The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

University of Cape Town

Families of Children with Traumatic Brain Injuries:

Stressors and needs in the South African context

Deirdre Oosthuizen - OSTDEI001

A minor dissertation submitted in partial fulfilment of the requirements for the award of the degree of Master of Arts (MA) in Psychological Research

Faculty of Humanities
University of Cape Town
2010

University of Cape Town

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Date:

ACKNOWLEDGEMENTS

First, and foremostly, to My Lord and Saviour Jesus Christ without whom this dissertation would not have been possible.

Thank you to my parents, sister, and the rest of my family for their constant support and love throughout this project.

To my many wonderful friends and homegroup for their support, encouragement, and many prayers.

Dr. Kevin G. F. Thomas: Supervisor of this project. A truly sincere thank you for all of his time, effort, and his guidance on this project.

Leigh Schrieff: PhD candidate and Co-Supervisor. A huge thank you to Leigh for all her support, and guidance on this project. It has been truly appreciated.

Scholarships: Harry Crossley Foundation PG scholarship, Sylvia Gavron Psychology scholarship, Ernst & Ethel Eriksen Trust, and University Research Scholarship. My sincerest thanks to these schorlarships for their financial assistance.

University of Cape Town

TABLE OF CONTENTS

University of Cape Town

University of Cape Town

University of Cape Town

University of Cape Town

University of Cape Town

LIST OF FIGURES

LIST OF TABLES

University of Cape Town

University of Cape Town

Abstract

Background. The effects of a traumatic brain injury (TBI) can be devastating not only for the child that sustains the injury but also for his or her family. A TBI can negatively affect a child cognitively, emotionally, and behaviourally. In developing countries such as South Africa these negative effects of TBI are often compounded by the impact of other health crises such as HIV/AIDS, as well as by the existence of relatively few economic resources and a lack of rehabilitation services. Injury-related consequences, further compounded by developing world contexts, seem to suggest that families of children with TBI have many stressors and strains that need to be addressed. *Aims.* The current study sought to explore the needs and stressors of caregivers of children with TBI, and how local contextual factors contribute to those needs and stressors. *Methods.* The sample consisted of four groups (n = 18 caregivers in each). These four groups included parents/caregivers who cared for a child with either a mild head injury, a moderate/severe head injury, or an orthopaedic injury, and a control group of caregivers with healthy children. The Parenting Stress Index, Family Burden of Injury Interview, and Family Needs Questionnaire were administered to each participant. *Results.* South African caregivers of children with TBIs are critically stressed. Much of their stress is related to the child's behaviour and ways of relating to their caregiver. Caregivers in the Moderate/Severe TBI group reported experiencing particular difficulty with their own reactions to the injury, and reported feeling depressed and incompetent, as well as isolated and restricted by their role as parent. Caregivers also reported experiencing a need for health information, professional support, community support, involvement in the child's care, and emotional support. They reported, however, that few of these needs were being met. Results also showed that South African caregivers of children with TBI displayed more stressors and needs than similar samples in developed countries. *Conclusions.* We suggest that a better understanding of the experience of families of children with TBIs is needed amongst TBI

University of Cape Town

service providers. It is hoped that this study's results will aid that understanding, and that they will provide information for policy makers who can set into motion a sequence of services that more adequately aid both the child with TBI and his/her family.

Keywords: traumatic brain injury, acquired brain injury, pediatric TBI, cross-cultural TBI, families, stress.

University of Cape Town

Introduction

Participants in the Task Force for Children and Adolescents at the International Brain Injury's Association's 2003 conference concurred that "issues for children after TBI continue to be problematic in hospital, home, school, and community" (Savage, DePompei., Tyler, & Lash 2005, p. 92). In South Africa, head injuries are one of the main contributors to childhood mortality and morbidity (Lalloo & van As, 2004). When a child sustains a traumatic brain injury (TBI), there may be a number of negative sequelae, including cognitive dysfunction and emotional and behavioural difficulties (Vanderploeg, 2000).

These TBI-related cognitive, emotional, and behavioural impairments affect not only the injured child, but also his/her family. Families have to deal with a number of emotional, financial, and adaptational stressors as a result of the injury (Watanabe, Shiel, McLellan, Kurihara, & Hayashi, 2001). Prigatano and Gray (2007) showed that families of children who have sustained a TBI have a need for professional services and support in order to cope with the situation; not having these services places an enormous amount of strain on them

Unfortunately, despite the consequences of TBI for the affected child and his/her family, and the similarly clear need for community and professional services in helping families to cope, South African research into pediatric TBI, and the impact on affected families, is scarce. Additionally, dedicated paediatric rehabilitation units in South Africa are limited (Levin, 2004). Placed especially within the context of a country affected by a poor socioeconomic situation, such a lack of information and services adds negatively to the stresses and strains of caring for a child with TBI.

Rationale for the Current Study

This study explored families' experiences of having a child with a TBI, framed within the unique context of South Africa. The sudden occurrence of brain injuries, and the often

University of Cape Town

uncertain associated effects and course of the injury, puts families in an unfamiliar situation. Therefore, as discussed above and as evidenced by experiences in developed countries, high-quality health care services (including neuropsychological rehabilitation) are necessary to support affected children and their families. It is important to note, however, that although the experience of TBI in a developing country like South Africa may be similar to the experience of TBI in developed countries (from which most of the literature emanates), the degree of stress and the amount of need experienced by families in developing as contrasted with developed countries may be vastly different.

Developing countries, by definition, have fewer economic resources than developed countries, and consequently (a) the children of those countries are at higher risk for diseases such as HIV/AIDS and tuberculosis, in addition to their TBI, and (b) have health services that do not provide the full range of services needed by children with TBI and their families. Therefore, in considering the impact of the injury on the child and his/her family, one requires an understanding of the local context, as this is likely to affect the child and family's outcomes.

University of Cape Town

Although injury severity is vitally related to outcome directly after the insult, research suggests that psychosocial factors become increasingly important over time post-injury (Anderson, Catroppa, Haritou, Morse, Rosenfeld, 2005). These factors include family function, social support, stimulation level available to the child, and access to resources; these all impact on the process and success of the child's recovery (Aylward, 1997; Taylor, Wade, Yeates, Klein, & Stancin, 1999; Taylor et al., 2002). When negative psychosocial factors occur concurrently with biological complexities, the literature suggests that the child will experience a "double hazard". Hence, for instance, children with a TBI (or other cerebral insult) who emerge from disadvantaged backgrounds are likely to experience a slower rate of recovery and greater impairment than children from better-resourced backgrounds (Breslau, 1990; Taylor & Alden, 1997; Anderson, Catroppa, Haritou et al., 2005; Schwartz et al., 2003; Taylor et al., 2002). This is the case for children who have a lower socioeconomic status (SES) because they are already in a situation that is more likely than their higher SES counterparts to be emotionally and financially stressed. The injury might then add significantly to this already difficult environment. Parents may therefore not be able to adequately provide the resources or support that affected low SES children need. The implication of one's environment having an influence on recovery makes a strong case for the importance of appropriate family and child intervention as well as rehabilitation programs, especially in the context of a developing country.

Better informed assessment and rehabilitation techniques assist the child toward more effective recovery. They not only assist the child, but better informed assessment and rehabilitation techniques also assist the family by addressing more of their needs and therefore decreasing their stress levels. A child who is effectively rehabilitated, and who is therefore more able to deal with his/her difficulties, is more likely to be able to make positive contributions to society in the future. The reason for this increased likelihood is that the effectively rehabilitated child will be less dependent on other people, and will be more likely to attain career, relationship, and other life goals. This independence adds value and esteem to the affected individuals' life. The family too is then better able to contribute to society as their concern for their child's future is decreased, as is the potential financial burden of caring for an unemployed person.

To date, there is little developing-world research on the experiences of families and family systems of children with TBI. This study therefore aimed to fill the current literature gap. More specifically, I aimed to explore the stressors and needs of caregivers, and to what extent these needs have been met. I also aimed to explore whether these stressors and needs are injury and/or severity related. I did this by comparing self-reports of participants in four

University of Cape Town

groups: (a) Moderate/Severe TBI; (b) Mild TBI; (c) Orthopedic Injury; and (d) Healthy Control. Hence, I attempted to answer the question of whether having a TBI, as opposed to an orthopedic injury, increased caregivers stressors and needs. I also attempted to answer the question of whether it is the case that the more severe the child's TBI, the more stressors will be experienced by the family. Lastly, I explored whether these TBI-related stressors and needs are similar or worse than those found in developed world countries.

This study finds its relevance not only in the additional understanding it can provide of families' experiences of having children with TBI: To date, there is little developing-world research on the experiences of families and family systems of children with TBI. This study also finds its relevance in the additional understanding it can provide of families' experiences of having children with TBI in a developing world context. More broadly, its findings can be used in the upsurge of brain research in South Africa, which, one hopes, has as one of its major goals the establishment of a larger number of dedicated neuropsychological rehabilitation services. The results of this research will also help inform governmental policies regarding children affected by TBI. As an end goal, I hope the findings will contribute to research programmes that seek to increase the quality of life of many TBI-affected South African children, and their families.

University of Cape Town

Literature Review

This literature review will focus on the psychosocial, as well as physical and neuropsychological, effects of TBI on affected children and their families. Most studies reviewed here emerge from developed countries. One justification for reviewing this literature as background to a South African study is that there is evidence that the effects and impact of TBI on injured children and their families is fairly similar across cultures (Al-Adawi et al., 2004; Simpson, Mohr, & Redman, 2000). Although as suggested above, the degree of stress and extent of children and family needs across cultures may vary vastly. The majority of research on the psychosocial impact of the injury in the child and family was conducted from 1991 to 2003, and therefore most of the literature in the psychosocial area will come from this time period. More recent international research focuses on pre-injury predictors of child injury and family outcomes, on family coping strategies, and on the most effective family interventions post-TBI.

Pediatric Traumatic Brain Injury

The term *traumatic brain injury* refers to a "traumatic insult to the brain, capable of producing brain damage and associated with functional impairment" (Anderson, Northam, Hendy, & Wrennall, 2001, p. 129). Although the terms *head injury* and *TBI* are often used interchangeably by researchers, it is more accurate to distinguish between the two: a head injury indicates a trauma to the head, and does not necessarily indicate a trauma to the brain as well (Bruns Jr. & Hauser, 2003).

TBIs are classified as either 'open' or 'closed', depending on whether the skull is penetrated or not. Closed head injuries account for the majority (about 90%) of pediatric TBIs (Anderson et al., 2001). Such injuries cause the brain to be shaken forward and backward and rotated, resulting in diffuse axonal injury (DAI). Motor vehicle accidents often lead to this kind of damage. A DAI can lead to "neural tearing throughout deep cerebral structures, particularly at the junctions between grey and white matter, including the area around the basal ganglia, hypothalamus, cerebellum and brain stem, corpus callosum, and frontal and temporal poles" (Amacher, 1988; Anderson et al., 2001, pp. 132; Gale, Johnson, Bigler, & Blatter, 1995). In pediatric TBI, because the child's brain is still developing, it might therefore be more vulnerable to the long-term neuropsychological sequelae that may result from such an insult (Baxter, Cohen, & Ylvisaker, 1985; Hessen, Nestvold, & Anderson,

University of Cape Town

2007).

Epidemiology of TBI. The prevalence of TBI in South Africa has not been well documented, with pediatric statistics even more scarce than those of TBI injured adults. However, one study by Nell & Brown (1990) did find that the incidence of TBI in South Africa is higher than that of most other countries, with an estimated 316 people per 100 000 locally versus an average of 200 (range: 150-375) per 100 000 people worldwide sustaining TBIs (Nell & Brown, 1990). With specific regard to pediatric TBI, Kibel, Bass, and Cywes (1990) found that 28 % of children admitted, over a 5-year period, to the Red Cross War Memorial Children's Hospital (RXH) trauma unit in Cape Town presented as a result of a head injury. Therefore, a large number of South Africans are likely to incur injuries of this nature in their childhood (Levin, 2004).

South African researchers Nell and Brown (1990) estimated, based on random sampling of 1.5 million Johannesburg magisterial district residents across eight catchment hospitals, that of those over the age of 15 years who sustain a TBI, 87.5% present with mild TBI, 7.9% with moderate TBI, and 4.6% with severe TBI (see Appendix A for how severity of injury is typically measured). This trend is similar in the pediatric population: A recent epidemiological study based at RXH reviewed 2093 cases of pediatric TBI over a 2-year period (Miller & Stander, 2009). This study reported a severity distribution of 91% mild TBI, 4% moderate TBI, 3% severe TBI, and 2% of unknown severity. These data indicate that although most children do not sustain severe traumatic brain injuries, a significant number do. Those individuals will therefore be permanently and quite acutely affected by their injuries. Additionally, Miller and Stander (2009) found that the incidence rate of TBI is highest in younger children (56.8% amongst children aged 0-4 years), and that this incidence rate decreases with age to 28.5% amongst children aged 5-8 years, and 14.7% amongst children aged 9-12 years.

University of Cape Town

Impact of TBI on the developing brain. The developing brain continues to mature until around early adolescence. This process involves the elaboration of the central nervous system (CNS), especially with regard to myelination, synaptogenesis, and dendritic arborisation (Reiss, Abrams, Singer, Ross, & Denckla, 1996). These processes are involved in the development of interconnections between systems and the functioning of cerebral systems. Although synaptic processes seem relatively immune to environmental influences, it has been suggested that myelination and dendritic development are quite vulnerable to the impact of environmental stimulation or deprivation (Goldman-Rakic, Bourgeois, & Rakic, 1997). Neuropsychological research shows that disruption to myelination can result in reduced attention, slowed response speed, and generally impaired information-processing capacity (Van der Knaap et al., 1991). In addition, disruption to, or environmentally-based deprivation of, dendritic development can lead to more non-specific, as opposed to experience-specific, dendritic branch growth , thus possibly resulting in less effective learning in certain contexts (Kolb, 1995; Kolb, Forgie, Gibb, Gorny, & Rowntree, 1998; Kolb & Gibb, 1999).

Rather than developing in a simple linear fashion, CNS development is complex. Various functions and processes develop simultaneously in the maturing brain. This kind of development means that although these processes are developing simultaneously, their development differs, and there are therefore differing critical or 'sensitive' periods for differing processes and areas of the brain. Interruption during one of these sensitive periods may halt development or lead to a change in the course of development.

Plasticity versus vulnerability in the developing brain. The long-term outcome of early cerebral damage is controversial; there has been great debate in the literature as to whether the brain is more 'plastic' in childhood or more vulnerable (see, e.g., Anderson et al., 2001, Anderson et al., 2009). Those in favour of plasticity theories suggest that the child's

University of Cape Town

brain is better able to recover function as time goes on post-recovery, because the developing brain is more able to transfer functions from damaged to non-damaged cerebral sites after insult (Huttenlocher & Dabholkar, 1997; Kennard, 1936, 1940). This ability to reorganise is thought to explain why similar cerebral insults can have a less severe impact on children's cerebral functioning than on adult cerebral functioning.

In contrast, early vulnerability theories hypothesize that the earlier the insult, the more detrimental the consequences, especially on development. Hebb (1949) was one of the major proponents of this theory. He suggested that a cerebral insult can lead to irreversible loss of function if the brain is damaged in a region that is undergoing a critical stage of development (see also Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005; Anderson et al., 2001; Kolb, 1995). Empirical research suggests that a further problem may be that the full extent of the deficit may only be seen in the long term. This latent effect may be the result of a deficit in one region having a cumulative effect on the child's cognitive development, with the impact becoming more noticeable as the brain matures and takes on more functions (Brenner et al., 2007; Milner, 1974). In support of early vulnerability studies, a number of studies show that early cerebral impairment has long-term negative implications on the child's abilities to acquire knowledge and skills, such as learning and executive function (Anderson, Catroppa, Morse, et al., 2005; Anderson, Godber, Smibert, & Ekert, 1997; Ewing-Cobbs et al., 1997; Wrightson, McGinn, & Gronwall, 1995).

Contemporary research suggests, however, that perhaps neither plasticity theory nor vulnerability theory is completely wrong or completely right, but that each instead represents opposite extremes along a continuum (Lesser & Kaplan, 1994). More specifically, there is the suggestion that plasticity and vulnerability coexist, and that both have an influence on the consequences of the child's injury (Chapman & McKinnon, 2000). This assertion would suggest that the child's outcomes are determined by the interaction of a number of factors,

University of Cape Town

such as the nature of the lesion, age at onset, environmental factors, and so on. The impact of environmental factors on the outcomes of the injury will be discussed further below.

Neuropsychological sequelae of pediatric TBI. There may be numerous post-TBI neuropsychological impairments, with the extent of those impairments depending on the nature and degree of the injury. The most common of these impairments are in the domains of attention, memory, information processing speed, and executive functioning. Although there is a large body of research in this regard (see, e.g., Catale, Marique, Closset, & Meulemans 2009; Kolb & Gibb, 1999; Levin & Eisenberg, 1979; Van Heugten et al., 2006; Wrightson et al., 1995), my focus here is only on the ecological consequences of these neuropsychological impairments.

With regard to attention, the ability of the child to learn new skills and knowledge may be compromised if he/she is unable to be effectively attend to the environment (Anderson & Moore, 1995; Ewing-Cobbs et al., 1997; Gronwall, Wrightson, & McGinn, 1997). With regard to memory, this process seems to be particularly vulnerable to insult, and the younger the age of the child, the worse and more generalised the deficit. This kind of impairment can negatively affect the child's ability to gain and increase knowledge and skills (Anderson, Catroppa, Morse, & Haritou, 1999). In addition, the speed at which the child processes information is often noticeably affected by a cerebral insult (Ponsford, Sloan, & Snow, 1995; Ponsford et al., 1997). This impairment impacts on the child's ability to perform tasks quickly and efficiently, keep information in mind, attend to the environment, and perform effectively in the motor and language domains. Lastly, a TBI can impair the child's executive functioning. Anderson et al. (2001, p. 92) describe executive functions as "the component that directs attention, monitors activity, and coordinates and integrates information and activity". Therefore, executive dysfunction may produce difficulties with planning and organisation, perseveration, concrete thinking, ineffective feedback monitoring,

University of Cape Town

and poor generation and implementation strategies (Elliott, 2003; Gioia, Isquith, Kenworthy, & Barton, 2002; Stuss & Benson, 1987; Walsh, 1978).

Psychosocial impact on the child. A TBI not only affects a child's cognitive functioning, but can also affect his/her other domains of functioning, including personality, behaviour, and social functioning (Cattelani, Lombardi, Brianti, & Mazzucchi, 1998; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990). For instance, Hawley, Ward, Magnay, and Long (2002) reported that parents of 56.4% of moderate/severe brain injured children and 20.2% of mildly brain injured children rated their children as having 'personality changes'. Other post-TBI changes may include the child becoming quite troublesome, more susceptible to mood swings, more aggressive, less self-controlled, and behaving more inappropriately in social situations (Hawley, Ward, Long, Owen, & Magnay, 2003; Martin, 1988). Research also indicates further emotional and behavioural problems such as hyperactivity, irritability, low frustration tolerance, apathy, impulsivity, failure to establish friendships, and even age-inappropriate behaviour (e.g., an older child may start wetting the bed; Asarnow, Satz, Light, Lewis, & Neumann, 1991; Greenspan & MacKenzie, 1994; Prigatano & Gray, 2008). Although these deficits may only be temporary, they are frequently not, especially in the case of severe TBI, and the child may need years of rehabilitation in order to make progress in overcoming functional difficulties.

University of Cape Town

Child pre-injury predictors of outcome. The impact of TBI on the child is not only related to the severity of the injury, but also to factors such as the child's pre-morbid intellectual ability, level of education, social circumstances, socioeconomic resources, and pre-morbid personality and social adjustment (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). A child who is not very aware of how much he/she has mentally regressed, who has good financial, health, and social support, especially from the primary caregiver, whose pre-morbid personality was not temperamental, and who was socially well-adjusted before the injury, is more likely to have a better recovery from the TBI than a child who has fewer of these positive psychosocial circumstances (Aylward, 1997).

In summary, the literature shows that pediatric TBI has numerous implications for the affected child. The injury can affect the developing brain in a number of ways, and although some of the developing processes are mostly immune to environmental influences, others are not. Additionally, there is a debate surrounding whether the developing brain is more able to recover from a TBI than the adult brain, or whether the developing brain is more vulnerable to injury than the adult brain. More recent research suggests that both theories are at least partially correct, with each having an effect on the developing brain and influencing the consequences of the injury. With regard to the neurocognitive consequences of a TBI, there are effects on the child's attention, memory, information processing speed, and executive functioning, all of which lead to impaired ability to acquire knowledge and skills. Unfortunately, these negative consequences of the injury are not only cognitive, but psychosocial too. An injury can also negatively affect the child's personality, behaviour, and social functioning. Lastly, the consequences of the injury are not just related to the severity of the injury, but are also related to numerous pre-injury factors. These factors include the child's premorbid intellectual ability, level of education, social circumstances, socioeconomic resources, and premorbid personality and social adjustment.

University of Cape Town

Psychosocial Impact of the Child's TBI on the Family

Family systems theory explains that individuals can only be understood within the context of their family, such that the whole family system is affected by change in one individual (Lavoie, 1995). Hence, it is important to view the whole family in terms of TBI.

Psychological stress. The occurrence of TBI, especially amongst loved ones, is usually quite a shock for families, and often involves feelings of guilt, disbelief, anger, and/or sorrow (Lavoie, 1995; Martin, 1988). Once the acute stages of TBI have been stabilised, families then have to deal with an enormous amount of stress due to the often long-term cognitive, emotional, and behavioural changes in the child (Watanabe, Shiel, Asami, Taki, & Tabuchi, 2000). There is also often further stress associated with the uncertainty surrounding the course and degree of recovery that the child will experience, and the extent to which these will affect the child's future (Prigatano & Gray, 2007; Wade, Taylor, Drotar, Stancin, & Yeates, 1996). Marsh, Kersel, Havill, & Sleigh (1998) found clinically significant levels of depression, anxiety, and impaired social adjustment in one-third of their sample of carers of people with severe TBI. Similarly, Ponsford and Schönberger (2010) found clinically significant depression in 27% of their sample of relatives of people with TBI, even at 2 years post-injury. Wade et al. (1996) looked at the initial injury impact in a sample of 96 families of children with moderate or severe TBI and 69 families of children with orthopedic injuries. They found that the TBI sample reported significantly more psychological stress than participants in the orthopedic sample. Additionally, 45% of the TBI sample had clinically significant levels of psychological distress.

University of Cape Town

Although the studies by Marsh et al. (1998), Ponsford and Schönberger (2010), and Watanabe et al. (2000) investigated the impact of injured adults on families, the behavioural effects of TBI have been shown to be similar in adults and children. Therefore, the impact of TBI on families of children is likely to result in the same types of stressors as in families of adults with TBI (Brooks, 1991).

Demands caused by the injury. Demands placed on parents usually include providing constant care, attention, and guidance. Other demands include accepting and coming to terms with the situation, and increased financial burden due to medical bills, time taken off work, and adjustments being made to the home in order to accommodate the injured child (Hawley et al., 2003; Rotondi,Sinkule, Balzer, Harris, & Moldovan, 2007). In South

Africa, where many people live below the poverty line, the majority of parents will no doubt experience significant financial strain should a child suffer a TBI.

