assist in the future development of support groups, reported needs of parents with TBI children will be compared with responses from two control groups: parents of orthopedically injured children (ORTHO group) and parents of diabetic children (DIAB group). These groups were selected based on their similarities and differences with a TBI population. First, each group was selected in order to control for issues which may arise due to any trauma or sudden change in health. While the ORTHO group would have been sufficient if the crisis were the only variable of interest, however, the DIAB group was also selected in order to ascertain the impact of a sudden change in one's child which is chronic and enduring; both diabetes and TBI can result in significant and enduring behavioral changes in the child, as well as a need to modify the child's and the family's lifestyle. Finally,

these groups were also selected based on the degree of medical support the child receives subsequent to his or her injury/diagnosis, which is somewhat different for each of the three populations. In order to further support the justification of the two comparison groups, these rationales will be discussed in more detail.

First, these populations were selected because of similarities in their initial presentation. The parents of all three groups are faced with the sudden, unexpected trauma or diagnosis of their child. Therefore, parents of all groups must deal with an initial crisis which resulted in the hospitalization of their child. Family's tend to cope with crisis in different manners, and it is conceivable that it is the crisis itself which contributes to future family dysfunction and subsequent parental needs. For this reason, orthopedic control groups have frequently been used in the TBI literature to ascertain whether family needs develop as a consequence of any traumatic injury or if there are unique needs (both met and unmet) when the central nervous system is involved. Previous studies in the adult population have indicated that the needs of relatives of critically ill patients do differ when the presence or absence of a brain injury is taken into account (Engli & Kirsivali-Farmer, 1993). Furthermore, as noted above, parents of orthopedically injured children generally report decreasing feelings of distress and burden over time while the distress levels of parents of TBI children steadily increase over time (Florian, Katz, & Lahav, 1989; Wade et al., 1995).

The second reason that the two comparison groups were selected was because they lie along a continuum describing the amount of continuing medical services offered

by the community. The parents of orthopedically injured children are generally supported during their child's stay in hospital and during any necessary outpatient physiotherapy sessions. Once this treatment has ended, however, parents are generally able to cope on their own, with regular visits to their general practitioner. Parents of diabetic children, on the other hand, are dealing with a chronic condition, and are typically offered continuous support through the hospital's diabetes clinics. From the day the child is diagnosed, and until the child is an adult, there are readily available resources and support services available for both the parent and the child. The support services the parents of TBI children lie somewhere in between these groups on the continuum of community support. Therefore, an analysis of parents' needs along this continuum may offer some insight into possible support mechanisms for the parents of TBI children.

Finally, the DIAB population was also included because DIAB and TBI parents share the need to cope with behavioral changes in their child and a need to change some of their parenting styles and expectations. In order to understand these similarities, it would be useful to briefly review some important characteristics of diabetic children and their families. A diagnosis of Diabetes leads to many profound changes in a child's life. Once diagnosed, children face significant diet restrictions, a need for set meal times, learning to monitor blood sugar levels and daily insulin injections. Limitations on social activities and day-to-day family life may also need to be made (Gardner, 1998; Seiffge-Krenke, 1998). Furthermore, the child may require repeated hospital admissions and frequent medical follow-up care due to episodes of hypo- or hyperglycemia (Gardner,

1998). These changes may lead the children to see themselves as being different from their peers making them more self-conscious and less secure (Gardner, 1998).

Adapting to these changes can place a significant degree of stress on both the child and on the parent. Not surprisingly, therefore, diabetic children have been shown to be at an increased risk for the development of psychological and psychiatric problems (Holden, Chmielewski, Nelson & Kager, 1996); although many children may experience a healthy and uncomplicated adjustment, other children are at risk for difficulties with low self-esteem, social dependency, and other psychological disturbances such as depression, anxiety and social withdrawal (Brown, 1985; Burns, Green & Chase, 1986; Mayou, Peveler, Davies, Mann & Fairum, 1991). For most children, this adjustment period resolves within the first year; however, in other children, psychological difficulties may persist for as long as 6 years post diagnosis (Kovacs et al., 1990). While children may adapt to the initial diagnosis, they (especially adolescents) may still chafe at the added restrictions in their life and the requirement for unusually strong self-discipline and responsibilities for self care (Anderson, Auslander, Jung, Miller & Santiago 1990), which may result in acting out. Remembering that it is the behavioral changes that are most difficult for TBI parents to cope with, these changes make the diabetic population a strong control group to measure parent adaptation.

Because it is often the parents who have to enforce the new lifestyle regimen, their adaptation to the child's disease can significantly affect the degree of the child's metabolic control (Auslander, Bubb, Rogge, & Santiago, 1993; Florian & Elad, 1998;

Hauser et al., 1990; Schafer, McCaul, & Glasgow, 1986). More specifically, studies have shown that parental self-esteem, family cohesion and structure, communication, family resources and coping skills, and mothers' feelings of a sense of empowerment and understanding of the child's condition are all positively related to the child's metabolic control (Auslander et al., 1993; Florian & Elad, 1998; Seiffge-Krenke, 1998)

Interestingly, few studies were found which documented the specific emotional difficulties these parents experience while coping with their child's diagnosis as is seen in the TBI literature. Nonetheless, the emphasis on the role of family functioning and its impact on metabolic control clearly suggests that some, if not all, parents have some initial difficulties adapting to the child's illness, and for some this difficulty may persist for years. Furthermore, the few studies found in this area, do document similar symptoms in these parents as has been found in the TBI population. For example, Northam, Anderson, Adler, Werther & Warne (1995) focused specifically on family functioning independent of metabolic control, and found a significant degree of maternal distress subsequent to diagnosis (characterized by anxiety and social disruption). In addition to these symptoms, Kovacs et al., (1985) also found mild depression in mothers of newly diagnosed children. This study also demonstrated a slight decline in psychological symptoms over the first year post diagnosis followed by an increase in symptomatology as time went on. Recall that this pattern is somewhat similar to that seen in the TBI population, although it has not been shown as robustly in the diabetic literature.

In summary, the two comparison groups were selected based on the similarity of injury/illness onset, and because of differences in the extent of medical care received following the injury/illness. The DIAB group was further selected based on the chronic nature of this disease, the potential for behavioral changes in the child, and the need for parents to cope with the changes in their expectations for their child's future. Given the similarities and differences between the TBI group and its two control groups, the predictions for this study are as follows:

- 1) Parents of orthopedically injured children will rank fewer needs as being important relative to the parents of diabetic children and the parents of TBI children.
- 2) Parents of diabetic children and parents of TBI children will rank a similar number of needs as being important **but** parents of TBI children will report that fewer needs have been met relative to parents of diabetic children.
- 3) An examination of the pattern of unmet needs will also indicate that parents of TBI children will report more needs for emotional and professional support than parents of diabetic and orthopedically injured children.

## **Methods**

### **Design**

This study used a between subject comparison of three groups of participants: parents of diabetic children (DIAB group), parents of traumatically brain-injured children (TBI group), and the parents of orthopedically injured children (ORTHO group). The children of all participants were one or more years post-injury or post-diagnosis date.

### **Participants**

Participants for the DIAB group were recruited through a regional hospital diabetes program in Canada (Victoria, British Columbia), where the hospital mailed out questionnaires to their entire diabetic patient list (regardless of time since diagnosis). The participants of the ORTHO group were recruited through regional hospitals in the United States (Oklahoma City, Oklahoma); patient lists were provided for children who had been injured between one and three years ago, and then questionnaires were mailed to each family on the list. In order to provide for a sufficient sample size, and to compare across the US-Canadian medical systems, participants for the TBI group were recruited through regional hospitals in both the United States (all patients were between 1 and 3 years post injury) and Canada (where patients had a wider range of time post injury). To be included in the study, the diagnosed child had to be currently living in the home, and be of school age (i.e., aged 4 - 18). Participants were excluded if their child has had a previous history of mental retardation, psychiatric disorders, previous TBI, other life-

threatening medical conditions (e.g., cancer), or learning disabilities (if not associated with the TBI being assessed by this study<sup>3</sup>).