Impact on siblings. A child's TBI does not just have an impact on that child's parents, but also on his or her siblings. Siblings may experience a number of difficulties as a result of the injury. For instance, Hawley et al. (2002) researched 525 parents of children who had experienced either a mild, moderate, or severe TBI. Most of those participants' children (408) had siblings. A number (18.9 %) of those siblings experienced difficulties in the first few months following the injury, including nightmares, behaviour problems, fear, anxiety, jealousy of the attention paid to the injured child, and guilt (especially in older siblings who felt they had some role to play in the injury). This number included 56.4% from the severe group, 33.3% from the moderate group, and 12.7% from the mild group.

Post-injury needs. In the aftermath of the TBI, family members have an often-unmet need for health/medical information, professional services, and support in order to cope with newly-created demands and burdens (Armstrong & Kerns, 2002; Watanabe et al., 2001). The role of social support was one of the factors considered in a study by Wade et al. (2004) on the interpersonal stressors and resources that predict parental adaptation following pediatric TBI. This study showed that social support is important for the psychological adjustment of caregivers of children with TBI. The impact of social support on the psychological adjustment of caregivers is influenced by both the quality of support (i.e., whether it is supportive or stressful) and the source of support (i.e., whether it is from friends, family, or a spouse). Support from spouse and friends was associated with less psychological distress

An example of the importance of these professional and social support needs was also demonstrated by Watanabe et al. (2001), who compared the needs of family members living with TBI individuals in either Japan or Britain. Their sample consisted of 12 Japanese and 18 British individuals. Participants in both groups rated their need for training and information

University of Cape Town

on the impact of the TBI on the patient as 'important'; the need for volunteer support groups, such as Headway, was rated as 'very important' by more than 60% of the British sample. There were no significant cross-cultural differences between the two groups in terms of the amount and nature of problems arising from the TBI. The researchers did find, however, that the British individuals were more knowledgeable on how to cope with these problems, and that the Japanese individuals were significantly more socially embarrassed regarding the TBI than the British sample.

Despite the above-mentioned impact of the child's injury on the family, the family are often key to the success of the child's rehabilitation and re-admittance into society. Therefore, it is important that the family are able to deal with the trauma of the child's injury and to adapt to the changes in the child.

Family pre-injury predictors of outcome. The impact of TBI on the family is not only related to the burden and needs caused by the injury, but also to the family's pre-injury functioning. Rivara et al. (1996) researched 81 families of children with mild, moderate, and severe TBI in order to determine (a) the factors most predictive of family outcomes, and (b) variables that promote positive outcomes and changes over time. Caregivers were given various measures to assess child and family functioning, at 3 months, 1 year, and 3 years post-injury. At 1 year post-injury, pre-injury family functioning was a better predictor of family outcomes than injury severity. Families who were cohesive, and who had stronger relationships and better coping resources had better 1 year post-injury outcomes. Family functioning was also shown to have a positive impact on the child, as the child's social competence and behaviour at 1 year post-injury was also predicted by pre-injury family functioning. At 3 years post-injury, coping, psychological well-being, social support and problem-solving, strong family relationships, cohesion, good communication, a positive belief system, and a positive mental health index, were all moderately to highly correlated

University of Cape Town

with positive family outcomes. In contrast, those families with high levels of stress 3 years post-injury had poorer family relationships, fewer coping skills, poorly functioning households, and more anxiety and depression

The effect of pre-injury family predictors on the child and family is further evidenced by epidemiological research demonstrating that childhood TBI occurs most frequently on weekends, holidays, and afternoons (i.e., at times when children are more likely to be involved in leisure activities). Such trends in the occurrence of childhood TBI have been interpreted as an indication that many such injuries result from reckless behaviour in poorly supervised environments (Dalby & Obrzut, 1991). Further, childhood TBI is more common in families where parents are socially disadvantaged, unemployed, or emotionally disturbed (Anderson et al., 1997; Anderson, Catroppa, Haritou, et al., 2005; Klonoff, 1971; Rivara et al., 1993; Taylor et al., 1995, Taylor et al., 2002).

University of Cape Town

In summary, the child's TBI has an enormous impact on the psychosocial functioning of his/her family. Firstly, the family is placed under a large amount of psychological stress due to the often long-term cognitive, emotional, and behavioural changes in the child. Secondly, the injury creates numerous demands for the family; these demands place both financial and time strain on the family. The caregivers of the injured child are not the only family members affected by the injury; the child's siblings may also be negatively affected by the injury. He/she might experience nightmares, behavioural problems, fear, anxiety, jealousy, and guilt. These strains and burdens can lead to a number of often unmet needs for the family, including needs for health information, professional services, and support to cope with the situation. Lastly, as is the case for the child's injury outcomes, pre-injury functioning has an effect on family outcomes post-injury. Families who, pre-morbidly, are cohesive, have good coping skills, are psychologically sound, have strong family relationships, have good communication skills and a positive belief system and a positive mental health index are more likely to have positive family outcomes post-injury.

TBI in the South African Context

A number of studies have noted the importance of the context in which the child and family live as being an important determinant of outcomes (Rivara et al., 1993, Rivara et al., 1996; Taylor et al., 1999). Certainly, the occurrence of TBI in South Africa has its own unique context. This is because South Africa is a culturally diverse nation affected by HIV/AIDS, an uneven distribution of wealth and high levels of poverty, ill-equipped schools, high illiteracy rates, and health care services that are, for the most part, not of the same standards as those in developed countries (Levin, 2004). This context adds to the psychosocial stressors and consequences faced by children with TBI and their families.

As noted earlier, most pediatric TBI literature emerges from developed First World countries, where children with TBI are not faced with the same sociocultural circumstances as those in South Africa. Therefore, in this section as much literature as possible will be used that directly relates to South Africa, and although some of the literature used does emanate from First World studies, this review aims to use such data with the South African context in mind.

University of Cape Town

TBI aetiology in South Africa. Both South African and international research suggests that the major causes of TBI are motor vehicle accidents (MVAs), falls, and violence (Hawley et al., 2003; Levin, 2004; Miller & Stander, 2009). For instance, Miller and Stander found, in their study of 2093 cases of pediatric TBI admitted to RXH over a 2-year period in the mid-2000s, that falls accounted for the highest TBI aetiology (47%), followed by pedestrian MVAs (32%), being struck by or against an object (12%), passenger MVAs (8%), and assault (5%). More severe outcomes were more often associated with MVAs involving passengers and with violent assaults.

The strong association between MVAs and TBI likely occurs because many South African children use minibus taxis that are often overloaded with passengers and whose drivers appear to have little regard for their own or their passengers' safety. In addition, disadvantaged suburbs tend to have a very high load of pedestrians, which infers a higher risk for accidents involving those pedestrians (Mokhosi & Grieve, 2004). With regard to violence, this frequently occurs in the form of child abuse, with over 20 000 child rape and attempted rapes being reported each year (Shilumani, 2004). Violence also occurs in the form of hijackings and gang-related activities, which sometimes result in children sustaining gunshot wounds to the head (Levin, 2004).

South African socioeconomic situation. In South Africa, a large number of individuals can be classified as having a low socioeconomic status (SES), particularly relative to income levels in developed countries. About 23% of South Africans are unemployed; this statistic excludes those employed on a part-time or informal basis (Labour Force Survey, 2007). In addition, about 57% of Black African and 26% of Coloured people are classified as living below the breadline (i.e., earning less than R250 per month; Van der Berg & Louw, 2004). In the RXH study by Miller and Stander (2009), 29.2% of participants were unemployed, and 52.8% earned less than R6000 per month. The implication here, then, is that many South African families who have a child with TBI cannot afford the costs of caring for an injured child, let alone any possible long-term rehabilitation services (Levin, 2004). Research on pediatric brain injury indicates that SES and availability of resources are important determinants of not just child outcomes, but also family outcomes after a TBI (Anderson, Catroppa, Haritou, et. al., 2005; Klonoff, 1971; Waaland & Kreutzer, 1988).

South African children with low-SES backgrounds are also those who are most affected by TBI: The abovementioned kinds of violence and MVAs mostly affect people of low SES in South Africa (Levin, 2004). Indeed, given that Black African and Coloured

University of Cape Town

people account for the majority of people from a low SES (Statistics South Africa, 2007), it is not surprising that Nell and Brown (1990) found that the incidence of TBI per 100 000 people was 355 for the Black African population, 298 for the Coloured population, and 109 for the White population in South Africa.

HIV/AIDS in South Africa. The figures on the number of children living with HIV/AIDS in sub-Saharan Africa are staggering. Globally, of the 2.1 million children living with HIV at the end of 2008, approximately 9 out of 10 lived in sub-Saharan Africa (UNAIDS, 2008). Research suggests that South African children from low-SES backgrounds are not just at a higher risk for TBI than those from higher SES backgrounds: Studies show that people from low-SES backgrounds are also more vulnerable to contracting HIV/AIDS, and of having family members who suffer from HIV/AIDS (Tladi, 2006).

Jaffe, O'Neill, Vandergoot, Gordon, and Small (2000) studied the prevalence of TBI amongst an HIV-positive population in the US. They found that of the 173 participants in their study, 128 had a lifetime prevalence of a blow to the head. Furthermore, of those who merely reported a blow to the head, but did not self-identify as having been traumatically brain injured, a significant number displayed 25 symptoms that are specific to mild TBI, as well as a high total number of symptoms. These data suggest that there is a high incidence of TBI amongst HIV/AIDS patients, and that even mild trauma to the head has a highly negative effect on this population. This co-occurrence was mostly likely due to the fact that 23.4% of their sample had been assaulted and 14.8% had been exposed to domestic violence.

The implication here is that, although no pediatric or South African studies have been conducted, children who originate from a low-SES background appear to be most at risk for having TBI with the added strain of HIV/AIDS. Further anecdotal evidence as described below suggests that HIV/AIDS puts children affected by TBI at risk for worse symptoms and, consequently, the need for more care from their families and from the public health sector.

University of Cape Town

Levin (2004), in her article on paediatric traumatic brain injury in South Africa, stated that she had several discussions with speech language pathologists in the pediatric field during 2002 and 2003. These professionals estimated that 40-60% of children affected by neurogenic communication disorders, including TBI, cerebral palsy, and post-meningitis syndrome, also have HIV/AIDS. Additionally, they suggested that those children with TBI and who were also HIV-positive presented with more severe symptoms and with a more rapid decline in their clinical symptomatology than those TBI children without HIV/AIDS.

Education in South Africa. In addition to the fact that many South African parents do not have the financial resources to provide effective care for an injured child, individuals in this country have varied understandings and perceptions of TBI due to their varying levels of education and cultural beliefs. For instance, it is estimated that approximately 14.3 % of South Africans have no schooling (Statistics South Africa, 2007). An inability to read and write will clearly have negative consequences for an individual's understanding of TBI and for his/her ability to learn more about it independently.

University of Cape Town

Traditional African cultural understandings of TBI. South Africa is an exceptionally diverse nation, and different cultural beliefs also have implications for people's understandings of the phenomenon of TBI. For instance, Mokhosi and Grieve (2004) showed that many Black African families attribute TBI to an external source, such as God, ancestors, and/or sorcery. These attributions often imply that TBI is a misfortune caused by the anger of an external spiritual power. Not all of these beliefs about the causes of TBI are negative, however, as some lead to finding comfort in attributing the injury to God's will.

Mokhosi and Grieve (2004) also noted that, within some South African cultures, TBI does not just affect what Westernised society would recognize as the immediate family: It also has an impact on larger communities, particularly in those that regard all relatives, including cousins and grandparents, as close family members. Finally, with regard to TBI within traditional African contexts, the family members of a child with TBI are often embarrassed because that child does not fulfil culturally-prescribed roles and expectations. For example, boys are expected to look after the family's animals, while girls are expected to prepare food and do other household chores; in both cases, a serious brain injury would compromise the ability to fulfil these roles and expectations. In addition, a severe injury might restrict the family's ability to attend traditional ceremonies.

Access to health care in South Africa. South African sociodemographic variables also influence the provision of care for those affected by TBI because many people do not live in close proximity to specialised medical care. About 43% of South Africans live in rural areas (World Bank, 2006), but most specialised medical services are found in urban areas; therefore, people who live in rural areas often do not have access to specialized medical care (Levin, 2004). Furthermore, in rural areas there are very few schools that specialise in educating children with special needs (let alone children with TBI specifically). Even in the vast majority of mainstream schools, teachers are neither trained nor equipped to handle children with special needs. For those who do attend special schools for the disabled, whether rural or urban, these schools do not usually educate children according to their specific disorders (Bubb, 2003).

University of Cape Town

Lacking health care facilities in South Africa. Even for those South African children whose families can afford the best possible medical care, health care services are, as mentioned above, relatively lacking in South Africa compared to developed countries (Levin, 2004). Government-run hospitals, for instance, are heavily under-resourced in terms of finances, staff, and space for patients. There are usually long queues of patients to be seen by a doctor, and because bed space is limited, patients are discharged as soon as their acute physical injuries are stabilised. Financial limitations also mean that many of these hospitals cannot afford medical equipment that is current or technologically advanced. In addition, there are not enough allied health care professionals, such as speech-language therapists, occupational therapists, and social workers, to meet the needs of patients. Even private hospitals, where resources are not limited to nearly the same extent as state hospitals, do not, for the most part, have adequate facilities, or staff with the required education and skills, to provide dedicated long-term rehabilitation services for pediatric TBI patients. There are also very few pediatric rehabilitation services for children with TBI in South Africa (Levin, 2004).

Pediatric TBI community and social support in South Africa. Even though the research discussed above provides evidence to show that families of children with TBI value social support and that social support assists families in coping with the consequences is available, very little such support is available in South Africa. Although there are two main national head injury associations, Headway and Brain-Injury Group (BIG); both are not pediatric-specific. Headway is an international charity organisation that has six branches in South Africa; its services are aimed at TBI survivors over the age of 18 years. They offer a number of services, depending on the branch. These include information and support to affected individuals and their families, as well as other rehabilitation services such as physiotherapy, occupational therapy, and psychological counselling. BIG is also a non-profit organisation that provides information and support to adults affected by TBI. In addition, they aim to create awareness of TBI and related issues, and to provide training for caregivers, as well as to professionals who communicate and interact with affected individuals.

University of Cape Town

In summary, TBIs do not occur in isolation from the injured individual's environment. The context in which the injured child lives is an important determinant of TBI outcome. Unfortunately, the South African context is one that is likely to add to the stressors and negative outcomes of the injury for families of children with TBI. South African children are (a) at high risk for incurring TBIs because of factors like high pedestrian load areas that expose children to potential MVAs and because of high violence rates, (b) at risk for also having HIV/AIDS in addition to their injury, (c) potentially having restricted access to health care, and (d) likely to receive health care services that are lacking when compared to services in developed countries. Furthermore, many South African families will potentially (a) not be able to afford the costs of caring for a child with a TBI, (b) not be able to learn more about the TBI because of low education rates, and (c) not have access to dedicated support services.

In conclusion, this literature review has showed that a TBI has important implications for the affected child affected and for his/her family. A child living in South Africa is more likely to incur a TBI, the effects of which have implications for the child's neuropsychological functioning, personality, behaviour, and social functioning. Additionally, these consequences are not just mediated by the injury and the severity thereof, but also by the child's premorbid functioning and environment. The family system and resources are hugely impacted by the TBI. The family is placed under major stress (including time and financial pressure) because of the changes in the child, and these stressors often lead to a number of post-injury needs. As with the child, these consequences are not just mediated by the injury and the severity thereof, but also the child's pre-morbid functioning and environment. Lastly, as discussed above, the occurrence of TBI in South Africa has its own unique context, unlike that of developed country contexts. This deprived environment has important negative consequences for the injured child and his/her family.

University of Cape Town

Specific Aims and Hypotheses

This study's broad aim was to investigate the experiences of South African families who care for a child with TBI, thereby filling the gap in the literature on this topic. In order to fulfill this endeavour, I aimed to explore more specifically:

(a) the stressors of caregivers: I wanted to investigate what exactly it is about the injury that was causing stress for caregivers. For example, was caregivers' stress related directly to behavioural changes in the child, or more related to caregivers not being able to cope with these changes?

(b) the needs of caregivers, and to what extent these needs were being met: I wanted to know what the typical needs of parents were so as to provide a better understanding for professionals and service providers.

(c) whether these stressors and needs are injury- and/or severity-related: I wanted to know if having a TBI as opposed to another injury (e.g., an orthopedic injury) caused more stress for caregivers. Additionally, I wanted to know whether it was the case that the worse the child's TBI, the more stressors and needs caregivers had.

(d) whether these TBI-related stressors and needs are similar to those found in developed-world countries: In developed-world countries, families report stressors due to a variety of factors including burden of care, financial and time strains, emotional strain, changes in family roles, and uncertainty about the future recovery of the affected child. I hypothesised that South African families would experience more stress and needs than families from First World countries because of social concerns particular to the South African context, such as high levels of unemployment and lack of access to health care services.

University of Cape Town

Design and Methodology

Research Design

The research design was quantitative, quasi-experimental, and cross-sectional. Data were collected using (a) a demographic questionnaire, and (b) three standardized questionnaires. These measures have all been previously used in similar studies to this one, that relate to parents'/caregivers' experiences of having children who have sustained a TBI. These standardized questionnaires cover a variety of topics, including (a) the types and degrees of stressors and strains experienced by parents/caregivers of traumatic brain-injured/injured child, and (b) the needs of parents/caregivers and their children following injury.

The research protocol was implemented at four different locations in Cape Town:

- Red Cross War Memorial Children's Hospital (RXH);
- Groote Schuur Hospital (GSH);
- a local primary school; and
- the University of Cape Town's Department of Psychology.

Participants were recruited into four groups:

(a) Mild TBI;

(b) Moderate/Severe TBI;

(c) Orthopedic Injury; and

(d) Healthy Control.

The Orthopedic Injury group was used to control for stressors and needs experienced as the result of having to care for a child with a physical injury; the Healthy Control group was used to control for the general stressors and needs associated with having to care for a child.

University of Cape Town

Participants

Inclusion criteria. Criteria related to socioeconomic status (SES), language, time since child's injury, and child's health history were applied to the sample of parents/caregivers who were potential participants (see Table 1).

With regard to SES, I specified that all participants be from a low SES background. This was done given that most patients from the RXH come from disadvantaged communities (Children's Hospital Trust, 2008) and that most TBI and all children with orthopedic injuries would be recruited from that hospital. I also chose to use participants from a low SES background because this represents a much larger proportion of South Africans, than those from a high SES. In addition, I wanted to see the impact of the double hazard effect (as mentioned on page 13), and the effect would not have been as visible with high SES participants. With regard to language, I specified that all participants be fluent in either English or Afrikaans. This criterion was put in place due to resource constraints, namely (a) the cost of employing research assistants who are fluent in Xhosa and (b) the costs involved in translating the questionnaires into Xhosa.

University of Cape Town

With regard to the child's age, I specified that all children of the caregivers enrolled in the study should be between the ages of 4 and 15 years old. The criterion of the child not being younger than 4 years was put in place so that the child was not too young for his/her parents to tell apart what behavioural and personality changes were a result of the injury. The criterion of the child not being older than 15 years was put in place so that one could assume the child's brain was not fully developed, thereby validating these results as truly 'pediatric'.

With regard to time since child's injury, I specified that all TBI children whose parents/caregivers would be enrolled in the study should have sustained their injury at least 1 year prior to enrolment. This criterion was put in place because most substantial TBI recovery takes place within the first six months of sustaining the injury, with recovery plateauing by one year post-injury (Fay et al., 2009; Jaffe, Polissar, Fay, & Liao, 1995). There is, however, research suggesting differing recovery time periods, so the recovery period chosen should not be taken as a certainty that the child's recovery has plateaued, but rather as a good estimate for recovery. Therefore, a criterion of 1 year from time of injury served to ensure that the child's recovery trajectory was likely to be stable at the time of assessment. I hoped that this would ensure and increase the reliability of responses from participants (i.e. responses that were not a function of the stage of recovery). Children who have sustained orthopedic injuries do not usually suffer from long-term consequences of the injury, and therefore a shorter time since injury criterion of at least 5 months was put in place for this group. This criterion also assisted in easier contact with potential participants because the shorter time since visiting the RXH ensured that the contact numbers were more likely to be operational.

With regard to the child's health history, parents of children with a history of neurological insult (before or since the TBI or orthopedic injury), or any history of psychiatric illness, were excluded from the study. This criterion was set in place so that the family was not affected by other injuries/illnesses that might have influenced responses on the questionnaires, thereby affecting the interpretability (and, possibly, the validity) of the results.

University of Cape Town

Table 1
Inclusion Criteria for Adult Participants and Their Children

	TBI	Orthopedic Injury	Healthy Control
Parent/caregiver			
Home language	English or Afrikaans	English or Afrikaans	English or Afrikaans
Socioeconomic status	Low	Low	Low
Child			

Age	4-15 years	4-15 years	4-15 years
Time since injury	≥ 12 months	≥ 5 months	N/A
Neurological history	None other than TBI	None	None
Psychiatric history	None	None	None

Recruitment of TBI sample. Between September 2007 and December 2009, I used RXH records to identify a list of children (*n* = 365) who had sustained a mild, moderate, or severe TBI at least 1 year previously and who had been to the hospital as a result of the injury. Similarly, a list of children (*n* = 32) with moderate/severe TBI and their contact details was obtained from GSH. This list, and those contact details, was obtained from the multidisciplinary team in Ward G25. This ward provides a post-acute rehabilitation service for children who have experienced a TBI. These children were all initially admitted to the RXH, and have folders there.

At the RXH, 365 patients described as having a "head injury" were identified in the trauma register; of this number, 230 fitted the inclusion criteria, and so their folder and contact details were recorded. We attempted to contact the parents, guardians, or caregivers of those 230 children who met the inclusion criteria, and made contact successfully in 77 cases. These individuals were informed about the study, and were invited to ask questions about it. Of the 77 contacted caregivers, 2 did not want to participate and 39 were contacted but either (a) never got back to the researcher regarding participation or (b) agreed to participate but then did not arrive for the interview (see Appendix B). Those who expressed an interest in participating, and who met eligibility criteria, were scheduled for a meeting with the researchers at a date within 2 weeks of the initial contact. Similarly, the parents on the list obtained from GSH were telephoned, of which 8 agreed to participate in the study. A total of 28 caregivers of children with TBI were recruited from the RXH, and 8 caregivers

University of Cape Town

were recruited from GSH.

The final Mild TBI group consisted of 18 mothers or female caregivers of children (aged 4-14 years) who had sustained mild TBIs and who had been admitted to RXH at least 1 year prior. Within this group, 10 participants were English-speaking, 4 were Afrikaans-speaking, and 4 English and Afrikaans.

The final Moderate/Severe TBI group consisted of 18 mothers or female caregivers of children who had sustained moderate (*n* = 4) or severe (*n* = 14) TBIs and who had been admitted to RXH at least 1 year prior. Within this group, 9 of the participants were English-speaking, 7 were Afrikaans-speaking, and 2 were fluent in both English and Afrikaans.