A total of 92 questionnaires were returned (TBI = 21; DIAB = 47; ORTHO = 16). Seven participants were excluded from the study due to learning disabilities (n = 4; 1 ORTHO; 3 DIAB), psychiatric problems (n = 1; 1 ORTHO; 1 TBI), and other chronic medical conditions (n = 1; ORTHO - cancer). Due to the DIAB sampling method, the original DIAB sample included a wider range of time since diagnosis relative to both the TBI group and the ORTHO group. Consequently, 24 additional DIAB cases were excluded based on time since diagnosis (those under one year since diagnosis, and later outliers were excluded ) in order to better match the other 2 groups for time since injury.

Fifty-four total participants met selection criteria (TBI = 19; DIAB = 21; ORTHO = 14). Group means and standard deviations for demographic variables of the participants' children can be seen in Table 1. Analyses of Variance (ANOVAs) and Pearson Chi Square analyses were run to compare these characteristics across groups. No significant differences were found in terms of age at injury/diagnosis and current age, time since injury/diagnosis, number of days hospitalized, gender, number of 2-parent families, or gender of responding participant. Although several of the children (n=5) in the overall TBI group also had orthopedic injuries, the ORTHO group was limited to children who had no symptoms suggestive of a TBI (e.g., loss of consciousness). Table 2

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<sup>3</sup> The TBI group had twelve children (63.2%) in special education classes (all because of their injury).

summarizes the causes of injury for the TBI and ORTHO groups. Motor vehicle accidents and falls account for the majority of injury causes for both populations.

Table 1.  
Characteristics of Study Participants

Demographic Variable	Group		
	TBI (n = 19)	DIAB (n = 21 )	ORTHO (n = 14)
Age at injury/diagnosis (years)			
M	9.46	8.92	8.74
SD	4.38	3.50	5.07
Range	2.33 - 16	2.50 - 14.09	2.44 - 16.5
Current Age (years)			
M	13.25	12.04	10.95
SD	3.72	3.28	4.86
Range	5.75 - 18.42	5.75 - 17.58	4.11 -18.42
Time since injury/diagnosis (years)			
M	3.78	3.09	2.21
SD	3.13	1.18	.84
Range	1 - 13	1.25 - 5	1 - 3.5
Number of days child was hospitalized			
M	33.10	8.77 <sup>a</sup>	2.44
SD	50.46	3.37	1.67
Range	.5 - 180	4 - 14	1 - 5
Number of male patients			
n	9	8 <sup>b</sup>	10
%	47.4	40	71.4
Number of 2-parent families			
n	13	18	13
%	68.4	90	92.9
Number of participants who were mothers			
n	17	20	14
%	89.5	100	100

Note. - TBI = traumatic brain injury group; DIAB = diabetics group; ORTHO = orthopedic injury group

<sup>a</sup>2 subjects did not provide this information.

<sup>b</sup>7 subjects did not provide this information

\*Significant group difference,  $p < .01$ .

Table 2.  
Causes of Injuries for TBI and ORTHO children

Variable	Group					
	TBI		ORTHO		Total	
	n	%	n	%	N	%
Motor Vehicle Accident	5	27	4	29	9	27
Fall	4	21	4	29	8	25
Pedestrian/MVA	4	21	0	0	4	12
Bicycle Accident	4	21	0	0	4	12
Sports Accident	1	5	3	21	4	12
Other	0	0	2	14	2	6
Assault	1	5	0	0	1	3
Unknown	0	0	1	7	1	3

Note. TBI = Traumatic brain injury group; ORTHO = Orthopedic injury group

Children with TBI were classified into two severity groups based on loss of consciousness (Taylor et al. 1999): mild TBI and severe TBI (for the purposes of this study, moderate brain injuries were collapsed into this group). Severe brain injuries were defined based on a loss of consciousness of 15 minutes or longer. Conversely, the mild TBI group consisted of children with no or only brief loss of consciousness (less than 15 minutes). Using this classification, eight children (5 male, 3 female) were characterized as mild TBI, and 12 children were classified as severe (4 male, 8 female). Because of the sample size, this classification was used only for correlational analyses, and was not used to answer the 3 primary hypotheses

Table 3 summarizes the TBI sample when broken down into the US and Canadian samples. Group comparisons revealed a proportionately larger group of moderate-severe injuries in the US sample ( $\chi^2 (1, 19) = 6.38, p < .05$ ), and the US sample also had a

longer mean hospital stay ( $F(1,19) = 12.05, p < .01$ ). Canadian TBI participants were more likely to be single parents than the US sample (which consisted entirely of 2-parent homes) ( $X^2(1, 19) = 4.047, p < .05$ ). While not reaching significance, there was also a trend in time since injury with the Canadian group having more time relative to the US group ( $F(1,19) = 4.202, p = .056$ ). The groups were similar, however, in all other measured areas.

Table 3.  
Characteristics of TBI Groups based on country of sample origin

Demographic Variable	Group	
	Canadian TBI (n = 13)	USA (n = 6)
Age at Injury (years)		
M	8.38	11.80
SD	4.27	3.96
Range	2.3 - 15.6	6.3 - 16.0
Current Age (years)		
M	13.09	13.59
SD	1.61	4.30
Range	5.7 - 17.5	7.9 - 18.4
Time since injury (years)		
M	4.71	1.79
SD	3.39	.830
Range	1.2 - 13	1.0 - 3.16
Number of days child was hospitalized**		
M	11.62	79.67
SD	12.99	70.41
Range	.5 - 42	2.0 - 180
Number of male patients		
n	7	2
%	53.8	33
Number of 2-parent families*		
n	7	6
%	53.8	100
Number of children in Special Education		
n	7	4
%	53.8	66.7
Number of moderate-severe TBI children*		
n	5	6
%	38.5	100
Number of participants who were mothers		
n	11	6
%	84.6	100

\*significant group difference,  $p < .05$

\*\*significant group difference,  $p < .01$

### Measures

The Family Needs Questionnaire (Kreutzer, 1988) is a 40-item questionnaire designed to assess family members' perceived needs following the brain injury of a relative throughout the patients recovery period (i.e., acute through post-rehabilitation periods). The measure provides information about the extent to which needs are perceived as important (not important/slightly important/ important/very important), as well as how well these needs have been met (yes/no/partly). Items were selected based on interviews with family members and a literature review of the needs of family members with adult ABI patients. In 1993 Waaland et al., adapted this questionnaire to address the developmental issues and differences in needs for the caregivers of *children* (consequently, this is the version used in this dissertation). Factor analysis of the adult questionnaire has revealed 6 scales (Serio et al., 1997) addressing: (1) health information; (2) emotional support; (3) instrumental support; (4) professional support; (5) community services; and (6) involvement with care. Although no research to date has examined the factor structure of the pediatric measure, both tests still measure the same domains and it is not likely that they should significantly differ. Table 4 provides sample questions for each of these factor scales.

Table 4.  
Description of Needs Factors for the Family Needs Questionnaire

Factor	Description of Needs Content	Number of Items
Health Information	Information about the child's medical care, physical condition, and cognitive functioning, and educational process.	10
Emotional Support	Parent receives understanding, support and reassurance from spouse, other family members, and the community.	8
Instrumental Support	Practical assistance in keeping the house and receiving respite. Encouragement to engage in self-care routines (e.g., getting enough sleep and spending time with friends).	6
Professional Support	Access to resources for the child (in terms of rehabilitation programs, counseling, etc.), and for the Parent (e.g., resources to provide training and information on how to best manage the child's problems).	5
Community Support Network	Important people in the child's environment (e.g., peers, teachers, family) understand the child's problems. Also, that the parent has professional resources to turn to for advice, and friends/family to talk to who understand the child's problems.	5
Involvement with Care	Parents are integrated in the child's treatment; their opinions are solicited and used.	3

A demographics questionnaire (see Appendix A) was also included in the package mailed to families, assessing size of family, and presence or absence of a second caregiver. Characteristics of the children were also documented with specific reference to gender, birth date, cause and severity of injury, time spent in hospital, length of time since injury, current grade in school and whether their child is currently receiving any form of learning assistance (and if so, is it related to the child's injury/diagnosis). Where relevant, parents were also asked to indicate whether their child lost consciousness (and for how long), and the length of the child's coma (if known).

### Procedure

Contact letters and questionnaire packages were sent to participating hospital organizations who had agreed to send them to appropriate referrals. Each questionnaire package included an informational letter (see appendix B), the questionnaires as described above, and a self-addressed, stamped return envelope. Given that some TBI and ORTHO participants may have been involved in medico-legal suits, questionnaires were returned anonymously. Consent for participation was implicit in the return of questionnaires, as spelled out by the introduction letter and demographics questionnaire.

## Results

### Analysis of Importance Ratings

Based on the methodology of previous literature (e.g., Kreutzer et al., 1994; Witol et al., 1996), responses to the Family Needs Questionnaire were classified as “Important” if respondents circled either “important” or “very important” for an item; items rated as “not applicable,” “not important,” or “slightly important” were not counted for this frequency measure (or for the subsequent analyses). Using this cut-off, TBI participants (as a group) rated 28 items as being “Important”, DIAB participants rated 26, and ORTHO participants rated 14 items (see Table 5). Of these items, four fell in the top ten “Important” items endorsed by all three groups, demonstrating a desire for honest answers, understandable explanations from professionals, assurances that their child receives the best possible medical care, and to have professionals to turn to for advice or services as needed. Two additional items were endorsed by both the DIAB and TBI groups demonstrating a shared need for having others (e.g., teachers and the child’s friends) understand the child’s condition. A summary of the top ten ranked important needs by group, and the proportion of respondents who rated that item as important is provided in Table 6.

While an item may fall in the top ten for a group, that did not necessarily indicate that a majority of that group endorsed an item. Consequently chi-square analyses of the top items were run in order to assess whether there were differences in the proportion of the groups who endorsed each item. The results indicated that there were significant differences in the group’s proportion of parents who endorsed 9 out of the 15 top ranked

items seen in Table 6. Groups did not differ on items demonstrating a need for honest, understandable explanations, and assurances that their child is receiving the best medical care. They were also consistent for items demonstrating an involvement in their child's care or treatment and to be told regularly what is being done for their child.

Table 5.  
Means and Standard Deviations of Number of "Important" Needs, and Percentage of "Unmet Important" Needs and "Met Important" Needs

Variable	Group		
	TBI (n = 19)	DIAB (n = 20)	ORTHO (n = 14)
Number of "Important Needs"	28.6 (8.3)	26.9 (7.1)	14.8(7.7)**
Percentage of "Unmet Important" Needs	64.2 (24.1)*	40.1 (26.3)	24.7 (33.0)
Percentage of "Met Important" Needs*	35.6 (24.1)*	59.5 (27.1)	75.3 (33.0)

Note. TBI = traumatic brain injury group; DIAB = diabetes group; ORTHO = orthopedic injury group

\*Significantly different,  $p < .05$

\*\*Significantly different at  $p < .01$

Table 6.  
Top 10 needs most frequently rated as “Important” or “Very Important”

Item endorsed	TBI %	DIAB %	ORTHO%
<i>I need to...</i>			
have explanations from professionals given in terms I can understand	<b>95</b>	<b>100</b>	<b>93</b>
be assured that the best possible medical care is being given to my child	<b>90</b>	<b>100</b>	<b>100</b>
have my questions answered honestly	<b>90</b>	<b>100</b>	<b>100</b>
have professionals to turn to for advice/services when my child needs help***	<b>95</b>	<b>100</b>	<b>57</b>
have my child’s teachers understand his/her problems***	<b>95</b>	<b>91</b>	36
have my child’s friends understand his/her problems***	<b>85</b>	<b>95</b>	14
be told how long each of my child’s problems is expected to last***	<b>90</b>	33	43
have information on my child’s therapy or educational progress**	<b>90</b>	62	36
have enough resources for <u>my child</u> (e.g., rehabilitation programs, physical therapy, counseling).**	<b>95</b>	81	43

Note. Bold numbers indicate this item was in top 10 for this group

\*significant difference at  $p < .05$ ; \*\* significant difference at  $p < .01$ ;

\*\*\* significant difference at  $p < .001$

Table 6 cont.

## Top 10 needs most often rated as important or very important

Item endorsed	TBI %	DIAB %	ORTHO%
<i>I need to...</i>			
discuss feelings about my child with someone who has gone through the same experience**	85	67	29
be shown that medical, educational, or therapy staff respect my child's needs or wishes	85	95	100
be told about all changes in my child's medical status*	74	100	93
have complete information on the <u>medical care</u> of my child's disorder (e.g., medications, etc.).**	79	100	43
be shown that my opinions are used in planning my child's treatment, therapies, or education.	85	90	71
be told regularly what is being done with or for my child	79	86	100
have different staff members agree on the best way to help my child	68	71	43
give my opinions daily to others involved in my child's care, therapies, or education	58	33	43

*Note.* Bold numbers indicate this item was in top 10 for this group

\*significant difference at  $p < .05$ ; \*\* significant difference at  $p < .01$ ;

\*\*\* significant difference at  $p < .001$

The total number of items participants rated as “Important” were tallied and averaged across each group, and then compared using a one-way analysis of variance (ANOVA). It had been hypothesized that the ORTHO group would endorse significantly fewer needs as “Important” relative to the DIAB and TBI groups, while the DIAB and TBI groups were not expected to differ from one another. The results of this analysis did determine that there was a significant group difference in number of items ranked as important,  $F(2,51) = 15.01, p < .001$ . As predicted, a Tukey HSD Post Hoc analysis further confirmed that the ORTHO group reported significantly fewer important needs relative to the DIAB and TBI group ( $p < .01$ ). There was no significant difference between the TBI and DIAB group in their number of “Important” needs ( $p = .77$ ).

#### Pattern of Important Needs

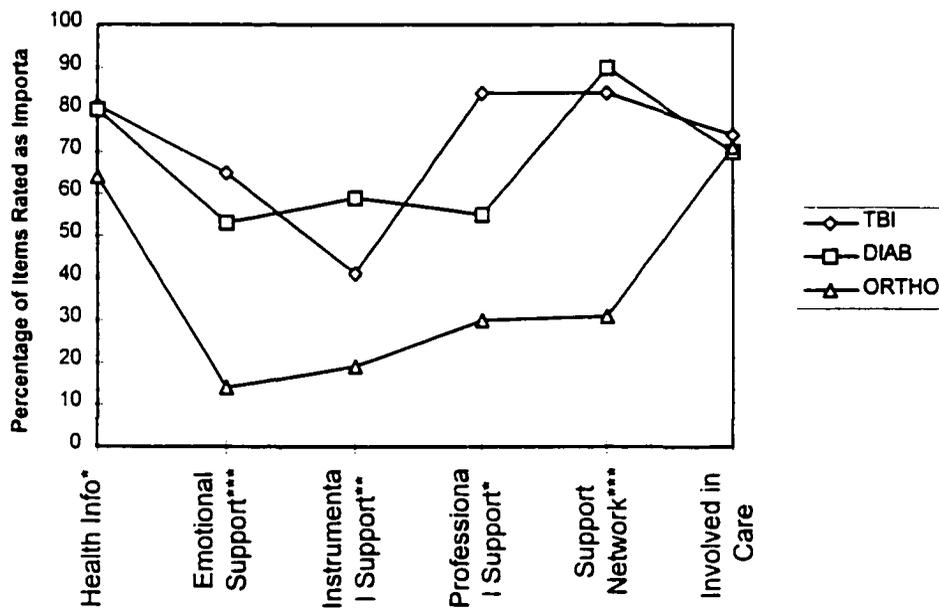
In order to assess the pattern of “Important” needs, a profile analysis was performed on the six factor scores: need for health information, need for emotional support, need for instrumental support, need for professional support, need for a support network, and need for involvement with care. The grouping variable was source of child’s injury or diagnosis, divided into parents of TBI children, parents of diabetic children, and parents of orthopedic children.