The information obtained from all 36 TBI group participants who arrived at the scheduled meeting was used in this study.

Recruitment of Orthopedic Injury sample. Between February 2009 and December 2009 I used RXH records to identify a list of children (*n* = 226) who had sustained an orthopedic injury at least 5 months previously and who had been admitted to the hospital as a result of the injury.

Using the trauma register, I identified 226 orthopedic injury patients; of this number, 135 fitted the inclusion criteria, and so their folder and contact details were recorded. We attempted to contact the parents, guardians, or caregivers of those 135; we made contact successfully in 53 cases. These individuals were informed about the study, and were invited to ask questions about it. Of the 53 contacted caregivers, 7 did not want to participate. The remaining 35 were contacted but either (a) failed to follow up with the researcher regarding participation or (b) agreed to participate but then did not arrive for the interview (see Appendix C).

Those who expressed an interest in participating were scheduled for a meeting with the researchers at a date within 2 weeks of the initial contact.

University of Cape Town

The final sample of participants in this group consisted of 18 caregivers, 16 of whom were either the child's mother or a female caregiver, and 2 of whom were the child's father. Within this group, 11 of the participants were English-speaking, 5 were Afrikaans-speaking, and 2 were fluent in both English and Afrikaans.

Recruitment of Healthy Control sample. As noted above, the RXH services a mostly disadvantaged community. Therefore a primary school located in a local low-SES community was used to recruit participants into this group. The school was also identified as suitable for use because, under the pre-1994 South African apartheid government, it fell under the South African Department of Education and Training (DET) system, and is therefore currently classified as previously disadvantaged (Case & Deaton, 1999). Children attending such a school are likely to be receiving similar services, and a similar quality of education, to those who are seen at RXH. The Western Cape Education Department granted me permission to conduct research at the school in question.

University of Cape Town

In June 2009, our research group, with permission from the school principal and other relevant authorities, sent a letter (see Appendix D) to parents of children attending the school. The letter contained information about the study and included a reply slip that allowed parents to fill in the following information:

- their contact details,
- their willingness to participate in the study, and
- whether their child had (a) ever been hospitalised or sustained a head injury, or (b) any history of neurological, developmental, or psychiatric disorders.

Those parents who returned the reply slip indicating their interest in participating, and whose children matched inclusion criteria, were sent the informed consent document, demographic questionnaire, and one of the standardized questionnaires. Of the 250 letters sent out to the school, 41 parents responded; 23 parents indicated their willingness to participate and 14 returned completed questionnaires.

The other 4 participants in this group were recruited from the wider UCT community. I recruited them by asking employees who are known to have children if they would be willing to participate. Of the 6 caregivers who were asked, 4 agreed to participate.

The final sample of participants in this group consisted of 18 caregivers, 16 of whom were either the child's mother or a female caregiver, and 2 of whom were the child's father. Within this group, 17 of the participants were English-speaking, and one was fluent in both English and Afrikaans.

University of Cape Town

Sample demographic information. Table 2 shows that, with regard to participants' children, the age and sex distribution across groups was reasonably equivalent. There were, however, statistically significant between-group differences with regard to time since injury ($R^2 = 0.24$). Post-hoc pairwise comparisons showed that time since injury was statistically significantly longer in the Moderate/Severe TBI group than in the Orthopedic Injury group ($p < .001$). Time since injury was also statistically significantly longer in the Mild TBI group than in the Orthopedic Injury group ($p = 0.02$), but there was no such difference between the two TBI groups, $p = 0.53$.

This pattern of between-groups differences was expected. However, as noted earlier, an inclusion criterion for participants in both TBI groups was that they should be caring for children who had sustained a TBI at least 1 year previously. In contrast, the time criterion for the Orthopedic Injury group was only 5 months, given that most children recover relatively quickly from such injuries.

Table 3 presents demographic information for participants in each of the four groups. The table shows that the sample of caregivers was relatively homogeneous across groups in terms of age, relationship to child, race, home language, and education. Caregivers' ages ranged from 23-62 years in the Moderate/Severe TBI group, from 28-49 years in the Mild

TBI group, from 25-58 in the Orthopedic Injury group, and from 26-52 years in the Healthy Control group. Furthermore, across the four groups, most caregivers had at least a high school education, and most were English-speaking.

Table 3 also shows that the distribution of income levels was not even across groups. Most participants in the Moderate/Severe TBI and Orthopedic Injury groups endorsed a figure within the lowest two income brackets (R0-4000), whereas most participants in the Mild TBI group endorsed a figure between R2000 and R6000. Overall, participants in the Healthy Control group tended to report higher levels of income This pattern is illustrated by the fact that (a) almost one-third of participants in this group endorsed a figure in the highest income bracket (above R10000), and (b) a χ^2 test detected a statistically significant difference in the distribution across groups of participants in the highest income bracket. Inspection of the means suggested that this effect arose because many more participants in the Healthy Control group than in the other groups endorsed a figure in this bracket.

University of Cape Town

Table 2

Demographic Characteristics of Participants' Children

Variable	Moderate/Severe TBI ($n = 18$)	Mild TBI ($n = 18$)	Orthopedic Injury ($n = 18$)	Healthy Control ($n = 18$)	*df*	χ^2/F	*p*
Age							
4-7 years	5	5	2	3	3	1.80	.615
8-11 years	10	10	9	12	3	0.46	.927
12-15 years	3	3	7	3	3	3.00	.392
Sex (M:F)	16:2	13:5	16:2	7:11	3	4.15	.245
Time since injury (months)[a]	17.50 (5.73)	15.67 (3.11)	10.94 (5.84)	-----	51	8.07	< .001***

[a] Values reported are means, with standard deviations in parentheses.

***$p < .001$.

University of Cape Town

Table 3

Demographic Characteristics of Participants

Variable	Group: Moderate/Severe TBI (*n* = 18)	Mild TBI (*n* = 18)	Orthopedic Injury (*n* = 18)	Healthy Control (*n* = 18)	*df*	χ^2/F	*p*
Relationship to child							
Mother	15	15	15	15	3	0.00	1.000
Father	0	0	2	2	3	4.00	0.261
Other	3	3	1	1	3	2.00	0.572
Race							
Coloured	18	14	15	17	3	0.63	.891
White	0	2	1	1	3	2.00	.572
Other	0	2	2	0	3	4.00	.261
Home language							
English	9	10	11	17	3	3.28	.348
Afrikaans	7	4	5	0	3	6.50	.089
Bilingual	2	4	2	1	3	2.11	.549
Education[d]							
Grade 1-8	2	4	6	4	3	2.00	.572
Grade 9-12	16	11	11	8	3	2.87	.412
Some college	0	2	1	4	3	5.00	.172
University degree	0	0	0	1	3	3.00	.392
Postgraduate degree	0	0	0	1	3	3.00	.392
Monthly income[e]							
R0-2000	5	6	8	1	3	5.20	.158
R2000-4000	4	7	4	4	3	1.42	.701

University of Cape Town

Variable	Group Moderate/Severe TBI ($n = 18$)	Mild TBI ($n = 18$)	Orthopedic Injury ($n = 18$)	Healthy Control ($n = 18$)	*df*	χ^2/F	*p*
R4000-6000	3	3	4	2	3	.67	.881
R6000-8000	1	1	0	4	3	6.00	.112
R8000-10000	2	0	1	2	3	2.20	.532
Above R10000	1	1	0	5	3	8.43	.038*

Note. Some of the participants omitted answers to a few of the demographic questions, and therefore sample sizes are < 18 for some variables. [a]Values reported are means, with standard deviations in parentheses. [b]Reported for $n = 16$ cases. [c]Reported for $n = 16$ cases. [d]Reported for $n = 18$ (Moderate/Severe TBI), $n = 17$ (Mild TBI), $n = 18$ (Orthopedic Injury), and $n = 18$ (Healthy Control) cases. [e]Reported for $n = 16$ (Moderate/Severe TBI), $n = 18$ (Mild TBI), $n = 17$ (Orthopedic Injury), $n = 18$ (Healthy Control) cases.

*$p < .05$

University of Cape Town

Materials

As noted above, the instruments employed were four paper-and-pencil questionnaires:

- a demographic questionnaire (see Appendix E),
- the Parenting Stress Index - Third Edition (PSI; Abidin, 1995),
- the Family Burden of Injury Interview/Short Form (FBII/SF; Taylor et al., 1995; see Appendix F), and
- the Family Needs Questionnaire (FNQ; Kreutzer, Complair, & Waaland, 1988; see Appendix G).

Each of these instruments was translated into Afrikaans for use with the Afrikaans-speaking participants. It was then checked by another first language Afrikaans speaker for mistakes and readability.

University of Cape Town

An extensive literature search, as well as personal communications with South African researchers in the field, revealed that the FBII/SF and FNQ measures have not been used before in South Africa. All three measures have, however, been used extensively in international research, suggesting that they are useful measures of family stressors and needs. The FBII/SF and FNQ were both designed in response to the lack of questionnaires that can be used specifically for pediatric TBI family research (Burgess et al., 1999; Serio, Kreutzer, & Witol, 1997). Of the three measures, only the FBII/SF has not been used in cross-cultural research. The PSI has been proven to be a useful cross-cultural measure in numerous studies (see, e.g., Krulik et al, 1999; Solis & Abidin, 1991). For example, Krulik et al. (1999) conducted a cross-cultural study on parenting stress and mothers of young children using mothers from Israel, Japan, Jordan, and the United States of America. Similarly, the FNQ has also proved to be a useful cross-cultural measure. For instance, Hora and de Sousa (2009) translated the questionnaire and made minor cultural adaptations for use in Brazil. In that study, the FNQ was shown to have both face and content validity in evaluating the needs of families of TBI individuals living in Brazil.

Demographic questionnaire. This instrument, which was designed specifically for the purposes of this study, was based on the demographic questionnaire used by the Medical Research Council of South Africa. It was altered for this study by deleting irrelevant items and adding in questions that were specific to each group, such as "What date did the head injury occur?" The purpose of the questionnaire was to capture information about key demographic characteristics of the participant (e.g., age, sex, education, income level) to later ensure that the groups were demographically homogeneous.

PSI. This 120-item instrument is designed to evaluate the amount of stress occurring in the parent-child relationship, so as to assess whether
(a) parenting and family characteristics are failing to support normal development and functioning in children; (b) children have behavioural and/or emotional problems; and
(c) parents might become dysfunctional in their parenting practices (FRIENDS National Resource Centre, 2006).

The instrument features the following six subscales relating to the child: Adaptability, Demandingness, Mood, Distractibility/Hyperactivity, Acceptability, and Reinforces Parent. An overall Child Domain score is derived by adding the scores of these six subscales. There are also seven subscales relating to the parent: Depression, Competence, Parental Attachment, Spouse, Isolation, Health, and Role Restriction. An overall Parent Domain score is derived by adding the scores of these seven subscales. A Total Stress score is derived by adding together the Child Domain and Parent Domain scores. A separate Life Stress score can also be calculated. This score measures the stressors that may have affected the family in the last 12 months (e.g., whether there has been the death of a family member, or whether the family has gone deeply into debt). The Life Stress score does not, however, contribute to the Total Stress score.

University of Cape Town

For each subscale and domain, raw scores are converted into percentile scores, which are derived from the frequency distribution of the normative sample. Normal scores are defined by those falling between the 15th and 80th percentiles. The measure's developer suggests that those scores that fall at or above the 85th percentile are clinically significantly abnormal, and that individuals scoring at this high level should be referred for professional consultation (Abidin, 1995).

With regard to psychometric properties reported in the test manual, coefficient alpha for internal consistency reliability is reported as ranging between .70 and .83 for the subscales of the Child Domain, and between .70 and .84 for the subscales of the Parent Domain. Internal consistency reliability coefficients for the Child Domain and the Parent Domain, and for the Total Stress scale, are all reported to be above .90 (Abidin, 1995).

Independent studies examining the test-retest reliability of the PSI have found it to be a reasonably sound instrument. These studies report coefficients ranging between .55 and .82 for the Child Domain, between .69 and .91 for the Parent Domain, and between .65 and .96 for Total Stress score (Abidin, 1995; Zakreski, 1983).

With regard to the validity of the instrument, the PSI has been empirically validated as predicting both parenting and child behaviour, as well as the child's emotional adjustment (FRIENDS National Resource Centre, 2006). A factor analytic study by the developer found that each subscale measures a moderately distinct source of stress (Abidin, 1995). An independent study conducted in Bermuda (Hauenstein et al., 1987) replicated the original factor analysis, and showed the robustness of the PSI's factor structure and reliability across cultures. The cross-cultural validity of this tool has further been confirmed in studies using a variety of American and international samples, including Chinese (Pearson & Chan, 1993), Portuguese (Santos, 1992), and Italian (Forgays, 1993).

FBII (Short Form). The original FBII instrument was specifically designed to be

University of Cape Town

administered to families affected by pediatric TBI; it assesses the burdens and challenges of families related to that injury (Burgess et al., 1999). The short form version of the instrument was obtained through personal contact with its author (S. Wade, 23 May 2007). To my knowledge, however, the FBII/SF has not been used in any previously published research.

The FBII/SF consists of 26 questions, each relating to a particular concern that has to do with the child's injury and consequences thereof. Respondents' rate, on a 5-point Likert-type scale, the level of stress associated with each concern (Burgess et al., 1999).

The FBII/SF is a version of the original FBII, which consists of 36 items, 4 of which are interviewer ratings of parents' coping abilities (Burgess et. al., 1999). The short form's questions have almost exactly the same content as the long form. The primary difference between the two versions is that the long form is constructed as a semi-structured interview; for example, interviewees are asked yes/no questions such as "Do you have concerns about how your child reacts or relates to you or your spouse/partner?" If the response is yes, the interviewee is asked to describe his/her concerns, and to then rate the stress related to this item on a 0-4 scale (where 0 indicates *Not at all Stressful* and 4 indicates *Extremely Stressful*). The interviewee is also asked whether this concern arises because of the child's injury or any consequences of the injury.

In contrast, the FBII/SF is administered in the form of a questionnaire. A statement (e.g., "Concerns about how your child reacts or relates to you or your spouse/partner") is presented to the respondent, who then rates the stress related to this item on the same 0-4 scale described above. The respondent also notes, by answering a yes/no question, whether the concern is related to the injury. Although there are no previously published studies documenting the psychometric properties of the FBII/SF, this version was used in the current study for the following reasons because it closely matches the original long form, and takes less time to fill in than the long form.

University of Cape Town

Both the short and long forms of the FBII generate five subscales relating to the following: changes in routine, work, and school schedules; concerns with the child's adjustment and recovery; and reactions of friends and family, the spouse, and siblings to the child's injury (Wade et al., 1996). Although the FBII was designed to be a pediatric TBI-specific questionnaire, its questions do not literally specify that the child has to have experienced a *brain* injury. Therefore, it is also suitable for administration to parents of children who have incurred an orthopedic injury. The long form has been used in previous research with both pediatric TBI and orthopedic populations (see, e.g., Wade, Taylor, Drotar, Stancin, & Yeates, 1998; Wade et al., 2002).

Burgess et al. (1999, p. 400) reported on the reliability of the FBII. They showed that it has a high internal consistency (Cronbach's alpha = .90), and that there were moderate correlations between scores at baseline and at 6 months post-injury ($r = .64$), between baseline and 12 months post-injury ($r = .52$), and between 6 months post-injury and 12 months post-injury ($r = .73$).

The same authors also found the FBII to be a valid measure of overall family burden. Specifically, the FBII Total Score was able to differentiate stress levels between mothers of children who had sustained a severe TBI from mothers of children who had sustained a moderate TBI. Additionally, the FBII was shown to be related to a previously validated measure of mothers' self-reports of psychological distress, the impact of children's health status on the family, and general family functioning. These relationships support the FBII's concurrent validity. Lastly, the FBII was able to predict maternal psychological adjustment one year from baseline assessment, suggesting that it can potentially be used to assess the risk for psychological distress and symptoms in family members of TBI children (Burgess et al., 1999).

University of Cape Town

FNQ. This 40-item questionnaire assesses the perceived needs of family members following the brain injury of a relative (Armstrong & Kerns, 2002). It measures the degree to which needs are perceived by the participant to be important, and how well those needs have been met. A factor analytic study of the FNQ revealed six discrete scales: Health Information, Emotional Support, Instrumental Support, Professional Support, Community Support Network, and Involvement with Care (Serio et al., 1997).

With regard to the psychometric properties of this instrument, internal consistency (using the Spearman Brown split-half reliability coefficient) is reported to be .75 (Kreutzer, Serio, & Bergquist, 1994). Cronbach's alpha calculations have revealed high internal consistency, with reliability coefficients ranging from .78 to .89 for the various subscales (Serio et al., 1997).

University of Cape Town

Procedure

I conducted most of the research interviews. However, when a participant was only Afrikaans speaking, an Afrikaans-speaking research assistant, who had been trained by me and my supervisor in the use of the measures, was made available. All 18 participants in the Healthy Control group and 3 participants in the Orthopedic Injury group filled in the questionnaires at home. Participants who filled in questionnaires at home were given written instructions (see Appendix H) as to how to fill out the questionnaires. Those who met with me or a research assistant were given verbal instructions as to how to fill out the questionnaires. All study procedures were approved by the Research Ethics Committee of the UCT Department of Psychology, the Research Ethics Committee of UCT Faculty of Health Sciences, the Western Cape Education Department, and the relevant authorities at RXH.

Mild and Moderate/Severe TBI groups. The parents, guardians, or caregivers of those children identified as matching the inclusion criteria were contacted telephonically, and a brief description of the study was given to them. For those who were interested in participating in the study, a meeting was scheduled for within 2 weeks of the initial contact. These meetings took place at RXH or in the UCT Department of Psychology. At the meeting, parents were given a more detailed verbal account of the study. They were then asked to read and sign an informed consent document (see Appendix I). They were then administered the demographic questionnaire, PSI, FBII/SF, and FNQ. They read and completed these independently, although a researcher was always available to answer questions and to offer assistance. For those participants who felt uncomfortable filling in the questionnaires independently, the researcher helped by reading the questionnaire items while the participant gave verbal answers.

Completion of these questionnaires took between 60 and 90 minutes. Participants were compensated R50 for travelling costs.

Orthopedic Injury group. The same procedure as outlined above was followed, except that these participants were only administered the demographic questionnaire, PSI, and FBII/SF. This is because the FNQ asks some TBI-specific questions. Completion of these questionnaires took between 45 and 75 minutes. Participants were compensated with R50 for travelling costs.

Healthy Control group. Those parents who returned the reply slip indicating their agreement to take part in the study, and whose children met the required criteria, were sent the informed consent document, demographic questionnaire and the PSI, along with instructions on how to complete them. I collected the completed questionnaires from the child's school 2 weeks later and reimbursed each participant R20. This reimbursement was given to the child to take home to his or her parent.

University of Cape Town

Statistical Analysis

The data were entered into an MSExcel worksheet and then cleaned. Missing data on questionnaires (e.g. ratings not given for particular items) were dealt with, for all of the measures, using the methodology described by Abidin (1995) for dealing with missing data when scoring the PSI. More specifically, these rules were followed: so long as not more than 1 item per subscale was missing, or 5 items altogether were missing, the average score for the completed items within the subscale was calculated and rounded to the nearest whole number. This whole number was then added to the scores of the completed items to get the required scores or score averages. This methodology was applied to the PSI, as well as the FNQ and the FBII/SF, because the latter two do not have standard instructions for dealing with missing data.

With regard to the FBII, a factor analysis reported in a previously published study (Wade et al., 1998) revealed that the Child, Spouse, and Other (family and friends) subscales were the only three of the five subscales that measure similar constructs in both TBI and orthopedic samples. Therefore, FBII/SF data from these three subscales only were analysed.

Data analysis was performed using STATISTICA (version 9; Statsoft Inc., 1984). Unless otherwise specified, the threshold for statistical significance was set at $\alpha = .05$. Multiple R^2 was reported as a measure of effect size.

The analysis proceeded across several steps. First, descriptive statistics for pertinent demographic variables (caregiver's and child's age, child's sex, relationship of caregiver to child, race of caregiver, severity of injury, time since injury, language, family income, and caregiver education) were analysed to see whether there were any significant demographic differences between the groups. (Those analyses are reported in the Participants section above.)

Second, I noticed that the completed FBII/SF questionnaires contained many missing

University of Cape Town

items. I undertook to investigate the pattern of missing data by calculating the number of missing responses by item, subscale, and total score. In addition, I examined whether the number of missing items was related to any of the participants' demographic characteristics. One question here, for example, was whether those participants with the lowest education level had the highest number of missing items. To capture such associations, I used Spearman's correlation coefficient.

Third, descriptive statistics, including measures of central tendency and dispersion, were calculated to provide an overview of the participants' responses to the various questionnaires. These analyses were also used to help determine whether parametric tests of between-group differences were appropriate. Examination of the probability plots were examined to see whether the assumption of normality was met, and Levene's test was used to examine whether the assumption of homogeneity of variance was met. One-way analysis of variance (ANOVA) tests were used to assess whether there were statistically significant between-group differences on any of the outcome variables derived from each measure. Where any of the assumptions underlying parametric statistical tests was not upheld, the appropriate non-parametric test was used.

University of Cape Town

Fourth, post-hoc pairwise comparisons were used to determine where the significant differences in between-group means lay. Either the Bonferroni multiple comparisons procedure or Tukey's Honest Significant Difference (HSD) test were used for variables with homogeneous variances. Paired *t*-tests with Bonferroni correction were used for variables with nonhomogeneous variances.

Results

Missing Data

All missing data were dealt with using the instructions for scoring given in the PSI manual (Abidin, 1995). These instructions were described in the Methods section.

One PSI questionnaire could not be used because the participant (who was in the Mild TBI group) did not fill it in at all. Two FNQ questionnaires could not be used: one participant, in the Mild TBI group, chose mostly the 'Not Applicable' response option, and therefore the questionnaire could not be scored. Another participant, in the Moderate/Severe TBI group, did not fill in the questionnaire at all.

The FBII/SF was the most problematic questionnaire with regard to missing data. The questionnaires of one participant in the Moderate/Severe TBI group, six participants in the Mild TBI group, and one participant in the Orthopedic Injury group could not be used because of excessive missing data. In an attempt to gain a greater insight into why so many data were missing on this questionnaire, I analysed the pattern of missing data. Tables 3, 4, and 5 present, for each group, the count of all of the participants' missing items by question and by domain, separately.