A multivariate analysis of variance (MANOVA) was used for this analysis. Using Pillai’s Trace Criterion, the profiles (see Figure 1) differed significantly from parallelism,  $F(10, 96) = 4.40, p < .000$ , indicating the groups did not demonstrate a parallel pattern of responses. Group differences were also found to be significant,  $F(2,51) = 12.61, p < .001$ .

Group differences for each variable were evaluated using a Tukey HSD analysis.

The ORTHO group, endorsed significantly fewer needs in four of the factors relative to the TBI and ORTHO group: needs for health information ( $p < .05$ ), needs for emotional support ( $p < .001$ ); needs for professional support ( $p < .001$ ), and needs for a support network ( $p < .001$ ). The ORTHO group also rated fewer important items on the need for instrumental support relative to the DIAB group only ( $p < .01$ ). The TBI and DIAB group only differed in the number of important needs on the factor measuring the need for professional support ( $p < .05$ ), where the DIAB population reported fewer important needs relative to the TBI group.

Figure 1.  
Profile of Important Items Endorsed for Each Factor



### Analysis of Unmet Needs

Methods of calculating met and unmet needs were also adapted from the approach used in previous literature (Kreutzer et al., 1994). For each participant, only those responses which were endorsed as important or very important were assessed (i.e., “Important needs” as defined above). Needs were then determined to be “Unmet” if respondents endorsed “partly met” or “unmet,” for an item. Using this method, the TBI group rated 19 out of 28 “Important” needs as being unmet or partly met (i.e., “Unmet”). The DIAB sample rated 10 out of 26 items as “Unmet”, and the ORTHO group rated 5 out of 14 items as “Unmet”. Table 7 summarizes the items most often rated as “Unmet” across the three groups and the proportion of participants who rated them as unmet. Six of the TBI’s most “Important” items were also rated as unmet, while only one of the “Important” items were unmet for both the DIAB and ORTHO groups.

Chi-square analyses indicate that the proportion of participants endorsing these needs as unmet were significantly different for all but 4 of the 21 items listed in Table 7. Those items which were rated similarly across groups demonstrated the same proportion of unmet needs for help getting over doubts regarding the child’s future, spending time with friends, to be shown that professionals respect their child’s needs, and to have complete information on their child’s physical problems.

Table 7.  
Important needs most frequently rated as “Partly Met” or “Unmet”

Item endorsed	TBI %	DIAB %	ORTHO%
<i><b>I need to...</b></i>			
have my child’s friends understand his/her problems***	<u>74</u>	<u>52</u>	0
have my child’s teachers understand his/her problems***	<u>84</u>	<u>29</u>	0
discuss feelings about my child with someone who has gone through the same experience**	<u>68</u>	29	14
have help in remaining hopeful about my child’s future*	74	<b>43</b>	14
have a professional to turn to for advice or services when my child needs help***	<u>74</u>	<u>24</u>	21
have complete information on my child’s problems in <u>thinking</u> (e.g., confusion, memory, or communication)***	<b>68</b>	05	14
be told how long each of my child’s problems is expected to last***	<u>68</u>	0	14
have enough resources for <u>my child</u> (e.g., rehabilitation programs, physical therapy, counseling)***	<u>68</u>	14	29
have enough resources for <u>myself or the family</u> (e.g., financial or legal counseling, respite care, counseling, nursing or day care)***	<b>68</b>	19	14

*Note.* Bold numbers indicate this item was in top 10 for this group (or top 5 for ORTHO)

Underlined numbers indicate the item also one of the 10 most important needs for this group

\*significant difference at  $p < .05$ ; \*\* significant difference at  $p < .01$ ; \*\*\* significant difference at  $p < .001$

Table 7 cont.  
Important needs most often rated as “Partly Met” or “Unmet”

Item endorsed	TBI %	DIAB %	ORTHO%
<i>I need to...</i>			
have complete information on the <u>medical care</u> of my child's disorder**	<b>63</b>	<u>14</u>	<u>21</u>
get a break from my problems and responsibilities*	42	<b>57</b>	07
pay attention to my own needs**	26	<b>52</b>	0
help getting over my doubts and fears about my child's future	63	<b>48</b>	21
get enough rest or sleep*	42	<b>48</b>	21
spend time with my friends	32	<b>43</b>	07
have other family members understand my child's problems*	53	<b>43</b>	07
have help from other members of the family in taking care of my child*	16	<b>38</b>	0
have different staff members agree on the best way to help my child*	58	<b>38</b>	14

*Note.* Bold numbers indicate this item was in top 10 for this group (or top 5 for ORTHO)

Underlined numbers indicate the item also one of the 10 most important needs for this group

\*significant difference at  $p < .05$ ; \*\* significant difference at  $p < .01$ ; \*\*\* significant difference at  $p < .001$

Table 7 cont.

Important needs most often rated as “Partly Met” or “Unmet”

Item endorsed	TBI %	DIAB %	ORTHO%
<i>I need to...</i>			
be shown that medical/educational/therapy staff respect my child’s needs	53	<u>19</u>	<b>36</b>
have complete information on my child’s <u>physical problems</u> (e.g., weakness, headaches, dizziness, problems with vision, or waking)	53	24	<b>29</b>
be told if I am making the best possible decisions about my child*	57	24	<b>21</b>

*Note.* Bold numbers indicate this item was in top 10 for this group (or top 5 for ORTHO)

Underlined numbers indicate the item also one of the 10 most important needs for this group

\*significant difference at  $p < .05$ ; \*\* significant difference at  $p < .01$ ; \*\*\* significant difference at  $p < .001$

Because each group endorsed a different number of “Important” needs, a comparison of unmet items was conducted by computing an Unmet Needs percentage (value determined by dividing the number of needs rated as “Unmet” by the number of items rated as “Important).” Table 4 summarizes the means and standard deviations of the proportion of “Unmet” (and Met) needs across groups. The Unmet Needs percentage was then compared across groups using a one-way ANOVA. It had been hypothesized that the TBI group would have fewer needs met relative to the DIAB group. The results of this analysis confirmed a significant group difference in number of “Important” items ranked as “Unmet”,  $F(2,51) = 8.819, p < .001$ . A Tukey HSD Post Hoc analysis further confirmed that the TBI group reported significantly more “Unmet” needs relative to both the DIAB ( $p < .05$ ) and ORTHO groups, ( $p < .001$ ). The “Unmet” needs of the DIAB and ORTHO group were not significantly different ( $p > .05$ ).

#### Analysis of Met Needs

The number of “Important Met” needs was also calculated across the three groups, with the TBI group reporting 9 out of 28 Important needs as “Met”, the DIAB group endorsed 16 (out of 26) items as “Met”, and the ORTHO group endorsed 9 “Met” items (out of 16). A summary of the top items rated as “Met” is presented in Table 8. Four of the TBI’s most “Important” items were rated as “Met”, while eight of the DIAB’s group and five of the ORTHO’s most “Important” needs were “Met”. All three groups reported being satisfied in their needs for honest answers to their questions, and in feeling as though their opinions were considered in the treatment and education of their child. All

three groups also reported the need to receive explanations from professionals in understandable terms was one of their top met needs, however the proportion of the TBI group who endorsed this was significantly lower than the other two groups,  $F(2,51) = 4.01, p < .05$ . A similar pattern was also seen with the need for assurances that their child was receiving the best medical care possible; although all three groups reported this item as being one of their best met needs, the proportion of the TBI group who endorsed this was significantly lower than the other two groups,  $F(2,51) = 10.01, p < .01$ .

Chi-square analyses indicated that the proportion of participants endorsing these needs as met were significantly different for all but 5 out of the 15 items listed in Table 8. Those items rated similarly across groups demonstrated the same proportion of met needs for having received honest questions and information regarding their child's progress, to be shown that their opinions are used in their child's treatment, to have other family members understand how difficult it is for the parent, and to have help in deciding how much independence to allow their child.

A Met Needs percentage was also calculated (number of met needs divided by number of important items) in order to compare the satisfaction of each group. Significant group differences were found using a one-way ANOVA,  $F(2,51) = 8.65, p < .001$ . A Tukey HSD Post Hoc analysis confirmed that the TBI group reported a significantly lower percentage of met needs relative to the DIAB group ( $p < .05$ ) and the ORTHO group ( $p > .001$ ). The DIAB and ORTHO groups did not differ in their percentage of met needs ( $p > .05$ ).

Table 8  
Important needs most frequently rated as “Met”

Item endorsed	TBI %	DIAB %	ORTHO%
<i><b>I need to...</b></i>			
have my questions answered honestly	<b><u>63</u></b>	<b><u>81</u></b>	<b><u>86</u></b>
have information on my child’s therapy or educational progress	<b><u>47</u></b>	<b>62</b>	29
be shown that my opinions are used in planning my child’s treatment, therapies, or education	<b>47</b>	<b><u>71</u></b>	<b>50</b>
have my spouse understand how difficult it is for me*	<b>42</b>	38	0*
explanations from professionals given in terms I can understand*	<b><u>37</u></b>	<b><u>76</u></b>	<b><u>71</u></b>
have other family members understand how difficult it is for me	<b>32</b>	24	0*
have help in deciding how much to let my child do by himself/herself	<b>32</b>	52	29
be assured that the best possible medical care is being given to my child***	<b><u>32</u></b>	<b><u>76</u></b>	<b><u>93</u></b>
be told regularly what is being done with or for my child*	<b>32</b>	62	<b><u>78</u></b>
have complete information on the <u>medical care</u> of my child’s disorder*** (e.g., medications, etc.)	16	<b><u>86</u></b>	21

*Note.* Bold numbers indicate this item was in top 9 for this group (or top 10 for DIAB)

Underlined numbers indicate the item also one of the 10 most important needs for this group

\*item was not ranked as important for this group, so met/unmet not calculated

\*significant difference at  $p < .05$ ; \* significant difference at  $p < .01$ ; \*\*\* significant difference at  $p < .001$

Table 8 cont.  
Important needs most often rated as “Met”

Item endorsed	TBI %	DIAB %	ORTHO%
<i>I need to...</i>			
have a professional to turn to for advice or services when my child needs help***	<u>21</u>	<b>76</b>	<b>36</b>
be told about all changes in my child’s medical status**	26	<b>76</b>	<b>71</b>
be shown that medical, educational, or therapy staff respect my child’s needs or wishes*	32	<b>76</b>	<b>64</b>
have enough resources for <u>my child</u> (e.g., rehabilitation programs, physical therapy, counseling)**	<u>26</u>	<b>62</b>	14
have my child’s teachers understand his/her problems**	<u>11</u>	<b>62</b>	<b>36</b>

*Note.* Bold numbers indicate this item was in top 9 for this group (or top 10 for DIAB)

Underlined numbers indicate the item also one of the 10 most important needs for this group

\*significant difference at  $p < .05$ ;    \* significant difference at  $p < .01$ ;    \*\*\* significant difference at  $p < .001$

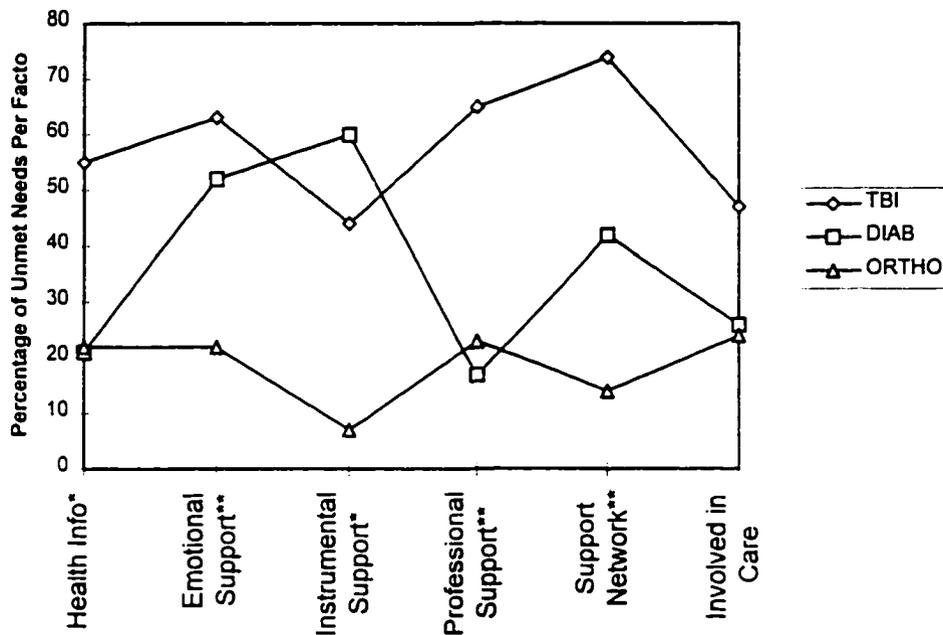
### Analysis of the Pattern of Unmet Needs

In order to assess the pattern of unmet needs across subjects, a profile analysis was performed on the six factor scores: need for health information, need for emotional support, need for instrumental support, need for professional support, need for a support network, and need for involvement with care. The grouping variable was source of child's injury or diagnosis, divided into parents of TBI children, parents of diabetic children, and parents of orthopedic children.

A MANOVA was used for the major analysis. Using Pillai's Trace criterion, the profiles (see Figure 2) deviated significantly from parallelism, indicating differing patterns of profiles across groups,  $F(10,96) = 3.57, p < .001$ . Group differences were also found to be significant,  $F(2,51) = 10.52, p < .001$ .

Group differences for each variable were evaluated using a Tukey HSD analysis. Parents of TBI children reported significantly fewer needs met relative to both the ORTHO and DIAB group on factors measuring Needs for Health Information ( $p < .05$ ), Needs for Professional Support ( $p < .01$ ), and Needs for a Support Network ( $p < .01$ ). The TBI group also reported significantly more unmet needs relative to the ORTHO group on factors measuring Needs for emotional support ( $p < .05$ ), and Needs for Instrumental Support ( $p < .05$ ). The ORTHO and DIAB group only differed on the factor measuring Need for Instrumental support, with the DIAB group having fewer needs met than the ORTHO ( $p < .001$ ).

Figure 2.  
Profile of Unmet Factor Needs by Group



\*significant at  $p < .05$

\*\* significant at  $p < .01$

#### Analysis of Canadian and US TBI Samples

Because the medical systems differ so significantly between the US and Canada, the TBI population for each country was compared across all three hypotheses (See Table 9 for a summary of their mean number of “Important” items, and met and unmet percentages).