University of Cape Town

The mean number of missing FBII/SF items per participant in each group was: Moderate/Severe TBI group = 2.22 (*SD* = 4.04, range = 0 to 14); Mild TBI group = 7.61 (*SD* = 8.51, range 0 to 25); Orthopedic Injury group = 1.72 (*SD* = 3.95, range 0 to 17). Since the assumption of homogeneity of variance was not upheld for these data distributions, the non-parametric Kruskal-Wallis ANOVA equivalent was used to test whether there were statistically significant between-group differences with regard to number of missing items. The analysis did not detect any significant between-group, $H(2, N = 54) = 5.49$, $p = .06$

Table 4

Missing Data on the FBII/SF: Moderate/Severe TBI group (n = 18)

Scale	Item #	Item content	Missing	N/A	Y/N missing	Total
Child	1	Changes in how child reacts/relates	0	0	0	0
	2	Difficulty managing child's behaviour	0	0	0	0
	6	Concerned about child's recovery	0	0	0	0
	11	Difficulty accepting injury	0	1	0	1
	16	Acceptance by peers	0	1	1	2
		Totals	0	2	1	3
Spouse	17	Concerned about spouse's reaction	0	5	0	5
	18	Disagreements about how to care for child/family	0	4	1	5
	19	Difficulty talking about the injury	0	3	0	3
	25	Difficulty finding time to be with spouse	1	3	1	5
		Totals	1	15	2	18
Other	20	Concerned about others' reactions	0	0	0	0
	21	Disagreements about the care of the child/family	1	1	1	3
	22	Concerned about what others think about how you discipline the child	1	1	0	2
	23	Difficulty talking to others about the injury	0	0	0	0
		Totals	2	2	1	5

Note. The column headed "Missing" reports the number of participants who did not respond to the given item. The column headed "N/A" reports the number of participants who gave a response of *not applicable* to the given item. The column headed "Y/N missing" reports the number of participants who did not respond to the question of whether or not a concern rating of 1-4 on the given item was or was not related to the child's injury.

University of Cape Town

Table 5

Missing Data on FBII/SF: Mild TBI group (n = 18)

Scale	Item #	Content	Missing	N/A	Y/N Missing	Total
Child	1	Changes in how child reacts/relates	1	3	2	6
	2	Difficulty managing child's behaviour	2	1	2	5
	6	Concerned about child's recovery	0	1	0	1
	11	Difficulty accepting injury	1	2	0	3
	16	Acceptance by peers	1	3	3	7
		Totals	5	10	7	22
Spouse	17	Concerned about spouse's reaction	1	6	0	7
	18	Disagreements about how to care for child/family	1	5	4	10
	19	Difficulty talking about the injury	1	5	0	6
	25	Difficulty finding time to be with spouse	1	6	4	11
		Totals	4	22	8	34
Other	20	Concerned about others' reactions	2	5	0	7
	21	Disagreements about the care of the child/family	1	5	5	11
	22	Concerned about what others think about how you discipline the child	1	6	4	11
	23	Difficulty talking to others about the injury	0	2	0	2
		Totals	4	18	9	31

Note. The column headed "Missing" reports the number of participants who did not respond to the given item. The column headed "N/A" reports the number of participants who gave a response of *not applicable* to the given item. The column headed "Y/N missing" reports the number of participants who did not respond to the question of whether or not a concern rating of 1-4 on the given item was or was not related to the child's injury.

University of Cape Town

Table 6

Missing Data on the FBII/SF: Orthopedic Injury group (n = 18)

Scale	Item #	Content	Missing	N/A	Y/N Missing	Total
Child	1	Changes in how child reacts/relates	0	0	2	2
	2	Difficulty managing child's behaviour	1	0	1	2
	6	Concerned about child's recovery	0	0	0	0
	11	Difficulty accepting injury	0	1	0	1
	16	Acceptance by peers	1	1	1	3
		Totals	2	2	4	8
Spouse	17	Concerned about spouse's reaction	1	2	0	3
	18	Disagreements about how to care for child/family	1	0	1	2
	19	Difficulty talking about the injury	1	3	0	3
	25	Difficulty finding time to be with spouse	0	2	1	3
		Totals	3	7	2	12
Other	20	Concerned about others' reactions	1	1	0	2
	21	Disagreements about the care of the child/family	1	0	1	2
	22	Concerned about what others think about how you discipline the child	0	0	1	1
	23	Difficulty talking to others about the injury	0	1	0	1
		Totals	2	2	2	6

Note. The column headed "Missing" reports the number of participants who did not respond to the given item. The column headed "N/A" reports the number of participants who gave a response of *not applicable* to the given item. The column headed "Y/N missing" reports the number of participants who did not respond to the question of whether or not a concern rating of 1-4 on the given item was or was not related to the child's injury.

University of Cape Town

As Table 4 shows, participants in the Moderate/Severe TBI group did not omit answers to many FBII/SF questions. It is worth noting, however, that there were 15 *not applicable* responses from participants in that group on the Spouse subscale. This pattern of data was expected, however, because six participants in this group reported not having spouses.

Reviewing Table 5, it is apparent that participants in the Mild TBI group omitted answers to many FBII/SF questions. As is the case above, some of the missing data on the Spouse subscale can be attributed to the fact that four participants in this group reported not having a spouse. That fact cannot, however, account for all of the missing data generated by participants in this group (e.g., 10 items on the Child subscale, and 18 items on the Other subscale, were answered as *not applicable*).

A review of Table 6 indicates that there were not a lot of missing data within the Orthopedic group. Again, the missing data in this group emerged primarily from the *not applicable* option of the Spouse subscale (10%).

In summary, Tables 4, 5 and 6 suggest that most of the missing data on the FBII/SF can be attributed to participants choosing the *not applicable* option in their responses to various items. This problem of choosing *not applicable* will be discussed further below.

On questionnaires such as the FBII/SF, the reasons participants fail to, or refuse to, answer a particular question can usually be categorized as being due to one of three reasons: sensitivity to the item, inability to understand the item, and non-applicability of the item to the participant (Thomas, Renaud, & DePaul, 2004). To explore which (if any) of these three reasons could account for the high rate of missing data on the FBII/SF, I examined the relationship between the number of missing items and participant characteristics. This relationship was analysed using Pearson's correlation for continuous variables, namely

University of Cape Town

caregiver's age, child's age, and time since injury, and Kruskal-Wallis ANOVA for categorical variables, namely severity, caregiver's relationship to child, race, language, income, education, marital status, or gender of the child.

As shown in Table 7, these analyses revealed no statistically significant relationship between the number of missing items and any of the demographic characteristics, except for marital status. Importantly, there was no statistically significant relationship between the number of missing items and the participant's years of education. This piece of data suggests that participants did not omit items because they had difficulty understanding questions.

As expected, there was a statistically significant relationship between number of missing items and the marital status of the participant (married or not married). However, as noted earlier, the sample included a number of participants (15 in total across the three groups) who were not married or who did not have a partner, and who therefore did not answer questions relating to having a spouse. Once the missing items for those 15 participants were excluded from the calculation, marital status was no longer statistically significantly correlated with number of missing items, $H(1, N = 54) = 3.41, p = .065$.

University of Cape Town

Table 7
Relationship between Demographic Variables and Number of Missing Items

Demographic variable	Test statistic	*p*
Injury severity	5.49	.06
Age of caregiver	-.11	.45
Relationship to child	3.73	.16
Race	1.02	.60
Language	0.86	.65
Income	6.32	.28
Education	4.20	.12
Marital Status	3.41	.07

Note. For continuous variables (caregiver age), the test statistic is Pearson's *r* correlation coefficient. For categorical variables (injury severity, relationship to child, race, language, income, and education), the test statistic is Kruskal-Wallis *H*.

As mentioned above, the ANOVA did not detect any statistically significant differences in missing responses based on injury severity. However, the p value was very close to statistical significance ($p = 0.6$) and if one examines Tables 4, 5 and 6 closely, the number of missing responses does appear to be correlated with group status. Therefore, a chi-squared analysis was used to explore this assumption more thoroughly. The χ^2 test did detect a statistically significant difference ($p < .001$) in terms of the distribution of missing responses across the three groups.

As a follow-up to this χ^2 test, I conducted an analysis of the standardised residuals. Table 8 shows the results of that analysis. As can be seen, the analysis revealed that membership in the Mild TBI group and in the Orthopedic group were significant contributors to the chi-square relationship between injury severity and participants choosing the *not applicable* option.

University of Cape Town

Table 8

Standardised Residuals of Missing Responses by Group Membership

Injury severity	Missing	Not Applicable	Y/N Missing
Moderate/Severe TBI	1.69	1.49	2.31*
Mild TBI	1.92	4.52*	3.46*
Orthopedic	0.24	3.03*	1.15

Note. * indicates a variable as a significant contributor to the relationship.

The most likely reason for this pattern of data is that the less-stressful nature of having a child with a mild TBI or with an orthopedic injury leads parents of such children to feel that because they have not experienced the concern in question, or have not noticed that concern, that it is not applicable to them. For example, they may not have had had any difficulty "talking about the injury" to their spouses, and may therefore chosen the *not applicable* response option. However, the more appropriate answer in such cases (from the researcher's perspective) would have been the *not at all stressful* option. One question that this pattern of responding raises is the extent to which the response options *not at all stressful* and *not applicable* overlap when participants are filling out the questionnaire. This question is, of course, difficult to answer. Following Witol, Sander, and Kreutzer (1996), I suggest that the *not applicable* response option be deleted from the questionnaire so that one is able to access more accurate information regarding the extent to which certain concerns either cause stress or are irrelevant.

With regard to the relationship of the injury to the concern in question, membership in either of the two TBI groups was a significant contributor to the relationship between injury severity and the Y/N missing responses. The most likely cause for this pattern of data is the nature of TBIs: The fact that they are 'invisible' (i.e. they are not visible physical injuries such as a broken leg) and that TBIs can cognitively impact on one's behaviour and personality (as discussed in the literature review) make it difficult for parents to distinguish concerns that are a result of the injury from characteristics of the child that are unrelated to the injury.

University of Cape Town

Parental Stress

The PSI was used to evaluate the amount of stress occurring in the parent-child relationship. Descriptive statistics for the PSI scores of each of the caregiver groups on all 14 subscales, as well as Child Domain, Parent Domain, Total Stress, and Life Stress indexes, are shown in Table 8. The table also shows the percentile rank corresponding to each mean percentage score. Those scores that fall into the critical (or clinically significant) percentile range (≥ 85) are highlighted.

Reviewing Table 9 reveals that the average Total Stress percentile score for participants in the Moderate/Severe TBI group fell within the clinically significant range. A large amount of this stress appeared to be associated with the child's behaviour and emotions: All of the Child Domain subscale scores fell into the critical percentile range. There were, however, also significant sources of stress emanating from the Parent Domain: Competence, Isolation, Role Restriction, and Depression subscale scores all fell within the clinically significant range. Additionally, these caregivers reported a clinically significant mean score for Life Stress (≥ 95). Within this domain, the death of a close family friend (*n* = 11, 61%), going deeply into debt (*n* = 10, 56%), and having a child start at a new school (*n* = 8, 44%) during the previous 12 months were the most frequently selected life stressors.

Table 9 also shows that the average Total Stress percentile score for participants in the Mild TBI group fell within the clinically significant range. Most of this stress appeared to be associated with the child's behaviour and emotions: Three Child Domain subscale scores fell within the clinically significant range, whereas no Parent Domain subscales did. These participants also reported a clinically significant mean score for Life Stress (≥ 90). Within this domain, income decreased substantially (*n* = 8, 44%), the death of a close family friend (*n* = 7, 39%), the death of an immediate family member (*n* = 7, 39%), and going deeply into debt (*n* = 7, 39%) during the previous 12 months were the most frequently selected life stressors.

Table 9 also shows that the child's behaviour and emotions are the source of the majority of the stress for participants in the Orthopedic group: the Reinforces Parent and Demandingness subscales within the Child Domain fall into the critical percentile range. The Parent Domain and Total Stress scores fell within the normal range for this group. However, these caregivers also had an abnormally high mean score for Life Stress (≥ 90). Going deeply into debt (*n* = 8, 44%), separation (*n* = 8, 44%), and the death of a close family friend (*n* = 7, 39%), during the previous 12 months were the three most often selected life stressors.

Table 9 also shows that participants in the Healthy group were not abnormally stressed: Their average Child Domain, Parent Domain, and Total Stress scores all fell well

University of Cape Town

below the critical range. Interestingly, however, these caregivers also had a Life Stress score ≥ 85. Their most frequently selected life stressors were: income decreased substantially (*n* = 7, 39%), the death of a close family friend (*n* = 6, 33%), going deeply into debt (*n* = 6, 33%), and falling pregnant (*n* = 6, 33%) during the previous 12 months.

University of Cape Town

Table 9

Parental Stress as Measured by the Parenting Stress Index (PSI)

	Group							
	Severe/Moderate TBI		Mild TBI		Orthopedic Injury		Healthy Control	
Index/Subscale	Score	%ile	Score	%ile	Score	%ile	Score	%ile
Child Domain	65.15 (11.87)	**≥ 99**	50.36 (12.12)	**≥ 85**	49.6 (12.75)	**≥ 85**	42.36 (9.31)	≥ 50
Distractibility/Hyperactivity	69.38 (9.32)	**≥ 90**	61.18 (13.5)	≥ 75	58.4 (14.01)	≥ 65	52.59 (12.03)	≥ 45
Adaptability	69.19 (15.14)	**≥ 99**	55.08 (16.2)	**≥ 85**	50.3 (17.54)	≥ 75	43.84 (11.38)	≥ 50
Reinforces Parent	52.22 (15.55)	**≥ 95**	45.29 (15)	**≥ 85**	42.59 (15.66)	**≥ 85**	38.15 (12.48)	≥ 80
Demandingness	66.05 (18.42)	**≥ 95**	42.35 (16.19)	≥ 65	51.6 (16.85)	**≥ 85**	39.38 (11.55)	≥ 45
Mood	60.67 (12.44)	**≥ 95**	44.71 (13.73)	≥ 75	43.78 (17.97)	≥ 70	39.56 (15.52)	≥ 50
Acceptability	66.51 (18.97)	**≥ 99**	47.73 (19.69)	**≥ 85**	44.76 (15.62)	≥ 80	36.35 (11.42)	≥ 50
Parent Domain	57.96 (10.34)	**≥ 90**	52.53 (19.91)	≥ 75	50.33 (13.74)	≥ 70	43.48 (7.4)	≥ 40
Competence	57.26 (8.47)	**≥ 90**	50.77 (12.92)	≥ 75	47.69 (10.7)	≥ 65	44.87 (8.43)	≥ 55
Isolation	57.78 (19.47)	**≥ 85**	52.94 (24.55)	≥ 75	47.59 (18.99)	≥ 70	40.37 (10.66)	≥ 50
Attachment	39.84 (12.87)	≥ 70	39.33 (12.76)	≥ 70	40.32 (15.02)	≥ 75	35.24 (9.19)	≥ 50
Health	63.78 (17.11)	≥ 80	59.53 (19.12)	≥ 75	54.22 (14.4)	≥ 70	45.11 (11.21)	≥ 50
Role Restriction	69.05 (15.84)	**≥ 85**	57.65 (18.61)	≥ 65	59.21 (19.62)	≥ 65	49.52 (11.68)	≥ 40
Depression	64.57 (15.5)	**≥ 90**	52.81 (21.7)	≥ 75	51.23 (19.74)	≥ 75	44.2 (13.61)	≥ 45
Spouse	53.81 (15.69)	≥ 65	58.15 (17.7)	≥ 75	54.76 (14.61)	≥ 70	43.65 (8.25)	≥ 40
Total Stress	61.31 (9.86)	**≥ 95**	51.52 (13.34)	**≥ 85**	49.99 (12.75)	≥ 80	42.95 (7.4)	≥ 40
Life Stress	26.65 (17.83)	**≥ 95**	22.64 (79.76)	**≥ 90**	23.56 (13.96)	**≥ 90**	18.07 (17.91)	**≥ 85**

Note. Mean percentage scores are presented, with standard deviations in parentheses. Bold numbers indicate a clinically significant percentile rank.

University of Cape Town

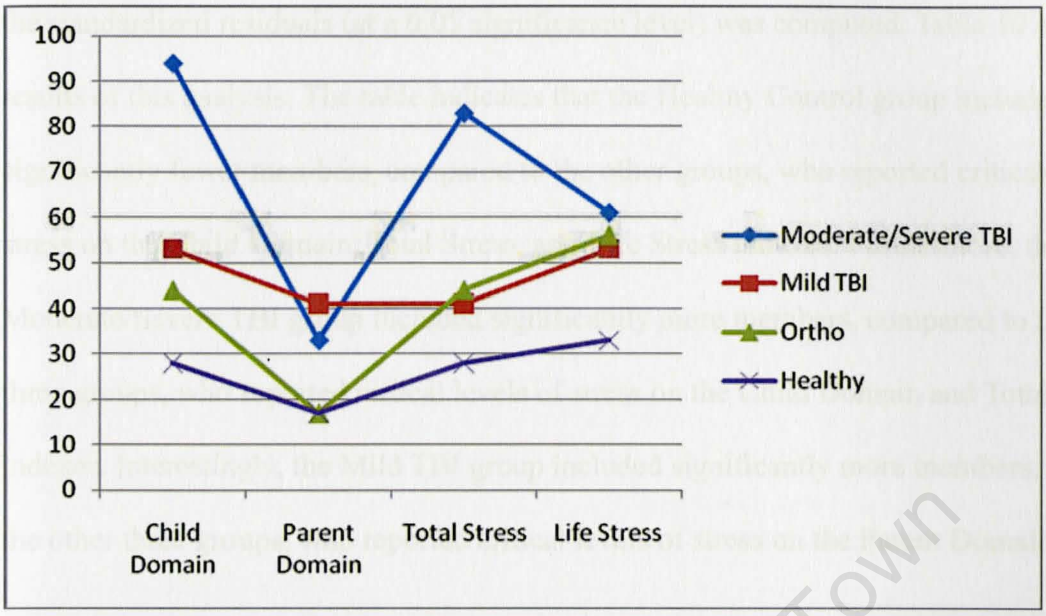


Figure 1. Number of participants in each group who scored within the critical range (≥ 85th percentile) on the PSI. Scores are given as a percentage.

University of Cape Town

Figure 1 shows the percentage of participants in each group who scored within the clinically significant range on the four major PSI indexes. Of particular note is that, within each group, more participants reported clinically significant distress in the Child Domain than in the Parent Domain. Furthermore, 94% of participants in the Moderate/Severe TBI group and more than 50% of participants in the Mild TBI group were critically stressed in the Child Domain. Also of interest is that more than half of the participants in the Moderate/Severe TBI, Mild TBI, and Orthopedic Injury groups had Life Stress scores falling within the clinically significant range. Furthermore, participants in both the Orthopedic Injury and Healthy Control groups reported the most distress on the Life Stress index. Clearly, this is a sample within which participants are experiencing numerous environmental stressors.

A χ^2 analysis was used to explore the data depicted in Figure 1 more thoroughly. The test detected statistically significant differences in the distribution, across the four groups, of individuals reporting critical levels of stress on the Child Domain ($p < .001$), Parent Domain ($p = .001$), Total Stress ($p < .001$), and Life Stress ($p = .030$) indexes.

To explore what these significant differences found in the $\chi 2$ test were, an analysis of the standardized residuals (at a 0.05 significance level) was computed. Table 10 shows the results of this analysis. The table indicates that the Healthy Control group included significantly fewer members, compared to the other groups, who reported critical levels of stress on the Child Domain, Total Stress, and Life Stress indexes. Furthermore, the Moderate/Severe TBI group included significantly more members, compared to the other three groups, who reported critical levels of stress on the Child Domain and Total Stress indexes. Interestingly, the Mild TBI group included significantly more members, compared to the other three groups, who reported critical levels of stress on the Parent Domain index.

Table 10
Standardized Residuals of Critically Stressed Group Members

	Group			
PSI Index	Moderate/Severe TBI	Mild TBI	Orthopedic Injury	Healthy Control
Child Domain	5.3	0.24	1.45	-3.62*
Parent Domain	1.15	2.69*	1.92	1.92
Total Stress	4.86*	1.14	0.71	-3
Life Stress	1.44	0.32	0.74	-2.49*

Note. * indicates that variable was a significant contributor to the relationship. A negative value indicates that fewer participants were represented than expected.

A series of one-way ANOVAs were conducted to analyse whether there were any between-group differences on the following PSI outcome variables: each of the 14 subscales, the Child Domain score, the Parent Domain score, the Total Stress score, and the Life Stress Score. Pre-analysis consideration of the assumptions underlying ANOVA showed that data for the Isolation subscale, Parent Domain score, and Total Stress score did not meet the assumption of homogeneity of variance, Levene's test $F(3,67) = 2.964$, 3.763, and 3.155. The non-parametric Kruskal-Wallis ANOVA equivalent was therefore used to analyse those non-

University of Cape Town

homogenous variables, and one-way ANOVA was used to analyse all homogenous variables. These analyses revealed that there were significant differences between the groups on all of the subscales and domains except for the Attachment subscale, Spouse subscale, and Life Stress score, as shown in Table 11. The effect sizes were relatively small for each of the subscales and domains, however those that did explain the most variance were Demandingness , Acceptability, Adaptability, the Child Domain, and Total Stress.

Table 11
Parenting Stress Index: Significance tests

	Between-group comparisons		
PSI outcome variable	*F/H*	*p*	R^2
Child domain	12.268	< .001***	0.355
Distractibility/hyperactivity	5.770	< . 01**	0.205
Adaptability	8.996	< .001***	0.287
Reinforces Parent	2.883	< .05*	0.114
Demandingness	10.091	< .001***	0.311
Mood	6.795	< .001***	0.233
Acceptability	10.457	< .001***	0.319
Parent domain[a]	12.983	< .001***	0.168
Competence	4.836	< .01***	0.178
Isolation[a]	7.939	< . 05*	0.121
Attachment	0.612	0.609	0.027
Health	4.714	< .01**	0.174
Role restriction	4.146	< .01**	0.157
Depression	4.028	< . 01**	0.153
Spouse	0.535	0.659	0.023
Total Stress[a]	19.32167	< .001***	0.287
Life Stress	0.920	0.436	0.039

Note. [a]Kruskal-Wallis test;
$*p < .05$. $**p < .01$. $***p < .001$

University of Cape Town

Post-hoc pairwise comparisons were performed using the Bonferroni multiple comparisons procedure for variables with homogeneous variances. The adjusted *p* for this comparison was .0083, because there were six comparisons done between the four groups. Paired *t*-tests with Bonferroni correction were used for variables with nonhomogeneous variances (i.e., the Isolation subscale, Parent Domain and Total Stress scores). The results of these post-hoc analyses are shown in Table 12.

As the Table shows, there were statistically significant differences between the scores of the Moderate/Severe TBI group and the Healthy control group on the overall Child Domain score, as well on five of the Child Domain subscales (Distractibility, Adaptability, Demandingness, Mood, and Acceptability). There were also statistically significant differences between the scores of the Moderate/Severe TBI group and the Healthy control group on on the overall Parent Domain score ($t(34) = 4.79$), as well on five of the Parent Domain subscales (Competence, Isolation ($t(34) = 3.33$), Health, Role Restriction, and Depression); and on the Total Stress score, $t(34) = 6.39$.

Table 12 also shows that there were statistically significant differences between the scores of the Moderate/Severe TBI group and the Orthopedic group on overall Child Domain score, as well as on three of the Child Domain subscales (Adaptability, Mood, and Acceptability); and on the Total Stress score, $t(34) = 3.10$.