An ANOVA measuring the frequency of “Important Items” demonstrated no significant differences between the two,  $F(1,18) = .460, p = .51$ . There were also no significant differences in the number of “Unmet Important” needs,  $F(1,18) = .229, p = .64$ .

Table 9.

Comparison of US and Canadian TBI Participants on Number of "Important" Needs, and Percentage of "Unmet Important" Needs and "Met Important" Needs

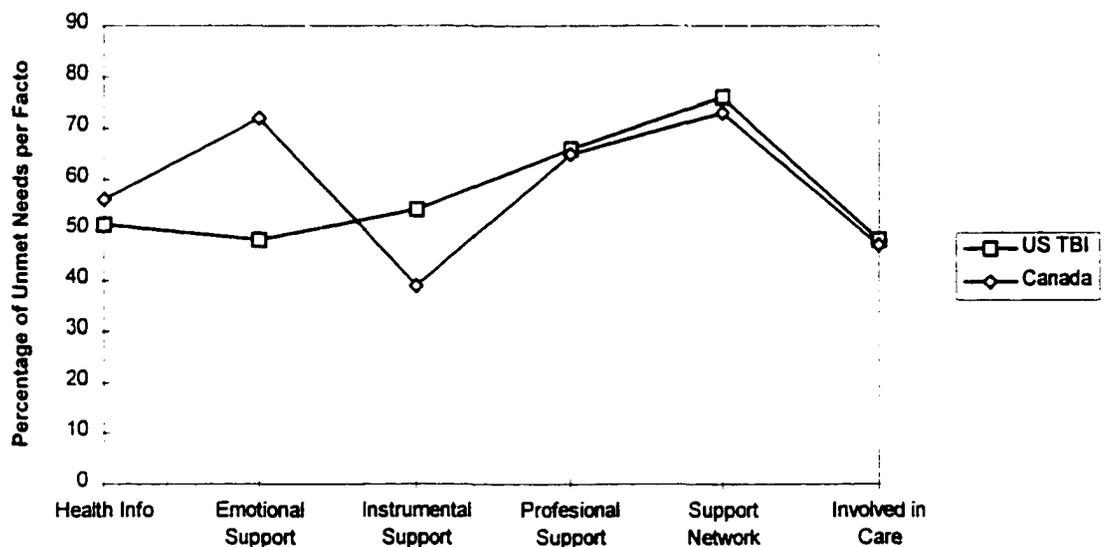
Variable	Group	
	US TBI (n = 7)	Canadian TBI (n = 12)
Number of "Important Needs"	30.29 (7.89)	27.58 (8.63)
Percentage of "Unmet Important" Needs	66.67 (17.68)	66.27 (27.66)
Percentage of "Met Important" Needs	39.33 (17.68)	33.46 (27.71)

Note. TBI = traumatic brain injury

The pattern of unmet needs was again assessed using a profile analysis on all six factors. Using Pillai's Trace criterion, the profiles (see Figure 3) deviated significantly from parallelism, indicating slightly different overall profiles,  $F(5,13) = 3.30, p < .05$ , but there were no significant group differences,  $F(1,17) = .018, p = .89$ .

Figure 3.

Profile of Unmet Needs for Canadian and US TBI groups



## Discussion

A review of family functioning following pediatric TBI clearly demonstrates that parents experience prolonged emotional difficulties while trying to cope with their child's injuries and their subsequent behavioral and cognitive sequelae. This finding is especially concerning because of recent evidence that family functioning is a significant mediator in the recovery of the child's functional outcome. Given the considerable difficulties these parents face, and their roles in the child's recovery, interventions that are developed based upon parents' self-reported needs may prove especially useful for both the patient and his or her parents. Previous literature concerning family needs has investigated the self-reported needs of families of adult patients both during the acute stages and the post-acute stages, however, there have been no pediatric studies which have examined parents' needs after the first year of recovery. Consequently, this study endeavored to examine the needs of TBI parents a year or more after injury in order to evaluate what needs had been met and which needs are still unfulfilled and may be amenable to treatment interventions.

The typical medical model for the treatment of TBI patients involves extensive medical interventions during the acute stages of recovery, but over time there is a withdrawal of resources. Diabetes, however, is seen medically as a chronic condition, and families typically receive extensive services from the time the child is diagnosed until the time the child reaches adulthood. In order to better apply the results of this study to clinical intervention models, TBI parents were, therefore, compared with DIAB parents in order to assess whether the traditional medical models for these diagnoses had

any impact on the number of met needs the participants reported. An ORTHO control group was also evaluated in order to assess whether type of injury or diagnosis also contributes to the needs of parents.

Three specific hypotheses about TBI parent needs had been postulated. First, it was believed that TBI parents would report a similar number of needs as being “Important” relative to the DIAB parents, but that both groups would endorse significantly more “Important” needs than the ORTHO group. Second, it was postulated that the TBI group would have significantly more “Unmet Important” needs relative to both control groups. Finally, it was hypothesized that the TBI group would specifically endorse more “Unmet” needs for emotional and professional support relative to both control groups.

#### Comparison of US and Canadian TBI Samples

Before the results of each hypotheses are summarized and discussed, the differences between the US and Canadian TBI samples will be addressed. This is of some importance, since access to medical care is significantly different between these two countries. Therefore, if medical systems affect parents’ needs, then any differences among the two head-injured groups would be expected to influence the greater analyses. Furthermore, if found, such differences would suggest that the sampling methods for the DIAB and ORTHO groups might also have resulted in some confounding data (recall that the DIAB group was obtained from a Canadian Hospital, while the ORTHO group was gathered in the US).

In addition to the inherent differences in medical systems, the US and Canadian TBI samples also demonstrated differences in some demographic variables. More specifically, the US TBI children had significantly longer hospital stays, and consisted of a greater proportion of moderate-severe TBI's relative to the Canadian sample. On the other hand, Canadian participants were more likely to be single parents, and while not significant, there was a trend for longer times post-injury relative to the US sample. Surprisingly, despite the demographic and medical system differences, there were no significant differences between these groups on any of the analyses performed for this dissertation. Based on the lack of any findings between these two groups, it is likely that the country of origin for each group is not a contributing factor to the results obtained and described below. These results also suggest that family needs (both those rated as important and those *remaining unmet*) following pediatric TBI may remain fairly constant regardless of the severity of the child's injury or initial trauma. Number of parents in the home also does not appear to influence reported family needs. Of further interest, is the suggestion that even an extended time post injury may not improve the overall met needs of TBI families once the acute period of recovery is passed.

#### Hypothesis I: Number of "Important Items"

Consistent with the proposed hypothesis, these findings indicated that the TBI and DIAB parents reported significantly more needs as being important relative to ORTHO parents. In fact, while the ORTHO group endorsed only 35% of the items as "Important," the TBI and DIAB groups endorsed nearly twice as many "Important" items (TBI = 70%;

DIAB = 65%). This proportion of needs for the TBI group is similar to those seen in the adult literature. For example, Witol et al (1996) also showed that in the year post-injury her families endorsed 67% of the items as being important. This supports the idea that regardless of the age of the patient, family members of all TBI patients continue to report a high proportion of needs following the first year post-injury.

When examining the top needs across all three groups, some patterns become evident. First, it appears that all parents (regardless of their child's injury/illness) place special emphasis on receiving honest answers and understandable explanations from professionals. They also desire assurances that their child is receiving the best possible medical care, and that they have professionals to turn to when their child needs help. However, it is of some interest that the proportion of ORTHO participants who endorsed the need to have access to professionals for advice or support was significantly smaller than those parents in the TBI and DIAB group. This example represents another common pattern in these results; it appears that of those needs listed as important, a greater proportion of participants in the TBI and DIAB groups endorsed each of these items compared to the ORTHO parents. More specifically, when examining the top 10 items rated as important by either the TBI or DIAB groups, it is notable that at least 85% or more of the participants endorsed each item as important. Within the top 10 items of the ORTHO group, however, 4 of the 10 items were endorsed by fewer than 75% of the participants (three of these being below 55%). Therefore, there appears to be a greater consistency of needs within the populations of TBI and DIAB parents while the parents of ORTHO children tend to have a greater variability in their perceived needs.