Additionally, there were statistically significant differences between the scores of the Moderate/Severe TBI group and the Mild TBI group on overall Child Domain score, as well as on the Demandingness subscale of the Child Domain. Of note is that the Acceptability subscale of the Child Domain was very close to significance ($p = .0086$). Furthermore, there were no highly statistically significant differences between the scores of participants in the Mild TBI, Orthopedic Injury, and Healthy Control groups

University of Cape Town

Table 12

Parenting Stress Index: Post-hoc pairwise comparisons

PSI outcome variable	Between-groups comparison					
	Mod/Sev vs	Mod/Sev vs	Mod/Sev vs	Mild vs	Mild vs	Ortho vs
Child domain	.0083**	≤ .001***	≤ .001**	1.00	.27	.39
Distractibility/hyperactivit	.32	.06	≤ .001***	1.00	.26	.98
Adaptability	.05	.0083**	≤ .001***	1.00	.19	1.00
Reinforces Parent	1.00	0.32	.03	1.00	.94	1.00
Demandingness	≤ .001***	.05	≤ .001***	.55	1.00	.15
Mood	.02	≤ .0083**	≤ .001***	1.00	1.00	1.00
Acceptability	.0086	≤ .0083**	≤ .001***	1.00	.29	.81
Parent domain[a]	.17	.06	≤ .001***	.68	.04	.09
Competence	.37	.04	≤ .0083**	1.00	.59	1.00
Isolation[a]	.24	.12	.002**	.71	.07	.17
Attachment	1.00	1.00	1.00	1.00	1.00	1.00
Health	1.00	.43	≤ .0083**	1.00	.05	.52
Role restriction	.28	.49	≤ .0083**	1.00	.93	.52
Depression	.34	.17	≤ .0083**	1.00	.95	1.00
Spouse	1.00	1.00	1.00	1.00	1.00	1.00
Total Stress[a]	.01	≤ .004**	≤ .001***	.75	.02	.06
Life Stress	1.00	1.00	.63	1.00	1.00	1.00

Note. Data shown are p values. Mod/Sev = Moderate/Severe TBI group; Mild = Mild TBI group; Ortho = Orthopedic Injury group; Healthy = Healthy Control group.

[a] Paired t-tests with Bonferroni correction

**p < . 0083. ***p < .00

University of Cape Town

Injury-Related Stress

The FBII/SF measured injury-related stress in participants in the Moderate/Severe TBI, Mild TBI, and Orthopedic Injury groups. A series of one-way ANOVAs sought to analyse between-group differences on four FBII/SF outcome variables: Child, Spouse, Other, and Total scores. The analyses revealed that there were significant between-group differences on all of the outcome variables except for the Spouse subscale, as shown in Table 13. The table also shows that effect sizes varied in magnitude from small to medium.

Table 13
FBII/SF: ANOVA results

	Between-groups comparison		
FBII/SF outcome variable	*F*	*p*	ESE
Child	12.518	< .001***	.37
Other	4.889	< .05*	.19
Spouse	2.345	.112	.13
Total	8.008	< .01**	.27

Note. ESE = effect size estimate, which in this case was R^2
*$p < .05$. **$p < .01$. ***$p < .001$

University of Cape Town

Post-hoc pairwise comparisons were performed using Tukey's Honest Significance Difference (HSD) test. Table 14 shows the results of these post-hoc analyses. As the table shows, there were statistically significant differences between the scores of the Moderate/Severe TBI group and the Mild TBI group on the Child, Other, and Total score measures. There were also statistically significant differences between the scores of the Moderate/Severe TBI group and those of the Orthopedic Injury group on all three of those measures. Of note again here is that there were no statistically significant differences between the scores of the Mild TBI and the Orthopedic Injury group.

Table 14

FBII/SF: Post-hoc pairwise comparisons

	Between-groups comparison		
FBII/SF outcome variable	Mod/Sev vs Mild	Mod/Sev vs Ortho	Mild vs Ortho
Child	.005**	< .001***	.52
Other	.031*	.026*	.98
Spouse	.823	.104	.353
Total	.038*	< .001***	.58

Note. Data shown are *p* values. Mod/Sev = Moderate/Severe TBI group; Mild = Mild TBI group; Ortho = Orthopedic Injury group.
$^*p < .05$. $^{**}p < .01$. $^{***}p < .001$

Table 15 presents data showing the mean of scores that participants assigned to the three domains (i.e., Concerns for child, Spouse's reaction, Other's reaction) and Total Score. As the table shows, for caregivers in the Moderate/Severe TBI and Orthopedic Injury groups the biggest injury-related concerns lay with the child and his/her behaviour since, and reactions to, the injury. In contrast, for caregivers in the Mild TBI group the biggest injury-related concerns lay with the spouse's reaction to the injury. This table also shows that participants in the Moderate/Severe TBI group gave an average stress rating of about 2 out of 4, indicating that on average they found the statements to describe events or situations as 'fairly stressful'. In contrast, participants in the Mild TBI and Orthopedic Injury groups gave an average stress rating of about 1 out of 4, indicating that on average they found the statements to describe events or situations as 'a bit stressful'.

University of Cape Town

Table 15

Injury-Related Concerns as Measured by the FBII/SF

	Group		
Subscale	Moderate/Severe TBI	Mild TBI	Orthopedic Injury
Concern for child	**2.29 (0.29)**	1.12 (0.53)	**0.73 (0.70)**
Spouse's reactions	1.63 (0.44)	**1.33 (0.52)**	0.63 (0.43)
Other's reactions	1.69 (0.18)	0.6 (0.39)	0.68 (0.34)
Total Score	1.87 (0.44)	1.02 (0.54)	0.68 (0.49)

Note. Mean scores are presented, with standard deviations in parentheses. Bolded numbers indicate the subscale on which the group gave the highest mean rating.

A one-way ANOVA revealed statistically significant differences between mean ratings on the Child, Spouse, and Other subscales, $F(2, 10) = 6.14$, $p = 0.018$, $R^2 = .55$. Post-hoc pairwise comparisons using Tukey's HSD test showed significant differences between ratings on the Child subscale and the Spouse subscale ($p = 0.027$), and on the Child subscale and the Other subscale ($p = 0.045$).

University of Cape Town

Family Needs

The FNQ measured the degree to which participants' needs in the Moderate/Severe TBI and Mild TBI groups for education and support had been met. Pre-analysis consideration of the assumptions underlying ANOVA showed that data for the Emotional Support subscale did not meet the assumption of homogeneity of variance, Levene's test $F(1,32) = 6.442$. A series of Mann-Whitney *U* tests analysed whether there were any differences between the two groups with regard to the following seven FNQ outcome variables: scores on the Health Information, Emotional Support, Instrumental Support, Community Network Support, Professional Support, and Involvement with Care subscales, and Total score. Table 16 shows the results of these analyses.

As can be seen in the Table, there were no statistically significant differences between the scores of Moderate/Severe TBI and Mild TBI participants on any of the FNQ subscales or on the FNQ Total score. Therefore, the rest of the FNQ analysis was run using the combined TBI groups, thereby investigating the needs of the larger TBI sample, rather than the two smaller groups. It is hoped that this bigger sample size contributes to the generalisability of these results to the general population, and to the power of the analysis to detect real trends.

Table 16
FNQ Data: Between-group comparisons

	TBI Group				
	Moderate/Severe	Mild			
Outcome variable	(*n* = 17)	(*n* = 17)	*U*	*p*	ESE
Health information	3.84 (0.1)	3.76 (0.1)	108	.195	.80
Emotional support	3.41 (0.27)	3.14 (0.24)	128	.578	1.06
Instrumental support	3.25 (0.26)	2.97 (0.31)	112.5	.271	.98
Professional support	3.82 (0.06)	3.65 (0.14)	107	.153	1.58
Community support network	3.68 (0.05)	3.34 (0.19)	92.5	.069	2.45
Involvement with care	3.39 (0.21)	3.49 (0.24)	131.5	.658	-.44
Total score	3.57 (0.16)	3.39 (0.20)	103.5	.162	.99

Note. Means are presented with standard deviations in parentheses. ESE = effect size estimate (in this case, Cohen's *d*).

University of Cape Town

Table 17 shows the mean rating of the combined TBI group on each FNQ subscale. As can be seen, the highest mean ratings of needs were on the Health Information and Professional Support subscales, whereas their lowest mean ratings of needs were on the Emotional Support and Instrumental Support subscales.

Table 17

FNQ Data: Ratings of needs for the combined TBI group ($N = 34$)

Subscale	M (SD)
Health information	3.80 (0.09)
Emotional support	3.28 (0.22)
Instrumental support	3.11 (0.25)
Professional support	3.73 (0.08)
Community support network	3.51 (0.12)
Involvement with care	3.44 (0.18)

A one-way ANOVA sought to detect whether there were statistically significant differences between the set of means shown in Table 16. The omnibus test statistic was significant and associated with a large effect size, $F(5, 31) = 17.89$, $p < .001$, ø = .74. The results of a set of post-hoc pairwise comparisons, using Tukey's HSD test, are shown in Table 18.

University of Cape Town

Table 18

FNQ Data: Post-hoc pairwise comparisons of ratings of needs for the combined TBI group ($N = 34$)

Subscale	1	2	3	4	5	6
• Health information	---	< .001***	< .001***	.974	.039*	.029*
• Emotional support	< .001***	---	.455	< .001***	.161	.695
• Instrumental support	< .001***	.455	---	< .001***	.005**	.084
• Professional support	.974	< .001***	< .001***	---	.326	.192
• Community network support	.039*	.161	.005**	.326	---	.991
• Involvement with care	.029*	.695	.084	.192	.991	---

Note. Data presented are p values.
*$p < .05$. **$p < .01$. ***$p < .001$

As the Table shows, ratings on the Health Information needs subscale were statistically significantly higher than those on the Emotional Support, Instrumental Support, Community Network Support, and Involvement with Care needs subscales. Other results of note include the fact that (a) ratings on the Professional Support needs subscale were statistically significantly higher than those on Emotional Support and Instrumental Support needs subscales, and (b) ratings on the Community Network Support needs subscale were significantly higher than those on the Instrumental Support needs subscale.

Other analyses of FNQ data followed the methods described by Kreutzer, Gervasio, and Camplair (1994). Hence, an FNQ response was categorised as *important* if the caregiver rated an item as either 'important' or 'very important'. The mean importance rating for each of the 40 items was thus calculated. The items were then ranked according to these mean importance ratings. In the current dataset, parents/caregivers in the two TBI groups rated, on average, 36 of the 40 FNQ questions as either 'important' or 'very important'.

Table 19 shows the seven highest-ranked items; these, therefore, are the most important needs experienced by parents/caregivers in the current TBI sample. Of note here is that all of these items are part of the Health Information subscale.

Table 20 shows the five lowest-ranked items; these, therefore, are the needs experienced as least important by this sample of caregivers. Of note here is that the least important needs were from the Instrumental Support subscale and the Emotional Support subscale.

Table 21 shows the needs most frequently rated as 'met' by participants. The endorsement of met needs is given as a percentage. To calculate this percentage, I considered, for each item, how many participants rated that particular need as having been met, and then divided that number by the total number of items (40) on the FNQ. On average, 39% of the

University of Cape Town

sample's needs were rated as having been 'met'. As the Table shows, the four items rated by the most participants as having been 'met' were from the Health Information subscale.

Table 22 shows the needs most frequently rated as either 'unmet' or 'partly met' by participants. Regardless of whether a need was rated as 'unmet' or 'partly met', both ratings were categorised as 'unmet' for this analysis, as suggested by Armstrong & Kerns (2002). As the Table shows, all of these 'unmet' needs were from either the Instrumental Support subscale or from the Emotional Support subscale.

University of Cape Town

Table 19

FNQ Data: Needs with the highest importance ratings

Item: I need...	Score
To have complete information on the patient's problems in thinking (e.g. confusion, memory, or communication)	3.88 (0.33)
To be told about all changes in the patient's medical status	3.85 (0.36)
To have complete information on the patient's physical problems (e.g., weakness, headaches dizziness, problems with vision)	3.85 (0.36)
To have information on the patient's rehabilitative or educational progress	3.85 (0.36)
To be assured that the best possible medical care is being given to the patient.	3.82 (0.39)
To have explanations from professionals given in terms I can understand.	3.82 (0.39)
To have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery)	3.82 (0.39)

Note. Mean scores are presented with standard deviations in parentheses.
All items are from the Health Information subscale.

University of Cape Town

Table 20

FNQ Data: Needs with the lowest importance ratings

Item: I need...	Score	Subscale
To spend time with my friends	2.71 (1.09)	Instrumental support
To be reassured that it is usual to have strong negative feelings about the patient	2.94 (1.13)	Emotional support
To have help keeping the house (e.g. shopping, keeping the house, cleaning, etc.)	2.97 (1.09)	Instrumental support
To have help from other members of the family in taking care of the patient	3.09 (1.03)	Instrumental support
To have my partner or friends understand how difficult it is for me	3.09 (1.03)	Emotional support

Note. Mean scores are presented with standard deviations in parentheses.

Table 21

FNQ Data: Family needs most frequently endorsed as 'met'

Item: I need…	Endorsement	Subscale
To be assured that the best possible medical care is being given to the patient	64%	Health information
To be told about all changes in the patient's medical status	61%	Health information
To have complete information on the medical care of traumatic injuries (e.g. medications, injections, or	61 %	Health information
To be shown that medical, educational, or rehabilitation staff respect the patient's needs or wishes	56%	Health information
To have a professional to turn to for advice or services when the patient needs help	56%	Community support network
To have the patient's teachers understand his/her problems	56%	Community support network

Note. Percentage represents the number of participants who endorsed that particular item.

University of Cape Town

Table 22

FNQ Data: Family needs most frequently endorsed as 'unmet' or 'partly met'

Item: I need…	Endorsement	Subscale
To spend time with my friends	85%	Instrumental support
To get a break from my problems and responsibilities	79%	Instrumental support
To have my significant other understand how difficult it is for me	73%	Emotional support
To discuss my feelings about the patient with someone who has gone through the same experience.	73%	Emotional support
To be reassured that it is usual to have strong negative feelings about the patient	73%	Emotional support
To pay attention to my own needs, job or interests	73%	Instrumental support
To have help keeping the house (e.g. shopping, keeping the house, cleaning, etc.)	73%	Instrumental support

Note. Percentage represents the number of participants who endorsed that particular item.

University of Cape Town

Discussion

Overall, this study sought to investigate South African caregivers' experiences of caring for children with TBIs. More specifically, the study had four aims: (1) to explore the stressors of caregivers, (2) to examine the needs of caregivers, and to what extent these needs have been met, (3) to examine whether these stressors and needs are injury- and/or severity-related, and (4) to compare these TBI-related stressors and needs to those found in developed-world contexts. The Results section dealt with the first three aims; the fourth will be explored in this section.

University of Cape Town

Aim 1: Contributors to Caregiver Stress

Total Caregiver Stress. Consistent with previous literature, caregivers of children with severe injuries resulting from TBIs had more stressors than caregivers of healthy children, and of children with mild TBI or orthopedic injuries (Anderson, Catroppa, Haritou, et al., 2005; Goldstrohm & Arffa, 2005; Hawley et al., 2002; Wade et al., 1996). In the current study, this severity- and injury-related result was derived from both PSI and FBII/SF data. More specifically, participants in the Moderate/Severe TBI group had reported experiencing significantly more stress than those in the Healthy Control group on all PSI subscales and domains. Those in the Moderate/Severe group also reported experiencing significantly more stress than those in the Orthopedic Injury group on the PSI Child Domain scale, three Child Domain subscales (Adaptability, Mood, and Acceptability), and the Total Stress index. Although the Moderate/Severe group had a higher score on the Total Stress index than the Mild TBI group, statistical analysis did not find any significant differences between these two groups on that measure.

With regard to the FBII/SF, participants in the Moderate/Severe TBI group reported experiencing significantly more burden than those in the Mild TBI and the Orthopedic Injury groups on the Child, Other, and Total subscales.

Impact of Child Characteristics on Parental Stress. Data from the PSI and FBII/SF also provide evidence showing that most of the Moderate/Severe TBI, Mild TBI, and Orthopedic Injury caregivers' stress is the result of the child's behaviour or characteristics, rather than the parent's own characteristics or behaviour, or the reactions of the caregiver's spouse, other children, or other family and friends to the child's injury. For instance, the PSI data suggested that 94% of participants in the Moderate/Severe TBI group and more than 50% of participants in the Mild TBI group reported critical levels of stress in the Child Domain.

University of Cape Town

The negative impact of the child's characteristics on caregivers' stress levels is in line with previous research on the stressors experienced by families of traumatically brain injured children. For instance, Prigatano and Gray (2007) found that 37% of their sample of caregivers of children with varying severities of TBI were highly distressed because of caring for their child. Specific concerns related to the child's academic performance, social skills, and ability to control emotions. Similarly, Hawley et al. (2003) found in their sample of caregivers affected by pediatric TBI that about 75% of parents in each of their mild, moderate, and severe TBI groups reported their child experiencing emotional problems, including temper, mood, and behaviour problems. At one year follow-up, little had changed for the majority of that sample, with 62% of caregivers' problems either staying the same or worsening.

Characteristics of the Injured Child Associated with Higher Stress Levels. The child characteristics that were associated with the most stress for the Moderate/Severe TBI caregivers were those found within the Acceptability and Adaptability subscales of the PSI; both scores had an average percentile rank of □ 99. High scores on the Acceptability subscale imply that the caregiver does not feel that his/her child possesses the physical, intellectual, and/or emotional characteristics that the caregiver had expected for the child (Abidin, 1995). High scores on the Adaptability subscale indicate that the child displays an inability to adjust to changes in his or her social or physical environment (Bendall, Culbertson, Shelton, & Carter, 1986; Breen & Barkley, 1988; Sigelman & Rider, 2003). Examples in this area include the child's overreaction to changes in sensory stimulation and to changes in routine. This inability to adapt to such changes may be part of the reason why previous research has found that the injured child has problematic peer relations and often loses friends after sustaining a TBI (Prigatano & Gray, 2007). Caregivers in the Mild TBI group also reported high levels of stress on the Acceptability and Adaptability subscales.

Participants in the Moderate/Severe TBI group also endorsed significant levels of stress on the PSI's Mood subscale (average percentile rank □ 95). These levels were significantly higher than those reported by both the Orthopedic Injury and Healthy Control groups. Parents who obtain high scores on the Mood subscale tend to experience their child's affective functioning as dysfunctional (Abidin, 1995). The child might frequently cry, and not show signs of happiness. Prigatano and Gray (2007, 2008) note that one of their participants' biggest concerns lay with the child not being able to regulate his/her emotions, especially with regard to anger feelings, frustration, and mood swings.

The Reinforces Parent subscale of PSI was a further area of high concern for participants in the Moderate/Severe TBI, Mild TBI, and Orthopedic groups. High scores on this subscale indicate that the parent does not experience the child as a positive source of reinforcement, and that the parent may even feel rejected by the child (Jarvis & Creasey, 1991; Moran, Pederson, Pettit, & Krupka, 1992).

The FBII/SF data are consistent with the PSI in showing that Moderate/Severe TBI caregivers' biggest injury-related concerns lie with the TBI child and his/her behaviour since, and reactions to, the injury. For instance, findings on the FBII/SF showed that the

University of Cape Town

Moderate/Severe TBI caregivers had a higher mean score on the Child subscale than the mean ratings of both the Mild TBI caregivers and the Orthopedic caregivers, and that on average caregivers in the Moderate/Severe group found items in this subscale to be 'fairly stressful'.

Characteristics of the Parent Associated with Higher Stress Levels. On average, participants in the Moderate/Severe TBI group were the caregivers in the current sample to report clinically significant levels of stress on the PSI's Parent Domain. Items found within the Depression and Competence subscales were particularly associated with high stress levels. High scores on the Depression subscale suggest the possible presence of clinically significant depression in the caregiver (Webster-Stratton & Hammond, 1988). High caregiver scores on the Depression subscale further suggest that these individuals might have difficulty mustering the physical and psychological energy needed to provide adequate parenting for their children (Dumas, Gibson, & Albin, 1989), and that they might also tend to show an incapacity to act assertively or authoritatively with their child (Webster-Stratton, 1990a, 1990b).

The current result with regard to the Depression subscale is consistent with previous research. For instance, Marsh et al. (1998) found clinically significant levels of depression, amongst other psychological sequelae, in one-third of their sample of caregivers of people with severe TBI.

High scores on the Competence subscale indicate that caregivers may either not have the practical knowledge or the child management skills to deal with their children. They also may not have found parenting to be as reinforcing as they had expected (Sommer, Whitman, Borkwowski, Schellenbach, & Maxwell, 1993; Stoiber & Houghton, 1993). Hawley and colleagues (2003) found that over 70% of families had unmet information needs, and that the lower the income of a family, the less likely they were to have received clinical follow-up and

University of Cape Town

adequate information on discharge of the child from hospital. The authors explain that parents need support, including information, in order to prepare them for future difficulties that may arise due to the TBI.

Participants in the Moderate/Severe TBI group also reported quite high stress levels on the Isolation and Role Restriction subscales of the PSI. High scores in the Isolation subscale suggest that parents are socially isolated from their relatives, peers, and other emotional support systems. Their relationship with their spouse might also be distant and lack parental support (Telleen, Herzog, & Kilbane, 1989). The impact of lack of social support will be discussed further in the next section. Parents who obtain high scores on the Role Restriction subscale may experience their parenting as restricting and frustrating in their efforts to maintain their freedom and identity. These parents are often resentful toward their children as they see the latter's demands and needs as controlling (Hauenstein, Marvin, Snyder, & Clarke, 1989).

University of Cape Town

Characteristics of Others Associated with Higher Stress Levels. Whereas items in the Parent Domain index of the PSI examined whether the caregiver was feeling isolated from his/her friends, the FBII/SF addressed the issue of stress caused by others for caregivers of children with TBI. Analyses of the FBII/SF data revealed that participants in the Moderate/Severe TBI group scored significantly higher than those in the Mild TBI and Orthopedic Injury groups on the Other subscale of the FBII/SF. This Other burden, as experienced by the Moderate/Severe TBI group, is associated with increased concerns about others' reactions to the injury, disagreements with others about the care of the child/family, concerns about what others think about how the caregiver's discipline of the child, and difficulty talking to others about the child's injury. It is possible that the high ratings of the Moderate/Severe caregivers on the Isolation subscale of the PSI and the Other subscale of the FBII are in some way related. Perhaps it is the impact of burden from others that is causing caregivers to becoming isolated, or perhaps caregivers' concern for their child's injury is causing them to isolate themselves, and this is putting strain on their social relationships? How these relationships become strained is not within the scope of this study; however, the fact that caregivers are isolating themselves from others, and have strained relationships with others because of their child's injury, is of major concern.

The impact of interpersonal stressors and resources on parental adaptation following pediatric traumatic injury was considered by Wade et al. (2004). They assessed caregivers of children with severe TBI, moderate TBI, and orthopedic injuries, and followed up 6 months later, 1 year later, and then over an extended period, averaging 4 years. They found parental distress was directly influenced by social stressors and resources, but was not injury-related. This result suggests that regardless of the child's injury, social relationships are important for the wellbeing of the caregiver. Furthermore, the positive influence of caregivers' psychological adjustment is influenced by both the quality of support (i.e., whether it is supportive or stressful) and the source of support (i.e., whether it is from friends, family, or a spouse). Support from friends was positively related to psychological adjustment, whereas stressful relations with friends were not related to caregivers' wellbeing. However, stressful relations with a spouse and extended family members either had as much or more of an influence on caregiver wellbeing as the support provided from positive relations.

University of Cape Town

Life Stress. It is also important to note that the average PSI Life Stress score for all four groups of caregivers was in the clinically significant range. Indeed, this was the only domain or subscale where participants in the Healthy Control group reported clinically significant stress levels. Within this domain, the items relating to "death of a close family friend" and "going deeply into debt" during the previous 12 months were the two most often selected life stressors across all four groups. These stressors were followed by "income decreased by more than 20%" in the last 12 months and "pregnancy", respectively. Although the participants did not provide reasons for the causes of these life stressors, I suggest that the South African context of high rates of unemployment, crime, and HIV/AIDS may have contributed to this pattern of data.

Aim 2: Caregiver Needs

The combined Moderate/Severe TBI and Mild TBI results for the FNQ show that, for caregivers of TBI children, the highest needs lie in the areas of Health Information and Professional Support. This pattern of data suggests that caregivers have a need for honest and understandable injury and recovery-related explanations from professionals (Armstrong & Kerns, 2002). They also need to have professionals available for advice during both acute and long-term phases in the child's recovery. Considering that Community Network Support had a mean rating of 3.51, and that the highest score one can give an item is '4', one might assume that Community Network Support is also greatly needed. Therefore, support, such as in the form of TBI support groups and counselling services should also be made available for family members of the injured child (Murray, Maslany, & Jeffery, 2006). Instrumental Support may have a significantly lower rating than the other subscales because family and friends can be used for such things as helping keep the house.

University of Cape Town

Although the current data suggest that the needs described by items within the Health Information and Community Network Support are adequately being met at present, even these highest endorsed subscales had fairly low endorsement percentages: only 56-64% of caregivers endorsed these needs as being met. These percentages translate into showing that between just below half of caregivers and a third of caregivers are not having even their highest endorsed needs met. Furthermore, while caregivers of children with TBI gave an average mean rating of 3.8 for Health Information and an average mean rating of 3.51 for Community Support, up to almost a half of caregivers did not receive these services.

The Emotional Support and Instrumental Support domains had the lowest rating of needs met. Although these domains had the lowest mean ratings compared to the rest of the subscales, they both had ratings above 3 (out of 4), suggesting that both are 'important' domains to participants. The fact that they are important to participants, and yet have the highest 'unmet' endorsements, suggests the need for more adequate provision of services in these areas. Consistent with this finding, Wade and colleagues (1996) showed in their study of the impact of pediatric TBI on the family that there was a marked discrepancy between the families perceived burden versus their actual burden. Their sample of 96 caregivers of children with moderate and severe TBI also had high distress, yet, like the sample in the current study, their self-reports of the type of help that they needed did not reflect the extent of their emotional distress. Wade et al. (1996) suggest that this finding may indicate that caregivers are not able to express their emotional needs effectively. Therefore, the responses of families who are asked about the help that they may need may not necessarily reflect the psychological impact of the TBI they may be experiencing. Alternatively, they might also perceive their emotional distress as normal, considering their circumstances, and therefore feel no need to seek professional intervention. Regardless of their perceived burden, understanding, support, and reassurance from their family, friends, and community, as well as getting a break from their responsibilities and spending time with friends may be important in helping meet their actual burden of emotional needs.

The importance this group of caregivers gives to certain FNQ subscales is in line with previous research suggesting that Health Information needs are often rated as important, whereas perceived needs for Emotional Support are usually rated as less important. Furthermore, Emotional Support needs are also less likely than Health Information needs to be met (Kreutzer et al., 1994; Murray et al., 2006; Witol, et al., 1996). For example, Witol et al. (1996) collected data on the needs of 38 family members following the traumatic brain

University of Cape Town

injury of relative, at 6 months and 24 months post-injury. At time I and time Π, this sample's most highly ranked 'important' items tended to fall in the Health Information subscale (endorsed by up to 100% of participants), whereas Emotional Support needs tended to be amongst the most highly rated 'not important' needs. Witol and colleagues participants also tended to rate Health Information needs amongst the highest rated 'met' needs, whereas Emotional Support needs tended to be amongst the highest rated 'unmet' needs, with an increase in the percentage of participants choosing needs in the latter category as 'unmet' by time Π.

Time Burden. No specific subscale addressed the concern of the time burden of caring for a child with a TBI. However, this concern was raised by the participants in that four FNQ Instrumental Support items fell into the 'needs most frequently unmet' category, and that the two highest-rated of these items were "I need to spend time with my friends" (85%) and "I need to get a break from my problems and responsibilities" (79%). Other highly-rated needs expressed via this subscale were "I need to pay attention to my own needs, job, or interests" (73%) and "I need to have help keeping the house (e.g., shopping, keeping the house, cleaning, etc.)" (73%). The stress of spending so much time caring for the injured child may also account for the fact that participants in the Moderate/Severe TBI group obtained clinically significant scores on the Isolation and Role Restriction subscales of the PSI.

University of Cape Town

Aim 3: Injury- and Severity-Related Impact on Caregivers' Stress and Needs

This current data showed a clear injury-related relationship to caregivers' stress in some areas assessed in this study, and a somewhat injury-related relationship in other areas. This data also showed a clear severity-related relationship to caregivers' stress. This injury and severity-related relationship was derived from both PSI and FBII/SF data. More specifically, participants in the Moderate/Severe TBI group reported, via the PSI, that they were experiencing more stress than did those in the Mild TBI group, Orthopedic Injury group, and Healthy Control group, especially in the Child Domain. These results point out that caregivers stress was related to: (a) their children having TBIs, as opposed to Orthopedic injuries or no injuries, and (b) the severity of their children's injury, i.e., the worse their children's injuries, the more stressed caregivers themselves felt. Although participants in the Mild TBI group did obtain clinically significant Total Stress scores while participants in the Orthopedic Injury and Healthy Control groups did not, statistical analysis did not find any significant differences between these three groups on that measure. The FBII/SF data are consistent with the PSI in showing a severity-related relationship to caregivers' stress. For instance, findings on the FBII/SF showed that the Moderate/Severe TBI caregivers had a higher mean score on the Child subscale than the mean ratings of the Mild TBI caregivers and the Orthopedic caregivers alike.

University of Cape Town

Interestingly, however, there were no statistically significant differences between the FNQ-reported needs of participants in the Moderate/Severe TBI group and those in the Mild TBI group. Overall, this pattern of data suggests that the worse the child's injury, the more stressed the caregiver is, yet there is not necessarily the same dose-response relationship with regard to needs. Future research might seek to clarify this situation.

The literature has mixed findings regarding the impact of the severity of the TBI on the family. Some studies suggest no severity-related differences in the impact of the injury on the family, while others find strong support for severity-related differences in family stressors due to the TBI. Overall, the suggestion is that severity is just one factor amongst many that impact on families caring for a TBI child. Taylor et al. (1999) suggest that the more preinjury family dysfunction that is present, the more injury severity impacts on family functioning (or dysfunction) post-injury. Although the current study does not have any direct evidence of pre-injury family functioning, low SES (as was found in most of the individuals in the current sample) is associated with higher family dysfunction (Magnuson & Duncan, 2006) Therefore, I would suggest that a strong association between TBI injury severity and parenting stress has been found here because many of the families in this study may have had low pre-injury family functioning.

Aim 4: Comparisons to Developed-World Contexts

Comparisons to international literature have been made throughout this Discussion section. A reasonable summary of these comparisons points to the fact that this South African sample has at least an equal, and more likely an even greater amount of stress, and has more needs rated as important, than samples from developed countries. This conclusion is further evidenced by the fact that participants in the current Moderate/Severe and Mild TBI groups had mean PSI Total Stress scores that were in the clinically significant range (percentile rank □ 95 and □ 85, respectively). Within the Moderate/Severe TBI group, 83% of participants had Total Stress index scores in the clinically significant range; that number was 41% for the Mild TBI group. Hawley et al. (2003) found, in their study on the impact of pediatric TBI on the family, that 50% of caregivers in a Severe TBI, 25% in a Moderate TBI group, and 33.3% in a Severe TBI group had a PSI Total Stress index score that fell within the clinically significant range.

University of Cape Town

With regards to the needs of families caring for a TBI relative as described in international studies, an average of 27 out of 40 FNQ items were rated by a Canadian sample ($N = 66$) as being important (Murray et al., 2006). On average, 43% of the sample's needs were rated as having been 'met'. The sample used in this Canadian study were caregivers of adults with TBI. In a pediatric international study using a Canadian and American sample, caregivers of children with traumatic brain injuries ($N = 19$) were compared to caregivers of diabetic children and caregivers of children with orthopedic injuries (Armstrong & Kerns, 2002). This sample rated an average of 28 out of 40 FNQ items as being important, with an average of 35.6% of the sample's needs having been rated as 'met'. In the current study, however, the average number of FNQ items rated by participants in the two TBI groups as being important was 36 out of 40 items, and on average, 39% of the sample's needs were rated as having been 'met'. This comparison shows that South African families are likely to experience a greater number of needs than their developed world counterparts. However, the average number of needs being met seems to be low regardless of the country participants originate from.

University of Cape Town

The reasons for the differences and similarities between this South African sample and developed world samples may be quite varied. I compared the Canadian sample's lowest rated items with this study's lowest rated items and found that while items on the Emotional Support and Instrumental Support have low ratings for both samples, South Africans rated those items as nevertheless 'important', whereas Canadians were more likely to rate those items as 'slightly important'. The reason that South Africans found these items more important than Canadians is possibly because Canadians have a number of those lowest rated items as a standard part of their lifestyle and medical facilities, and therefore do not place as much importance on them as South Africans might. An example of an item is the need "to be told daily what is being done with or for the patient". In Canada, daily patient updates are likely standard practice, and therefore not seemingly important to a Canadian caregiver, whereas limited medical resources in South Africa might result in caregivers not being given regular updates. With regard to Emotional Support, South Africans are likely to have more environmental stressors than developed country citizens, increasing their need for Emotional Support. Developed countries are also more likely to have the professional services, such as counsellors, for caregivers in need of emotional support. Both of these reasons might decrease the importance Canadian caregivers place on certain items.

It is interesting that regardless of country of origin, all three samples had so few of their needs met. These results can either point to an international deficiency in the provision for caregivers of individuals with TBI needs, or point to the problem of families' needs not being adequately understood. Hopefully studies such as this one can be used to guide service providers more specifically as to what those caregivers' needs are.

Recommendations

With the above findings in mind, I suggest that a number of additional services be provided for South African families, especially the primary caregivers in those families. These recommendations will hopefully assist families in adapting to their child's TBI, and thereby also assisting the child's recovery.

Health information and parent training. Several previously published studies have shown that one of the biggest needs of, and requests made by, families of people with TBI is information (see, e.g., Murray et al., 2006; Kreutzer et al., 1994). The current study confirmed those findings, and showed that this TBI sample's biggest need is for honest and understandable injury and recovery-related explanations information about their child's health. Parents are likely to be more distressed when they care for children with disorders of unknown aetiology and prognosis; distress is alleviated when parents know what to expect of their children's disorders (Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005). Therefore, helping parents obtain practical and realistic information as to, for example, what the best contributors to outcome are may help significantly in reducing their distress levels (Prigatano & Gray, 2007).

Other information-based support should also include education and training for parents in the areas of child discipline, child management skills, and practical child

University of Cape Town

development knowledge. This type of education seems important especially for caregivers of children with moderate or severe TBI. I say this because caregivers of children with moderate or severe TBI were the most distressed with regard to concerns about their child's injury. This group also had the most difficulty with feelings of depression and incompetence; therefore, they are most in need of support that is able to help them feel more capable of dealing with their child and his/her injury.

The time a parent spends caring for an injured child should also be addressed, with parents educated as to ways in which to reduce some of the stress associated with having to spend a lot of their free time caring for their child. These educational services could be delivered in the form of group workshops and printed educational materials.

Social support. A second highly needed and requested way of addressing family needs is through social support (Murray et al., 2006). Professionals need to make themselves available for discussion of concerns with caregivers, and should make referrals to other professionals and services (e.g., disability grants). In addition, dedicated support groups for parents of children with TBI are needed so that families have people they can turn to for support and who understand what they have been through. The emotional needs of caregivers who are depressed or who feel incompetent as a parent can be also be met through the provision of self-esteem enhancing therapy (Abidin, 1995).

Advocacy. Caregivers need to be made aware of the litigation routes they can take. Two examples of this are (1) being made aware of application procedures to the Road Accident Fund to cover medical bills; and (2) looking at what necessary legal procedures need to be taken to claim from TBIs caused by offenders, such as in the case of pedestrian motor vehicle accidents. Caregivers also need to be made aware of grants such as the Care Dependency grant, which is given to parents who care for a child who has a severe disability and who is in need of full-time and special care (South African Government Services, 31

University of Cape Town

March 2010).

On a broader scale, the needs of the participants in this study have broader implications for policies regarding the range of services that are made available for families and children with TBIs. For example, in the education sphere alone better policies regarding
(a) the number of schools for children with special needs,
(b) the placement of injured children in appropriate specialised education facilities, and
(c) the provision of funding for parents to send their children to these facilities.
Anecdotally, many of the participants in this study were having major problems finding a specialised school that had space for their child, or one where the parent could afford to pay the transport fees for their child to attend the specialised school.

Siblings. Although the current study did not focus on this area, attention to siblings and their reaction to the TBI is important. As previously noted, siblings often have numerous emotional reactions to the injury, including guilt, fear, and anxiety. Some may even have behavioural problems as a result of the injury, and start to 'act out'. It is important that professionals recognise and meet the needs of siblings by ensuring that they are also given social support to deal with the effects of the injury to their brother or sister.

University of Cape Town

School involvement. Once the child has recovered from the acute phases of the TBI, the injury then often becomes 'invisible' to people who interact with the child. Because a brain injury is not a visible physical injury, and thus cannot be easily discerned simply by looking at an individual (especially in the cases of mild to moderate TBI), the injured child's needs are in danger of being overlooked at home and at school (Wade et al., 1996). Prigatano and Gray (2007) suggest that professionals help parents communicate effectively with the child's school about the impact of TBI and the subsequent needs of the child. Indeed, one of the factors Hawley et al. (2002) investigated in their study on the impact of pediatric TBI on the family was the involvement of schools in the child's recovery. They found that TBI can become overlooked in the school setting. Only 20% of schools made any special provision for a child returning after a brain injury, and even if the TBI was severe, special arrangements were made for only 55% of these children. School teachers tended to make special arrangements for children with visible injuries (e.g., fractured legs), but few children with 'invisible' injuries were offered any help.

Assessment of at-risk families. As discussed in the Introduction, family functioning may be an important mediator of behavioural outcome in children with TBI. In fact, it might be an even more important mediator than pre-morbid neurocognitive function. Davis et al. (2009) suggests that caregivers of persons with moderate to severe TBI's be screened regarding their pre-injury histories in order that those caregivers who are most at risk for distress be identified. I suggest that families' pre-morbid functioning and environment be assessed in order to identify those families who have problematic backgrounds or who live in neighbourhoods with few resources. Interventions that take into account the child's pre-morbid functioning, the child's current presentation post-injury, the family's pre-injury functioning, the family's current functioning, and the environment in which the family live, will facilitate the allocation of necessary resources to the caregivers who are most in need.

Community-oriented approaches to rehabilitation. Levin (2004) suggests that community-oriented approaches are best for rehabilitation, especially in South Africa. The reason this is necessary is because the demand for rehabilitation services usually exceeds the supply, and ecological approaches to intervention have been shown to be more effective than child-centred approaches. Levin suggests that existing strengths within communities should be identified, and mobilised. In addition, professionals should make connections with **non-governmental organisations (NGOs)** in order to establish better resources for communities. Professional services, for example those involved in the child's rehabilitation (such as neuropsychologists, occupational therapists physiotherapists, and hospital counsellors) should

University of Cape Town

also be further developed to enhance and support community resources. Watanabe et al. (2001) recommend, in their paper on the needs of families of people with a TBI, that better community awareness of TBI may help to establish support groups and possibly help reduce social stigmatization of children and families.

Limitations

Small sample size. Due to resource- and time-related recruiting restrictions, the sample used in this study was small, and therefore these results should be interpreted with caution. However, this study did include three clinical samples, which are notorious in the literature for being hard to find.

A review of some of the prominently used pediatric TBI literature throughout this study found that sample sizes ranged from $N = 19$ to $N = 109$, with an average sample size of about 85 participants per study (Armstrong & Kerns, 2002; Burgess et al., 1999; Hawley et al., 2003; Prigatano & Gray, 2007, 2008; Rivara et al., 1996; Wade et al., 1996; Wade et al., 2004).

University of Cape Town

Missing Data. The large amount of missing data on the FBII/SF calls for additional cautious interpretation of current data. All researchers involved in the study, including myself, should have made the difference between "Not Applicable" and "Not at all stressful" clearer to participants. This instruction would have helped avoid any misinterpretation of the use of "Not Applicable". Unfortunately, we were not aware of this problem at the time of data collection; it only became clear during data analysis. Had participants been more aware of this differentiation, more participants might have chosen "Not at all stressful", and therefore we might have been able to use more participants' FBII/SFs in the data analysis. I therefore concur with Witol et al. (1996) that the instrument might deliver more clearly interpretable and useful data if the *not applicable* option were to be removed.

Prognostic value of the GCS. There is a debate in the literature as to the prognostic value of the Glasgow Coma Scale, particularly in the context of pediatric research, where many studies have identified variables other than level of consciousness as more important indicators of injury severity and long-term outcome (Fletcher, Ewing-Cobbs, Francis, & Levin, 1995c). However, the Red Cross Children's Hospital is the only dedicated children's hospital in South Africa, and within their records the GCS score given to children with TBIs is the only reliable indicator of severity that we were able to obtain. Other prognostic values, such as length of unconsciousness or degree of post-injury amnesia are not consistently or reliably recorded in their medical records.

Biased family view. The participants in this study were only one family member of a bigger family unit. Our results therefore reflect the stressors and needs of one family member, who may perceive family functioning quite differently from other family members. However, the main caregiver, usually the child's mother, was used in this study. Therefore, as the person most likely to play a role in the child's recovery, addressing her stressors and needs would be of the most importance. Reports from other family members, as well as direct observational methods, would however provide a more thorough picture of the effects of TBI on families.

University of Cape Town

Conclusion

This study's focus emerged from the fact that TBI is a debilitating disease not only for injured children, but also for their families and, in particular, for their primary caregivers. I found that, regardless of severity of injury, caregivers of children with TBIs are significantly stressed, with increased injury-severity leading to increased levels of caregivers' stress. Much of these caregivers' stress had to do with the child's behaviour and ways of relating to their caregiver; a significant amount of stress was also related to the parents' self-described parenting characteristics, however. Some of the caregivers of children with moderate or severe TBIs reported feeling depressed and incompetent, and feeling isolated and restricted by their role as parent. The reactions of and opinions of others regarding the child's injury seemed to also add to caregivers' burden of children with more severe injuries.

Caregivers are not only stressed by the child's injury, and by their own reactions to the injury, but they also have many needs relating to the injury. Caregivers need accurate, up-to-date, and honest information, they need professionals that are available to talk to them, they need to feel that they have a say in their child's care, and they need emotional support from friends, family, and professionals alike. All of the aforementioned needs are important to caregivers, regardless of the severity of the child's injury; importantly, however, only a small portion of these needs were being met in the current sample.

Added to the significant caregiver burden and needs of caring for a child with a TBI, as was found in this study, is the fact that South Africans face a unique situation, which is unlike that of the families affected by TBI in developed countries. Previous studies in this country have established that South African children are more likely to incur a TBI, more likely to receive a lower standard of health care, and more likely to have another debilitating health concern (such as TB or HIV), when compared to their developed-world counterparts. South African caregivers of children with TBI are also in a negative situation. Specifically, they are likely to be in a financially stressed situation, likely to have less access to necessary resources, such as information and support, and likely to have numerous life stressors. The abovementioned negative factors add to the argument that service providers at every level should seek out how best to assist parents in their newfound role as caregiver of a child with a TBI. Addressing these concerns, however, needs to start at a relatively macro level; in other words, the biggest change agents who need to address the stressors and needs of those families who care for children with TBIs are policymakers. Policymakers should take note of the requirements of affected families and then set into motion a sequence of services that

University of Cape Town

more adequately aids both the child and the family. An evaluation of current governmental and healthcare policies, and their impact on (a) children who have incurred a TBI and (b) the families of those children, need to be assessed at every level – with regard to medical facilities, education, support, and resources available to children and families. This evaluation is particularly important in the case of families from disadvantaged backgrounds. Where policies are lacking in addressing the needs of injured children and their families, service providers and communities most affected by TBI need to be consulted as to how to go about more adequately aiding the child and the family.

My hope is that the findings from this study are used as a tool for those service providers and policymakers. I say this because this study not only describes and identifies the burdens and needs of families, but also highlights the fact that TBI is a significant burden for families who look to policymakers and service providers to help aid both their child and their own needs.

University of Cape Town

References

Abidin, R. R. (1995). *Parenting Stress Index* – Manual (3^{rd} ed). Charlottesville, VA: Pediatric Psychology Press.

Al-Adawi, S., Dorvlo, A. S. S., Burke, D. T., Huynh, C. C., Jacob, L., Knight, R.,… Al-Hussaini, A. (2004). Apathy and depression in cross-cultural survivors of traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences, 16*, 435-442.

Amacher, A.L. (1988). *Pediatric head injuries*. St Louis, MO: Warren H. Green.

Anderson, V., Catroppa, C., Haritou, F., Morse, S., & Rosenfeld, J. (2005). Identifying factors contributing to child and family outcome 30 months after traumatic brain injury in children. *Journal of Neurology, Neurosurgery & Psychiatry, 76*, 401-408.

Anderson, V., Catroppa, C., Morse, S. A., & Haritou, F. (1999). Functional memory skills following traumatic brain injury in young children. *Developmental Neurorehabilitation, 3,* 159-166.

Anderson, V., Catroppa, C., Morse, S. A., Haritou, F., & Rosenfeld, J. (2005). Functional plasticity or vulnerability after early brain injury? *Pediatrics, 116*, 1374-1382.

Anderson, V., Godber, T., Smibert, E., & Ekert, H. (1997). Neurobehavioral sequelae from cranial irradiation and chemotherapy in children: An analysis of risk factors. *Pediatric Rehabilitation, 1,* 63-76.

Anderson, V., & Moore, C. (1995). Age at injury as a predictor of outcome following pediatric head injury. *Child Neuropsychology, 1,* 187-202.

University of Cape Town

Anderson, V., Morse, S.A., Klug, G., Catroppa, C., Haritou, F., Rosenfeld., J., & Pentland, L. (1997). Predicting recovery from head injury in school-aged children: A prospective analysis. *Journal of the International Neuropsychological Society, 3*, 568-580.

Anderson, V., Northam, E., Hendy, J., & Wrennall, J. (2001). *Developmental Neuropsychology. A clinical approach.* East Sussex: Psychology Press Ltd.