An examination of the pattern of needs by factor scores demonstrated no differences between groups in terms of their need to feel involved in their child's medical care; this appears to be a consistently important factor regardless of a child's medical condition. The ORTHO group, however, endorsed fewer items than the TBI and DIAB group on most of the other factors (the only exception being that there is no difference between the TBI and ORTHO group for needs for Instrumental Support). This is not surprising given the generally lower number of endorsed needs, however, it lends credence to the hypothesis that the needs of ORTHO parents after the acute recovery of their child's injuries, are relatively low compared to parents of children with chronic difficulties.

While the TBI and DIAB groups endorsed many similar needs, they are, nonetheless, different in one important area: TBI parents reported a significantly greater need for Professional support relative to DIAB parents (although DIAB parents still reported greater needs in this area relative to ORTHO parents). Given that this factor includes questions that would not likely apply to children with diabetes (i.e., to be told how long will my child's problems last (parents understand this is a life-long condition), and to be shown what to do when my child is upset or acting strange) this difference makes intuitive sense.

#### Hypothesis IIa: Number of Unmet Needs

The results of this study confirmed that TBI parents have a greater proportion of unmet needs relative to both DIAB and ORTHO parents. In fact, while TBI parents

reported that 64% of those items rated as “Important” were still unmet, DIAB and ORTHO parents reported far fewer unmet needs (40% and 25% respectively). These results indicate that the majority of the TBI parents’ needs remained unmet as long as 3 years post-injury. Of further concern, is that once again, TBI parents are more consistent in reporting unmet needs relative to ORTHO parents, and even DIAB parents. Thus, while over 65% of TBI parents agreed upon 9 of the top 10 unmet needs, significantly fewer parents in the other two groups agreed upon their unmet items. In fact, less than half of the DIAB parents agreed on 8 of their top 10 unmet items, and even fewer in the ORTHO group consistently endorsed items as being unmet (36% or fewer of the population agreed on unmet needs). Therefore, TBI parents more consistently report unmet needs compared to the other two groups.

An examination of specific unmet needs indicates that TBI parents are reporting persisting difficulties in several areas. First, they report a desire to have their child’s teachers and peers understand their child’s problems. They are also concerned about having enough resources for their child and their family. Of considerable concern, is their unmet need for professionals to turn to when needed, and for gaining a clear understanding of their child’s problems and medical care. Finally, these parents report that they have not yet been able to discuss their feelings with others who have gone through similar experiences, nor have they been able to receive help to remain hopeful about their child’s future.

These last two unmet needs are of some interest, given that the only study to examine support groups designed to offer a supportive environment for sharing their

concerns and fears (Singer et al., 1994) found that providing this kind of intervention did not help in alleviating parents' levels of depression or anxiety. It may be that providing this environment is not sufficient for improving mood, and that parents' other needs would also have to be met in order to improve their general psychological functioning. This is an important consideration to keep in mind for the development of specific interventions for these parents, as it suggests that more active educational interventions may also be necessary for improving parents' overall level of functioning.

#### Hypothesis IIb: Number of Met Needs

Given that there was a significant difference in unmet needs, there are of course also differences in met needs across the three groups. While greater than half of the items rated as "Important" were met for both the DIAB and ORTHO groups (DIAB = 60%; ORTHO = 75%), only 36% of the TBI parents needs were reported as met. Despite the difference in the proportion of met needs, all three groups reported that they have received honest answers to their questions, and that their opinions have been respected in regards to the treatment and education of their children. While all groups also listed met needs for receiving explanations from professionals, and having been assured that their child was receiving the best medical care, the proportion of TBI parents who agreed these needs were met, was significantly lower than the proportion of DIAB and ORTHO parents. In fact, while over 75% of both the DIAB and ORTHO parents endorsed these items, less than 40% of the TBI parents found these needs had been met. Of further interest is that on nearly every item of the "top met needs", less than 50% of the TBI

parents agreed that these needs had been met (the one exception being that 63% of the parents felt they had received honest answers to their questions). Therefore, it may be misleading to suggest that 36% of the TBI parents' needs have been met, since half of the TBI parents do not agree with this report. Implications for these unmet needs will be discussed below.

### Hypothesis III: Pattern of Unmet Needs

TBI parents reported more unmet needs across three of the factors relative to both the DIAB and the ORTHO parents. Specifically, TBI parents reported more unmet needs in Factors measuring a need for Health Information, Professional Support, and Community Support Networks. What is striking is that this finding occurs despite the fact that both the TBI and DIAB parents agreed on the same number of important needs in each factor, it is just that the DIAB parents are apparently having their needs met more sufficiently. Thus, it appears that while the DIAB (and ORTHO) population(s) appear to have a solid understanding of their child's medical conditions, TBI parents are lacking this information even 3 years post-injury. Perhaps as an underlying feature of this, TBI parents also report a feeling as though professional resources, advice, and information have not been available to them. Whether or not this is a reality or the parents' perceptions was not addressed in this study.

The finding that TBI parents report a substantial number of unmet health and medical needs is a striking finding, because this differs significantly from literature for families of adult TBI patients. Previous studies which have investigated the needs of

family members 2 or more years post injury have concluded repeatedly, that health and medical needs are the items most often identified as *met* for family members. In fact, these studies even reported that medical needs were generally the *best met* needs for their participants (Kreutzer et al., Serio et al., Witol et al.). This difference may be representative of the fact that a child's recovery from TBI is not characterized by a return to pre-morbid functioning. Rather, recovery for children means meeting developmental milestones and acquiring new intellectual and behavioral skills as they age. When this does not occur, then parents may develop increased anxiety, confusion, and questions regarding their child's condition and expectations for the child's future. If they do not have the appropriate resources to help them answer their questions, parents would be expected to demonstrate increased questions about their child's functioning rather than decreased as these results have suggested. These findings are also a strong reminder of the fact that generalizing adult findings to pediatric conditions is not always appropriate.

Contrary to the prediction, TBI parents did not differ from DIAB (or ORTHO) parents in terms of their proportion of unmet needs for Emotional support. Unmet needs for this factor was high for both groups, suggesting that the resources that have helped the DIAB population meet their other needs does not impact their ability to satisfy their needs for emotional support.

### Limitations of study

In drawing conclusions about the meaning of these results, certain limitations must first be addressed. While the majority of the hypotheses of this study were in fact

confirmed, the actual reasons for TBI parents' unmet needs cannot be ascertained.

Without specific knowledge regarding what resources the TBI parents have used since the first year post-injury, it is unclear whether these results reflect services that are not providing the specific needs of families, or whether these families have not made use of available services over this time frame. Furthermore, even if these results do in fact reflect less involvement with the professional community, it would still be unclear if this is because the resources are unavailable, or if the TBI parents are not accessing what is in the community.

Future studies should, therefore, endeavor to investigate several factors in order to more clearly delineate why TBI parents are still reporting such a large degree of unmet needs. Several possibilities present themselves. First, it may be (as postulated) that once children recover from the post-acute sequelae from their head injury they are no longer followed by rehabilitation professionals, and parents do not have any resources to turn to. On the other hand, it may be that parents are still receiving services well past the post-acute period, but that these services are not adequately meeting their needs. Finally, it may also be possible that while services are available in the community, parents do not take advantage of them, perhaps because of a lack of awareness of these facilities, because previous experiences with these facilities were not helpful, because they are overwhelmed by the time and effort required to take advantage of these resources, or because of some other factors which are presently unclear.