Anderson, V., Spencer-Smith, M., Leventer, R., Coleman, L., Anderson, P., Williams, J., Greenham, M., & Jacobs, R. (2009). Childhood brain insult: can age at insult help us predict outcome? *Brain: A journal of Neurology, 132*, 45-56.

Armstrong, K., & Kerns, K. (2002). The assessment of parent needs following paediatric traumatic brain injury. *Pediatric Rehabilitation, 5*, 149-160.

Asarnow, R. F., Satz, P., Light, R., Lewis, R., & Neumann, E. (1991). Behavior problems and adaptive functioning in children with mild and severe closed head injury. *Journal of Pediatric Psychology, 16*, 543-555.

Aylward, G. (1997). *Infant and early childhood neuropsychology*. New York: Plenum Press.

Baxter, R., Cohen, S. & Ylvisaker, M. (1985). Comprehensive cognitive assessment. In M. Ylvisaker (Ed.), *Head injury rehabilitation: Children and adolescents* (pp.246–274). London: Taylor & Francis.

Bendall, R. D., Culbertson, J. L., Shelton, T. L., & Carter, B. D. (1986). Interrupted infantile apnea: Impact on early development, temperament, and maternal stress. *Journal of Clinical Child Psychology, 15*, 304-310.

Breen, M. J., & Barkley, R. A. (1988). Child psychopathology and parenting stress in girls and boys having attention deficit disorder with hyperactivity. *Journal of Pediatric Psychology, 13*, 265-280.

Brenner, L. A., Dise-Lewis, J. E., Bartles, S. K., O'Brien, S. E., Godleski, M., & Selinger, M.

University of Cape Town

(2007). The long-term impact and rehabilitation of pediatric traumatic brain injury: A 50-year follow-up case study. *Head Trauma Rehabilitation, 22*, 56-64.

Breslau, N. (1990). Does brain dysfunction increase children's vulnerability to environmental stress? *Archives of General Psychiatry, 47,* 15-20.

Brooks, D. N. (1991). The head-injured family. *Journal of Clinical and Experimental Neuropsychology, 13*, 155 – 188.

Bruns Jr, J., & Hauser, W. A. (2003). The epidemiology of traumatic brain injury: A review. *Epilepsia, 44*(10), 2-10.

Bubb, E. (2003). *Specialised schooling for post head injuries, psychosocial environment and prognosis for recovery.* Paper presented at the Head Trauma Congress, Paediatric Neurology and Development Association, Randburg, South Africa.

Burgess, E. S., Drotar, D., Taylor, H. G., Wade, S., Stancin, T., & Yeates, K. O. (1999). The family burden of injury interview: Reliability and validity studies. *The Journal of Head Trauma Rehabilitation, 14*, 394-405.

Case, A. & Deaton, A. (1999). School inputs and educational outcomes in South Africa. *The Quarterly Journal of Economics*, 114 (3), 1047-1084.

Catale, C., Marique, P., Closset, A., & Meulemans, T. (2009). Attentional and executive functioning following mild traumatic brain injury in children using the Test for Attentional Performance (TAP) battery Attentional Functioning. *Journal of Clinical and Experimental Neuropsychology, 31*, 331–338.

Cattelani, R., Lombardi, F., Brianti, R., & Mazzucchi, A. (1998) Traumatic brain injury in child hood: intellectual, behavioural, and social outcome into adulthood. *Brain Injury, 12*, 95-107.

Chapman, S. B., & McKinnon, L. (2002). Discussion of developmental plasticity: Factors

University of Cape Town

affecting cognitive outcome after pediatric traumatic brain injury. *Journal of Communication Disorders, 33*, 333-344.

Children's Hospital Trust. (2008, October 12). Popular Gun Run set to help the hospital. Retrieved from http://www.childrenshospitaltrust.org.za/event/3085/popular-gun-run.

Dalby, P.R., & Obrzut, J.E. (1991). Epidemiologic characteristics and sequelae of closed head-injured children and adolescents: A review. *Developmental Neuropsychology, 7,* 35-68.

Davis, L. C., Sander, A. M., Struchen, M. A., Sherer, M., Nakase-Richardson, R., & Malec, J. F. (2009). Medical and Psychosocial Predictors of Caregiver Distress and Perceived Burden Following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation, 24*, 145-154.

Dumas, J. E., Gibson, J. A., & Albin, J. B. (1989). Behavioural correlates of maternal depressive symptomatology in conduct disorder children. *Journal of Consulting and Clinical Psychology, 57*, 516-521.

Elliott, R. (2003). Executive functions and their disorders. *British Medical Bulletin, 65*, 49-59.

Ewing-Cobbs, L., Fletcher, J., Levin, H., Francis, D., Davidson, K., & Miner, M. (1997). Longitudinal neuropsychological outcome in infants and preschoolers with traumatic brain injury. *Journal of the International Neuropsychological Society, 3,* 581-591.

Fay, T. B., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Taylor, G. H. (2009). Predicting longitudinal patterns of functional deficits in children with traumatic brain injury. *Neuropsychology, 23*, 271-282.

Fletcher, J. M., Ewing-Cobbs, L., Francis, D., Levin, H. S. (1995c). Variability in outcomes after traumatic brain injury in children: A developmental perspective. In S. H. Broman

University of Cape Town

& M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 3-21). New York: Oxford University Press.

Fletcher, J. M., Ewing-Cobbs, L., Miner, M. E., Levin, H. S., & Eisenberg, H. M. (1990). Behavioural changes after closed head injury in children. *Journal of Consultation Clinical Psychology, 58*, 93-98.

Forgays, D. K. (1993). Parenting *Stress in Italian Employed and At-Home Mothers.* Unpublished research paper, University of Vermont, Burlington.

FRIENDS National Resource Center. (2006, February). *Parenting Stress Index, 3rd Ed. (PSI).* Retrieved from http://www.friendsnrc.org/download/outcomeresources/toolkit/annot/psi.pdf

Gale, S., Johnson, S., Bigler, E., & Blatter, D. (1995). Non-specific white matter degeneration following traumatic brain injury. *Journal of the International Neuropsychological Society, 1,* 17-28.

Gioia, G. A., Isquith, P. K., Kenworthy, L., & Barton, R. (2002). Profiles of everyday executive function in acquired and developmental disorders. *Child Neuropsychology, 8*, 121-137.

Goldman-Rakic, P. S., Bourgeois, J., & Rakic, P. (1997). Synaptic substrate of cognitive development: Life-span analysis of synaptogenesis in the prefrontal cortex of the nonhuman primate. In N Krasnegor, G. Lyon, & P.S. Goldman-Rakic (Eds.), *Development of the prefrontal cortex: Evolution, neurology, and behaviour* (pp. 9-26). Baltimore: Brookes.

Goldstrohm, S. L., & Arffa, S. (2005). Preschool children with mild to moderate traumatic brain injury: An exploration of immediate and post-acute morbidity. *Archives of Clinical Neuropsychology, 20*, 675–695.

University of Cape Town

Greenspan, A. I., & MacKenzie, E. J. (1994). Functional outcome after pediatric head injury. *Pediatrics, 94*(4), 425-432.

Gronwall, D., Wrightson, P., & McGinn, V. (1997). Effects of mild head injury during the preschool years. *Journal of the International Neuropsychological Society, 6,* 592-597.

Hauenstein, E. J., Marvin, R. S., Snyder, A. L., & Clarke, W. L. (1989). Stress in parents of children with diabetes-mellitus. *Diabetes Care, 12*, 18-23.

Hauenstein, E., Scarr, S., & Abidin, R. R. (1987). *Detecting children at-risk for developmental delay: Efficacy of the Parenting Stress Index in a non-American culture.* Unpublished manuscript, University of Virgina, Charlottesville

Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2002). Children's brain injury: a postal follow-up of 525 children from one health region in the UK. *Brain Injury, 16*, 969-985

Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury, 17*, 1-23.

Hebb, D.O. (1949). *The organization of behaviour.* New York: McGraw-Hill.

Hessen, E., Netsvold, K., & Anderson, V. (2007). Neuropsychological function 23 years after mild traumatic brain injury: A comparison of outcome after paediatric and adult head injury. *Brain Injury, 21*, 963-979.

Hora, E. C., & de Sousa, R. M. C. (2009). Cross-cultural adaptation of the instrument "Family Needs Questionnaire". *Latin American Journal of Nursing, 17,* 541-547.

University of Cape Town

Huttenlocher, P. R., & Dabholkar, A. (1997). Developmental anatomy of prefrontal cortex. In N. Krasnegor, G. Lyon, & P.S. Goldman-Rakic (Eds.), *Development of the prefrontal cortex: Evolution, neurology, and behaviour* (pp. 69-84). Baltimore: Brookes.

Jaffe, K. M., Polissar, N. L., Fay, G. C., & Liao, S. (1995). Recovery trends over three years following pediatric traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 76,* 17-26.

Jaffe, M. P., O'Neill, J., Vandergoot, D., Gordon, W. A., & Small, B. (2000). The unveiling of traumatic brain injury in an HIV/AIDS population. *Brain Injury, 14*, 35-44.

Jarvis, P. A., & Creasey, G. L. (1991). Parental stress, coping, and attachment in families with an 18-month-old infant. *Infant Behaviour and Development, 14*, 383-395.

Kennard, M. A. (1936). Age and other factors in motor recovery from precentral lesions in monkeys. *American Journal of Physiology, 115,* 138-146.

Kennard, M. A. (1940). Relation of age to motor impairment in man and in subhuman primates. *Archives of Neurology and Psychiatry, 44,* 377-397.

Kibel, S. M., Bass, D. H., & Cywes, S. (1990). Five years' experience of injury children. *South African Medical Journal, 78*, 387-391.

Klonoff, H. (1971). Head injuries in children: Predisposing factors, accident conditions, accident proneness and sequelae. *American Journal of Public Health, 61,* 2405-2417.

Kolb, B. (1995). *Brain plasticity and behaviour.* Hillsdale, NJ: Lawrence Erlbaum Associates Inc.

Kolb, B., Forgie, M., Gibb, R., Gorny, G., & Rowntree, S. (1998). Age, experience and the changing brain. *Neuroscience Biobehavioural Review, 22,* 143-159.

Kolb, B., & Gibb, R. (1999). Neuroplasticity and recovery of function after brain injury. In D.

University of Cape Town

Stuss, G. Wincur, & I. Robertson (Eds), *Cognitive neurorehabilitation* (pp. 9-25). New York: Cambridge University Press.

Kreuzer, J. S., Complair, P., & Waaland, P. (1988). The family needs questionnaire. *Rehabilitation Research and Training Center in Severe Traumatic Brain Injury.* Richmond: Medical College of Virginia.

Kreutzer, J. S., Serio, C. D., & Bergquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation, 9,* 104-115.

Krulik, T., Turner-Henson, A., Kanematsu, Y., Al-Ma'aitah, R., Swan, J., & Holaday, B. (1999). Parenting stress and mothers of young children with chronic illness: A cross-cultural study. *Journal of Pediatric Nursing, 114,* 130-140.

Labour Force Survey (2007). Retrieved from: http://www.statssa.gov.za/PublicationsHTML/P0210September2007/html/P0210September2007.html

Lalloo, R., & van As, A. B. (2004). Profile of children with head injuries treated at the trauma unit of Red Cross War Memorial Children's Hospital, 1991-2001. *South African Medical Journal, 94*, 544-546.

Lavoie, R. D. (1995). Life on the waterbed: Mainstreaming on the homefront. *Attention*!, *2(1)*, 25-29.

Lenhard,W., Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H. J., & Henn, W. (2005). Psychological benefit of diagnostic certainty for mothers of children with disabilities: Lessons from Down Syndrome. *American Journal of Medical Genetics, 133*, 170-175.

Lesser, B., & Kaplan, P. (1994). Long-term monitoring with digital technology for epilepsy. *Journal of Child Neurology, 9*(Suppl.), S64-70.

University of Cape Town

Levin, K. (2004). Paediatric traumatic brain injury in South Africa: Some thoughts and considerations. *Disability and Rehabilitation, 26*, 306-314.

Levin, H., & Eisenberg, H. (1979). Neuropsychological impairment after closed head injury in children and adolescents. *Journal of Pediatric Psychology, 4*, 389-402

Lezak, M. D., Howieson, D. B., Loring, D. W., Hannay, H. J., & Fischer, J. S. (2004). *Neuropsychological assessment* (4th ed.). New York: Oxford University Press.

Magnuson, K. A., & Duncan, G. J. (2006). The role of family socioeconomic resources in the black-white test score gap among young children. *Developmental Review, 26,* 365-399.

Marsh, N. V., Kersel, D. A., Havill, J. H., & Sleigh, J. W. (1998). Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury, 12*, 225-238.

Martin, D. A. (1988). Children and adolescents with traumatic brain injury: Impact on the family. *Journal of Learning Disabilities, 21*, 464-470.

Miller, J., & Stander, A. (2009). *A two-year demographic profile study: Pediatric traumatic brain injury admissions to the Red Cross War Memorial Children's Hospital* (Unpublished honours thesis). University of Cape Town, South Africa.

Milner, B. (1974). Hemispheric specialization: Scope and limits. In F. Schmitt & F. Worden (Eds.), *The neurosciences: Third study program* (pp. 75-89). Boston: MIT Press.

Mokhosi, M. T., & Grieve, K. W. (2004). African families' perceptions of traumatic brain injury. *South African Journal of Psychology, 34*, 301-317.

Moran, G., Pederson, D. R., Pettit, P., & Krupka, A. (1992). Maternal sensitivity and infant-mother attachment in a developmentally delayed sample. *Infant Behaviour and Development, 15*, 427-442.

University of Cape Town

Murray, H. M., Maslany, G. W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20*, 575-585.

Nell, V., & Brown, D.S.O. (1990). *The epidemiology of traumatic brain injury in Johannesburg: mobility, mortality and etiology* (Technical Report 90/1). Pretoria: Unisa Health Psychology Unit.

Pearson, V., & Chan, T.W.L. (1993). The relationship between parenting stress and social support in mothers of children with learning diasabilities: A Chinese experience. Social *Science & Medicine, 37,* 267-274.

Ponsford, J., & Schönberger, M. (2010). Family functioning and emotional state two and five years after traumatic brain injury. *Journal of the International Neuropsychological Society, 16*, 306-317.

Ponsford, J., Sloan, S., & Snow, P. (1995). *Traumatic brain injury: Rehabilitation for everyday adaptive living.* Hove, UK: Lawrence Erlbaum Associates Ltd.

Ponsford, J., Willmott, C., Rothwell, A., Cameron, P., Kelly, A., Ayton, G., … & Nelms, R. (1997). Cognitive and behavioural outcome following mild traumatic brain injury in children. *Journal of International Neuropsychological Society, 3, 225.*

Prigatano, G. P., & Gray, J. A. (2007). Parental concerns and distress after paediatric traumatic brain injury: A qualitative study. *Brain Injury, 21*, 721-729.

Prigatano, G. P., & Gray, J. A. (2008). Parental perspectives on recovery and social reintegration after pediatric traumatic brain injury. *Journal of Head Trauma Rehabilitation, 23*, 378-387.

Reiss, A., Abrams, M., Singer, H., Ross, J., & Denckla, M. (1996). Brain development, gender and IQ in children: A volumetric imaging study. *Brain, 119,* 1763-1774.

Rivara, J. B., Jaffe, K. M., Fay, G. C., Polissar, N. L., Martin, K. M., Shurtleff, H. A., & Liao,

University of Cape Town

S. (1993). Family functioning and injury severity as predictors of child functioning one year following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 74*, 1047-1055.

Rivara, J. B., Jaffe, K. M., Polissar, N. L., Fay, G. C., Liao, S., & Martin, K. M. (1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation, 77*, 754-764.

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation, 22*, 14-25.

Santos, S. (1992). Adaptação Portuguesa, Para Crianças Em Idade Escolar, Do Parenting Stress Index (PSI): Resultados Preliminares. Revista *Portuguesa de Psicologia, 28,* 115-132.

Savage, R. C., DePompei, R., Tyler, J., & Lash, M. (2005). Paediatric traumatic brain injury: A review of pertinent issues. *Pediatric Rehabilitation, 8*, 92-103.

Schwartz, L., Taylor, H. G., Drotar, D., Owen, K., Wade, S. L., & Stancin, T. (2003). Long-term behavior problems following pediatric traumatic brain injury: Prevalence, predictors and correlates. *Journal of Pediatric Psychology, 28*, 251–63.

Serio, C. D., Kreutzer, J. S., & Witol, A D. (1997). Family needs after traumatic brain injury: A factor analytic study of the Family Needs Questionnaire, *Brain Injury, 11*, 1-9.

Shilumani, C. (2004). Editorial. *Health Systems Research, Research Co-ordination and Epidemiology, 6*, 1-4.

Sigelman, C. K., & Rider, E. A. (2003). *Life-span human development.* Wadsworth, a division of Thomson Learning, Inc: United States of America.

Simpson, G., Mohr, R., & Redman, A. (2000). Cultural variations in the understanding of

University of Cape Town

traumatic brain injury and brain injury rehabilitation. *Brain Injury, 14*, 125-140.

Solis, M. L., & Abidin, R. R. (1991). The Spanish version of the Parenting Stress Index: A psychometric study. *Journal of Clinical Child Psychology, 20,* 372-378.

Sommer, K., Whitman, T. L., Borkwowski, J. G., Schellenbach, C., & Maxwell, S. (1993). Cognitive readiness and adolescent parenting. *Developmental Psychology, 29*, 389-398.

South African Government Services (n. d.). Retrieved from http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/caredependencygrant/en_ZA

Stoiber, K. C., & Houghton, T. G. (1993). The relationship of adolescent mothers' expectations, knowledge, and beliefs to their young children's coping behavior. *Infant Mental Health Journal, 14*, 61-79.

Statistics SA. (2007). *South African Statistics, 2007.* Statistics South Africa: Pretoria.

Stuss, D., & Benson, F. (1987). The frontal lobes and control of cognition and memory. In E. Perecman (Ed.), *The frontal lobes revisited* (pp. 141-158). New York. IRBN Press.

Taylor, H.G., & Alden, J. (1997). Age-related differences in outcomes following childhood brain insults: An introduction and overview. *Journal of the International Neuropsychological Society, 3,* 555-567.

Taylor, H. G., Drotar, D., Wade, S., Yeates, K., Stancin, T., & Klein, S. (1995). Recovery from traumatic brain injury in children: The importance of the family. In S.H. Broman & M.E. Michel (Eds.), *Traumatic head injury in children* (pp. 188-218). New York: Oxford University Press.

Taylor, H.G., Wade, S., Yeates, K., Klein, S., & Stancin, T. (1999). Influences on first year recovery from traumatic brain injury in children. *Neuropsychology, 13*, 76-89.

University of Cape Town

Taylor, H. G., Yeates, K., Wade, S., Drotar, D., Stancin, T., & Minich, N. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in children: Behavior and academic achievement. *Neuropsychology, 16*, 15-27.

Telleen, S., Herzog, A., & Kilbane, T. (1989). Impact of a family support program on mothers' social support and parenting stress. *American Journal of Orthopsychiatry, 59*, 410-419.

Thomas, K. A., Renaud, M. T., & DePaul, D. (2004). Use of the Parenting Stress Index in Mothers of Preterm Infants. *Advances in Neonatal Care, 4*, 33-41.

Tladi, L. S. (2006). Poverty and HIV/AIDS in South Africa: an empirical contribution. *Journal of social aspects of HIV/AIDS, 3*, 369-381.

UNAIDS. (2008). *Report on the global HIV/AIDS epidemic 2008: Executive summary* (UNAIDS/08.27E / JC1511E). Geneva, Switzerland: UNAIDS. Retrieved from http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp

Vanderploeg, R. D. (ed.) (2000). *Clinician's guide to neuropsychological assessment* (2nd ed.). Mahwah, New Jersey: Lawrence Erlbaum.

Van der Berg, S. & Louw, M. (2004). Changing patterns of South African income distribution: Towards time series estimates of distribution and poverty. *South African Journal of Economics, 72*, 546-572.

Van der Knaap, M. S., Valk, J., Bakker, C. J., Schooneveld, M., Faber, J. A., Willemse, J., & Goosskens, R. H. (1991). Myelination as an expression of the functional maturity of the brain. *Developmental Medicine and Child Neurology, 33,* 849-857.

Van Heugten, C. M., Hendriksen, J., Rasquin, S., Dijcks, B., Jaeken, D., & Vles, J. H. S. (2006). Long-term neuropsychological performance in a cohort of children and adolescents after severe paediatric traumatic brain injury. *Brain Injury, 20*, 895–903.

University of Cape Town

Waaland, P. K., & Kreutzer, J. S. (1988). Family response to childhood traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 3*, 51-63.

Wade, S. L., Stancin, T., Taylor, H. G., Drotar, D., Yeates, K. O., & Minich, N. M. (2004). Interpersonal stressors and resources as predictors of parental adaptation following pediatric traumatic injury. *Journal of Consulting and Clinical Psychology, 72*, 776-784.

Wade, S. L., Taylor, H. D., Drotar, D., Stancin, T., & Yeates, K. O. (1996). Childhood traumatic brain injury: Initial impact on the family. *Journal of Learning Disabilities, 29*, 652-661.

Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (1998). Family burden and adaptation during the initial year after traumatic brain injury in children. *Pediatrics, 102*, 110-116.

Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., Yeates, K. O., & Minich, N. M. (2002). A prospective study of long-term caregiver and family adaptation following brain injury in children. *Journal of Head Trauma Rehabilitation, 17,* 96-111.

Walsh, K.W. (1978). *Neuropsychology: A clinical approach.* New York: Churchill Livingston.

Watanabe, Y., Shiel, A., Asami, T., Taki, K., & Tabuchi, K. (2000). An evaluation of neurobehavioural problems as perceived by family members and levels of family stress 1-3 years following traumatic brain injury in Japan. *Clinical Rehabilitation, 14*, 172-177.

Watanabe, Y., Shiel, A., McLellan, D. L., Kurihara, M., & Hayashi, K. . (2001). The impact of traumatic brain injury on family members living with patients: A preliminary study in Japan and the UK. *Disability and Rehabilitation, 23*, 370-378.

University of Cape Town

Webster-Stratton, C. (1990a). Enhancing the effectiveness of self-administered videotape parent training for families with conduct-problem children. *Journal of Abnormal Child Psychology, 18*, 479-492.

Webster-Stratton, C. (1990b). Stress: A potential disrupter of parent perceptions and family interactions. *Journal of Clinical Child Psychology, 19*, 302-312.

Webster-Stratton, C., & Hammond, M. (1988). Maternal depression and its relationship to life stress, perceptions of child behavior problems, parenting behaviors, and child conduct problems. *Journal of Abnormal Child Psychology, 16*, 299-315.

Witol A, Sander, A, Kreutzer, J. (1996). A longitudinal analysis of family needs following traumatic brain injury. *Neurorehabilitation, 7,* 175–187.

World Bank (2006). *World Development Indicators*. Washington, D.C.: The World Bank.