A study aiming to answer these questions should again assess family needs, but then include variables investigating the specific use of rehabilitation professionals.

Specifically, it would be important to ascertain what professionals parents have seen (e.g., physical therapists, occupational therapists, counselors, etc), when and how often they saw them, and how useful they found these services to be. It would also be important to know how parents accessed these professionals. For example, did they have to actively seek them out independently, or did other professionals (e.g., during the post-acute period) help to arrange the resources either directly (e.g., follow-up appointments) or by recommendation. If parents have not used other community resources since the first year post-injury, it would need to be determined whether that is because there are none, or whether parents are not utilizing what is available in the community. If the latter aspect is true, then research would need to determine why parents are not hooked up to resources that are there to provide for them. Pairing these findings with an analysis of met and unmet needs could be of considerable assistance in the development of new intervention programs, or in the modification of intervention programs which may already be in the community.

Sampling limitations are also an important consideration in drawing any conclusions from these results. Despite mailing out over 160 questionnaires to the ORTHO population, only sixteen were returned. Therefore representativeness of this population is in question. One possibility for such a poor return rate is reflected by comments made by those who did respond; several participants reported that these questionnaires did not seem to pertain to them or their situation, because their children had made complete recoveries, and there were no persisting consequences from their injuries. One letter was even sent by a mother indicating she felt her responses would not

be useful. Consequently, she sent the uncompleted questionnaire back so that it could be sent to someone who's answers "would be useful." If this hypothesis is correct, then the sample received would still likely represent the greater population. If, however, the sample size was limited for other reasons, then generalizability is in question.

Another sampling limitation was that in order to collect the orthopedic sample, participants had to be drawn from the United States rather than from Canada (as the diabetic population was). This poses the possibility that the differences found may be due, in part, to different medical systems or cultural biases. As an attempt to account for this, the TBI population was drawn from both countries. Analyses comparing the two TBI populations were then made to ascertain what impact citizenship may have contributed. Comparisons of these two groups did not indicate any significant differences, however, given the relatively small size of the TBI sample (especially when broken down into country of origin), important differences may not have been observable.

Finally, sampling limitations may also have arisen by including parents of a wide range of ages (aged 4 – 18). Adolescent children (and their parents) are, of course, faced with different challenges and dilemmas than children in elementary school. Clumping these children into one inclusive group would have made it difficult to recognize patterns of needs which may be unique to the parents of specific age groups.

### Summary, Conclusions, and Suggestions for Future Research

For all intents and purposes, this research is best considered as a pilot study.

Further investigations with larger sample sizes (and without confounds of samples from different countries) need to be conducted in order to confirm the findings reported herein. Samples should also be collected based on patient age groups in order to assess the unique needs of parents during different developmental stages. Furthermore, future studies should look at the availability of resources in the community, the frequency of which they used these services, and the parents' sense of how adequately they felt their needs were met. This would be useful for determining where changes in intervention may be most useful, and in order to be able to make clear conclusions about the meaning of unmet needs.

Given the caveats noted above, several conclusions can still be drawn from this study. Specifically, parents of TBI children do appear to report a significantly greater degree of important needs relative to ORTHO parents. Tragically, they report that the majority of their needs remain unmet even 3 years post-injury. The fact that they rate the same number of important items as DIAB parents, but then report fewer met needs may have important implications for rehabilitation professionals. For reasons which need to be further investigated, TBI parents are not currently having their needs met by the medical community. These differences should be investigated further so as to adapt the TBI medical model to better fit the TBI parents' needs. Regardless of the resources used by or available to the TBI population, these results could also still be useful for future studies interested in providing support groups for families. It would be of considerable

interest to determine whether brief psycho-educational groups focusing on these factors could be useful to TBI parents.

Observations about the differences among the three groups can also be used to rule out some explanations for the TBI's increased number of unmet needs. For example, ORTHO parents who are past the acute recovery of their child appear to have significantly fewer unmet needs relative to both DIAB and TBI parents. This suggests that having a child who suffers from a traumatic injury is not sufficient enough to disrupt parental adjustment or functioning. Furthermore, the chronic nature of a child's new disease or injury also does not appear to be solely predictive for increased unmet needs, since DIAB parents have been able to satisfy the majority of their needs. It would be interesting to investigate this further by evaluating whether it is in fact the services that the DIAB parents receive that make them more satisfied, or whether there are other characteristics unique to a child's disorder that makes this difference. If it becomes apparent that the services provided are in fact the deciding factor, a model of treatment for TBI based on DIAB services may prove to be useful.

Finally, it is also of some importance to note that parents of pediatric TBI differ from parents of adult TBI in that they have increasing needs for medical information over time. This may reflect the growing need of parents to understand and plan for the cognitive limitations of their child. As children get older, it is natural for parents to begin planning for their child's future. However, when they do not have enough information about their child's functioning or future expectations for development and achievement parents may experience increasing concern and hopelessness when they consider what is

to become of their child. Often the results from the adult TBI literature are applied to pediatric TBI, assuming the results should be similar. The results from this study strongly suggest the need to conduct further research on the family needs of pediatric TBI, as there appear to be some unique characteristics which could significantly alter the approach for useful interventions.

## Appendix A

The following information will further help us to understand what types of factors affect the families of parents with acquired injuries and chronic illnesses, and how we can best help them. Please type or print your answers below.

Your relationship to the child (e.g., mother, father) \_\_\_\_\_

Your occupation \_\_\_\_\_ Spouse's occupation \_\_\_\_\_

Child's date of birth (mm/dd/yr) \_\_\_\_\_

Please indicate the date of your child's injury or diagnosis of his/her illness \_\_\_\_\_

Child is presently living with:

\_\_\_\_ Natural Mother      \_\_\_\_ Natural Father      \_\_\_\_ Stepmother      \_\_\_\_ Stepfather  
\_\_\_\_ Brother(s) or Sister(s) (please indicate how many) \_\_\_\_\_  
\_\_\_\_ Other (Specify) \_\_\_\_\_

Child's current grade \_\_\_\_\_

Does your child receive any form of learning assistance? \_\_\_\_ Yes \_\_\_\_ No  
If yes, is it to help your child because of his or her injury or illness? \_\_\_\_ Yes \_\_\_\_ No

If your child was injured please indicate below what caused the injury:

\_\_\_\_ Sports accident      \_\_\_\_ Pedestrian accident      \_\_\_\_ Bicycle accident  
\_\_\_\_ Pedestrian or Motor vehicle accident      \_\_\_\_ Fall  
\_\_\_\_ Other (please explain) \_\_\_\_\_

If your child was injured:

Did he/she lose consciousness? \_\_\_\_ Yes \_\_\_\_ No      If yes, how long \_\_\_\_\_  
Was he/she in a coma? \_\_\_\_ Yes \_\_\_\_ No      If yes, how long \_\_\_\_\_

Are you involved in litigation for the cause of your child's injury? \_\_\_\_ Yes \_\_\_\_ No

Was your child hospitalized for this accident or at the time of his/her diagnosis? \_\_\_\_ Yes \_\_\_\_ No  
If so, how long \_\_\_\_\_

Please indicate if your child has had or been diagnosed with any of the following:

\_\_\_\_ Operations (if yes, please indicate for what \_\_\_\_\_)  
\_\_\_\_ Hospitalization for illness (if yes, for what \_\_\_\_\_)  
\_\_\_\_ Convulsions/Seizures      with fever \_\_\_\_      without fever \_\_\_\_  
\_\_\_\_ Tics (i.e., eye blinking, sniffing, any repetitive, non-purposeful movements)  
\_\_\_\_ Depression

- Anxiety disorders
- Attention deficit-hyperactivity disorder (ADHD)
- Eating disorder
- Significant emotional difficulties
- Other (please explain)

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