Wrightson, P., McGinn, V., & Gronwall, D. (1995). Mild head injury in preschool children: Evidence that it can be associated with persisting cognitive defect. *Journal of Neurology, Neurosurgery, and Psychiatry, 59,* 375-380.

Zakreski, J. R. (1983). *Prematurity and the single parent: Effects of cumulative stress on the child development.* Unpublished doctoral dissertation, University of Virginia, Charlottsville.

University of Cape Town

University of Cape Town

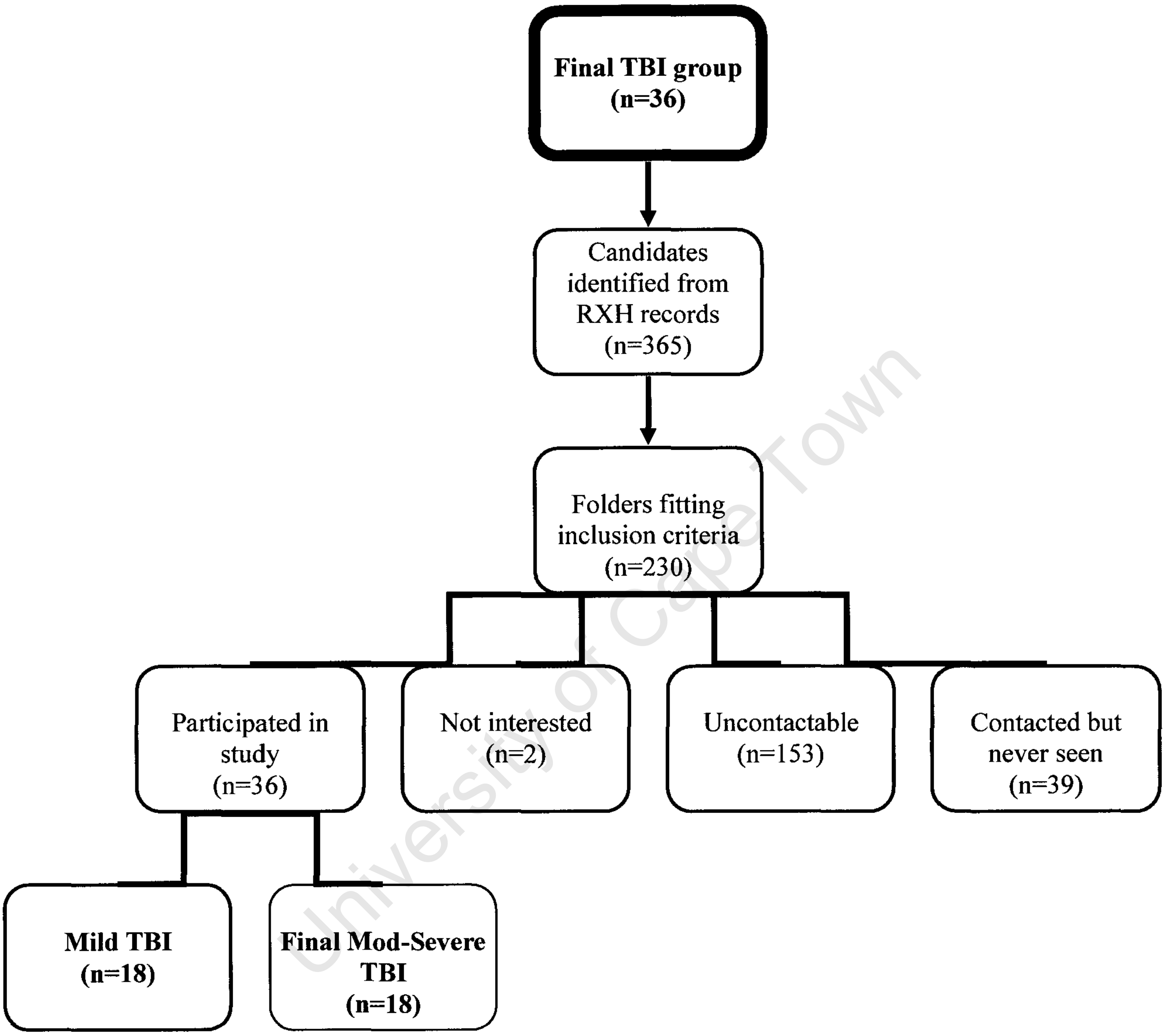
Appendix A

Measures of Severity of Injury

Hawley, Ward, Magnay, and Long, (2003) determined severity of participants brain injuries using the Glasgow Coma Scale (GCS) and length of unconsciousness caused by TBI. They classified a severe head injury as being an injury that caused unconsciousness for longer than 6 hours, and a GCS of 3-8; a moderate head injury as being an injury causing unconsciousness for more than 15 minutes, and a GCS of 9-12; and a mild head injury as being an injury causing unconsciousness for less than 15 minutes and a GCS of 13-15.

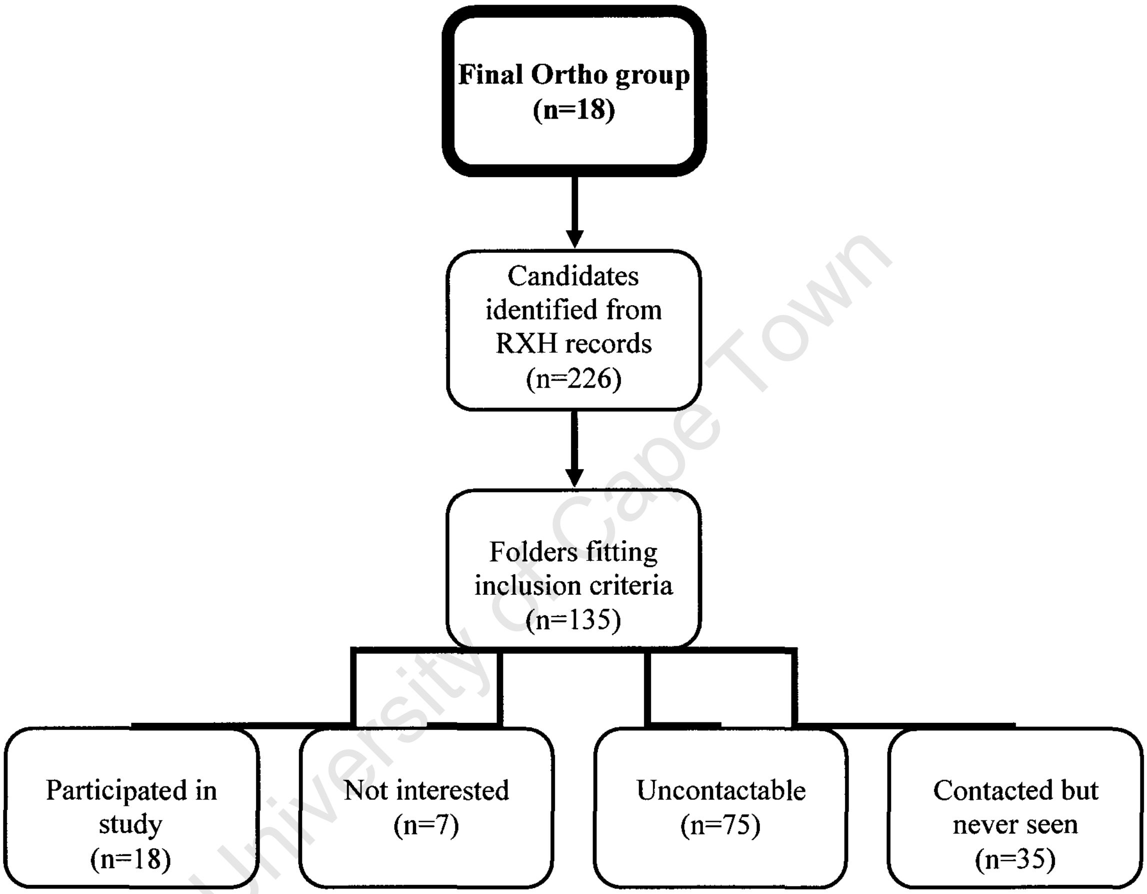
University of Cape Town

Appendix B
Flow Chart of TBI Participant Recruitment



University of Cape Town

Appendix C
Flow Chart of Orthopedic Participant Recruitment



University of Cape Town

Appendix D

Department of Psychology

Dear Parent,

I am currently doing some research and would appreciate your help. My research is looking at families experiences of looking after a child with a head injury. I would like to compare these families experiences to families who look after healthy children (ie have never had to go to hospital due to an injury).

I am therefore asking if you would be willing to fill in two questionnaires for me. The first asks general questions about you and your famiy, such as how big is your household. The second questionnaire asks questions about your child's behaviour and your parenting behaviour. It should not take you more than one hour to fill them both in.

If you are willing to fill the questionnaires in, please fill in the reply slip below and send it back to Silverlee Primary by Friday 12 June 2009. I will then give the questionnaires to the school who will send them home with your child.

Kind Regards,
Deirdre Oosthuizen
Masters Student
University of Cape Town

Reply Slip (please fill in the following and circle your choice)

I am interested in taking part in this research: Yes or No

I would prefer the questionnaire to be in this language: English or Afrikaans or Doesnt Matter

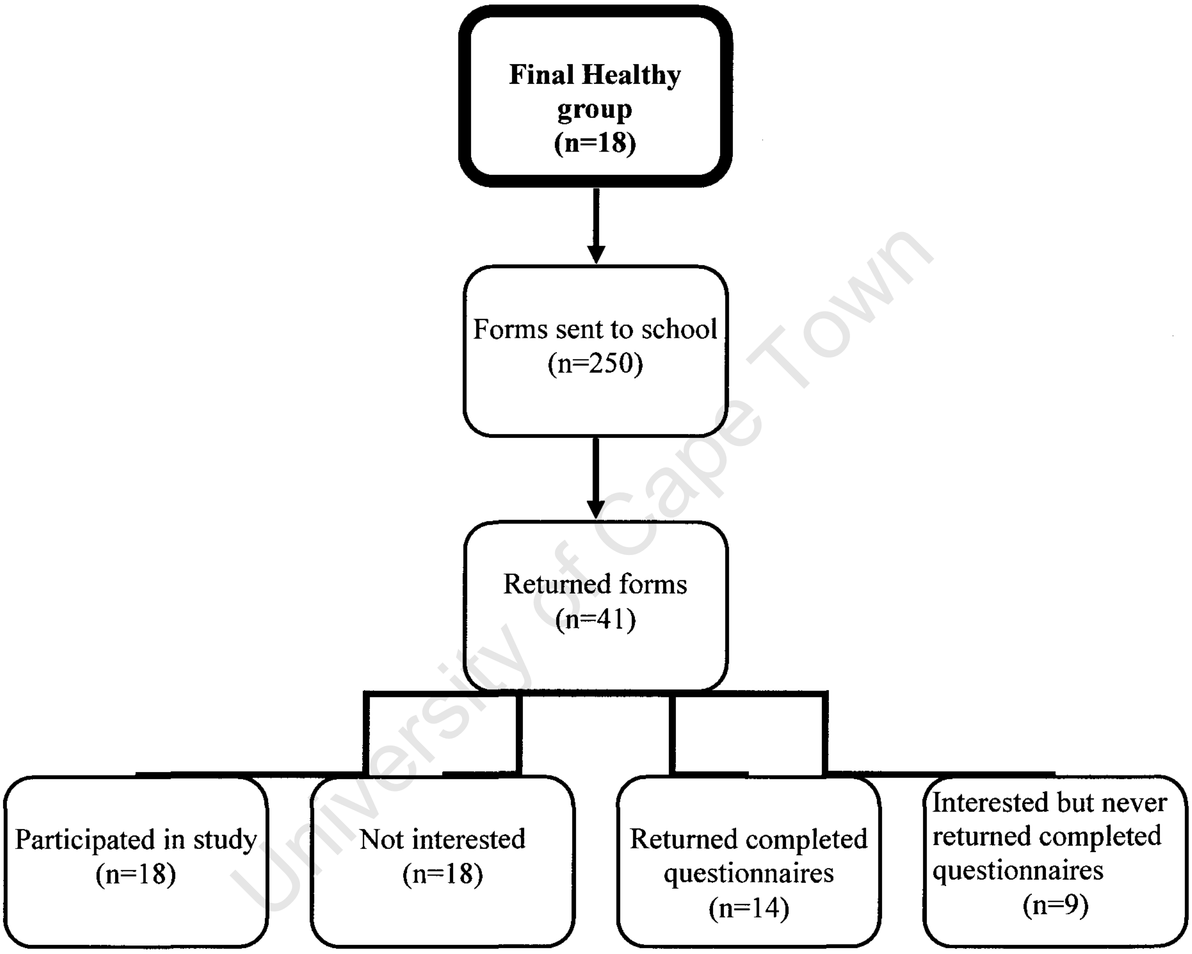
Name of parent:
Name of child:
Grade:
Age:
Male or Female

My child has had a previous head injury or other injury which has caused him/her to go hospital.

Yes or No

University of Cape Town

Appendix E
Flow Chart of Healthy Control Participant Recruitment



University of Cape Town

Appendix F

Demographic Questionnaire

Child's Name:______________________________

Caregiver's Name:______________________________

1. **Age of caregiver:** **Age of child:**
2. **Relation to child (please circle) : Father Mother Grandmother Grandfather Aunt Uncle Guardian**
3. **What is your race or ethnic background?**
    WHITE
    AFRICAN
    COLOURED
    ASIAN
    OTHER: (specify) __________
4. **Religion**:____
5. **Home Language**: ____
6. **Size of house (indicate the number of rooms in the house)**:______________________________
7. **Number of people who live in the house**:____
8. **Are you married, divorced, or living with a partner?** ____________________________________
9. **Do you live with your extended family (e.g., aunts, cousins, grandparents)**? ________________

    9.1. What term best describes the kind of neighbourhood in which you live?
    SUBURBAN
    URBAN
    TOWNSHIP

University of Cape Town

INTERMEDIATE

9. What is the name of the neighbourhood in which you live? ___________________

10. Household Income per month (tick appropriate income category):

0 -2000:	___________
2000-4000:	___________
4000-6000:	__________
6000-8000:	__________
8000-10000:	__________
Above 10000:	__________

11. Your occupation: ___________________________

12. Your spouses/partners occupation: ___________________________

13. Please give details about your child's injury: (how? where?)

____

____

____

____

14. Did your child experience a loss of consciousness due to the injury?

____

15. Premorbid functioning
(How did the child do at school before the accident? How was his/her behaviour at home/school?)

____

____

____

16. Has your child had a previous head injury? Yes / No

University of Cape Town

EDUCATION

17. Education of caregiver (highest grade completed): ________________________

2

18. Current grade of child (highest grade completed): ________________________

3

19. Has the child repeated a grade since the injury?: ________________________

20. Has the child had a learning disability before the injury (For example a lot of difficulty with maths or reading). Please explain. ________________________

21. Has most of the child's schooling been in a rural or urban setting (circle one)?

RURAL URBAN

22. How many children are in your child's class?

____

23. How many teachers are in the classroom (e.g., is there just one teacher or a teacher assistant also present)?

____

__

24. What type of school does your child attend (e.g.,, government, former model C government school, private school)?

____

____

University of Cape Town

Appendix G

Family Burden of Injury Interview – Short Form

Date: ____________

Family Burden of Injury Self-report Questionnaire

What is your relationship to the child? (circle 1)

Mother Father Grandmother Guardian Other
Explain: ______________

Please rate how much stress each of the following issues has caused for you since the child's injury using the following scale.

0 NOT AT ALL STRESSFUL	1 A BIT STRESSFUL	2 FAIRLY STRESSFUL	3 QUITE STRESSFUL	4 EXTREMELY STRESSFUL	NA Not Applicable

Statement	**Stress Rating**					
• Concerns about how your child reacts or relates to you or your spouse/partner Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Disciplining or managing your child's behavior Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• The behavior of your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Disciplining or managing your other children's behavior Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Concerns about how your other children are reacting to or accepting __________'s injury or any consequences of the injury	0	1	2	3	4	NA
• Concerns about your child's recovery from the injury, or about any possible problems related to the injury in the future	0	1	2	3	4	NA
• Consequences of the injury affecting the day to day life in your family	0	1	2	3	4	NA
• You or your spouse missing work or other commitments because of the injury or any consequences of the injury	0	1	2	3	4	NA

University of Cape Town

Please continue to rate how much stress each of the following issues has caused for you since the injury using the following scale:

0 NOT AT ALL STRESSFUL	1 A BIT STRESSFUL	2 FAIRLY STRESSFUL	3 QUITE STRESSFUL	4 EXTREMELY STRESSFUL	NA Not Applicable

4Statement	**Stress Rating**					
• Taking care of your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Taking care of daily chores, such as shopping or household tasks Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Difficulties handling or accepting feelings about the injury	0	1	2	3	4	NA
• Achieving your long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Achieving your spouse's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Achieving your injured child's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Achieving your other children's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Concerns about how your injured child is accepted by his/her peers Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Concerns about your spouse's/partner's reaction to your child's injury or any consequences of the injury	0	1	2	3	4	NA
• Disagreements between you and your spouse/ partner about how to take care of family problems Are these concerns related to the injury? Y N	0	1	2	3	4	NA

University of Cape Town

Please continue to rate how much stress each of the following issues has caused for you since the injury using the following scale:

0 NOT AT ALL STRESSFUL	1 A BIT STRESSFUL	2 FAIRLY STRESSFUL	3 QUITE STRESSFUL	4 EXTREMELY STRESSFUL	NA Not Applicable

• Talking about your child's injury with your spouse/partner	0	1	2	3	4	NA
• The reactions of others (outside your family) to your child's injury	0	1	2	3	4	NA
• Disagreements with others about how to best care for your family Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Disagreements with others about how to discipline your children, or the kinds of things you allow them to do/not do Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Talking about your child's injury with others	0	1	2	3	4	NA
• Finding time for your own activities Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Finding time to be with your spouse/partner and to do things together Are these concerns related to the injury? Y N	0	1	2	3	4	NA
• Finding time to do things with your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA

University of Cape Town

Appendix H

Family Needs Questionnaire

Your Name: Date:

INTRODUCTION: Family and/or friends of persons who have had a traumatic injury often find they have their own special needs. These needs may or may not have been taken care of during the patient's rehabilitation. Often, these needs change over time. We are interested in seeing how important some of these needs are to you and whether or not those needs have been met. The information you provide will help us to understand the needs of your family as well as other families of persons with serious injuries.

University of Cape Town

DIRECTIONS: For each of the following 40 questions please use the scales described below to tell us about your needs. *Each question contains two parts.*

PART I

For each statement, use the scale below to show how important you feel these needs are by placing a circle around the number which best describes your answer. After rating each statement as 1, 2, 3, 4, use the second scale (right) to relate whether each need is being met.

•	2	3	4
Not Important	Slightly Important	Important	Very Important

PART II

Use the next scale to tell us whether a need has been met. Circle Y (Yes) if the need has been met, circle P (Partly) if the need has only partly been met, and circle N (NO) if the need has not been met at all.

Y	P	N
Yes	Partly	No

EXAMPLES:

This person rated the need as "Important"

The need was rated as being "Partly Met"

1. I need to get enough rest or sleep **x** 1 2 3 4 Y **x** P N

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED………	**PART I** How important is this need?	**PART II** Has this need been met?
1. to be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	1 2 3 4	Y P N
2. to be told daily what is being done with or for the patient.	1 2 3 4	Y P N
3. to give my opinions daily to others involved in the patient's care, rehabilitation, or education.	1 2 3 4	Y P N
4. to be told about all changes in the patient's medical status.	1 2 3 4	Y P N
5. to be assured that the best possible medical care is being given to the patient.	1 2 3 4	Y P N
6. to have explanations from professionals given in terms I can understand.	1 2 3 4	Y P N
7. to have my questions answered honestly.	1 2 3 4	Y P N
8. to be shown that my opinions are used in planning the patient's treatment, rehabilitation, or education.	1 2 3 4	Y P N
9. to have a professional to turn to for advice or services when the patient needs help.	1 2 3 4	Y P N
10. to have different professionals agree on the best way to help the patient.	1 2 3 4	Y P N
11. to have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery).	1 2 3 4	Y P N

University of Cape Town

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED.........	PART I How important is this need?				PART II Has this need been met?		
12. to have complete information on the patient's patient's physical problems(e.g. weakness, headaches, dizziness problems with vision or walking)	1	2	3	4	Y	P	N
13. to have complete information on the patient's problems in thinking (e.g. confusion, memory, or communication).	1	2	3	4	Y	P	N
14. to have complete information on drug or alcohol problems and treatment.	1	2	3	4	Y	P	N
15. to be told why the patient acts different, difficult or strange	1	2	3	4	Y	P	N
16. to be told how long each of the patient's problems is expected to last .	1	2	3	4	Y	P	N
17. to be shown what to do when the patient is upset or acting strange.	1	2	3	4	Y	P	N
18. to have information on the patient's rehabilitative or educational progress.	1	2	3	4	Y	P	N
19. to have help in deciding how much to let the patient do by himself/herself.	1	2	3	4	Y	P	N
20. to have enough resources for the patient (e.g. rehabilitation programs, physical therapy, counselling)	1	2	3	4	Y	P	N
21. to have enough resources for myself or the family (e.g. financial or legal counselling, respite care, counselling, nursing or day care)	1	2	3	4	Y	P	N

University of Cape Town

22. to have help keeping the house (e.g. shopping, cooking, cleaning, etc.)	1 2 3 4	Y P N

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED………	**PART I** How important is this need?	**PART II** Has this need been met?
23. to have help from other members of the family in taking care of the patient.	1 2 3 4	Y P N
24. to get enough rest or sleep.	1 2 3 4	Y P N
25. to get a break from my problems and responsibilities.	1 2 3 4	Y P N
26. to spend time with my friends.	1 2 3 4	Y P N
27. to pay attention to my own needs, job or interests.	1 2 3 4	Y P N
28. to be told if I am making the best possible decisions about the patient.	1 2 3 4	Y P N
29. to have my significant other understand how difficult it is for me.	1 2 3 4	Y P N
30. to have my partner or friends understand how difficult it is for me.	1 2 3 4	Y P N
31. to have other family members understand the patient's problems	1 2 3 4	Y P N
32. to have the patient's friends understand his/her problems	1 2 3 4	Y P N
33. to have the patient's teachers understand his/her problems.	1 2 3 4	Y P N
34. to discuss my feeling about the patient with someone who has gone through the	1 2 3 4	Y P N

University of Cape Town

same experience.

35. to discuss my feelings about the patient with other friends or family. 1 2 3 4 Y P N

36. to be reassured that it is usual to have strong negative feelings about the patient. 1 2 3 4 Y P N

37. help getting over my doubts and fears about the future. 1 2 3 4 Y P N

38. help in remaining hopeful about the patient's future. 1 2 3 4 Y P N

39. Help preparing for the worst. 1 2 3 4 Y P N

40. to be encouraged to ask others to help out. 1 2 3 4 Y P N

University of Cape Town

Appendix I

Dear Parent,

Thank you very much for being willing to participate in this research project. Your input will be very valuable.

In this envelope you will find an informed consent form, a demographic questionnaire, and a Parenting Stress Index questionnaire.

The informed consent form explains to you what the study is about and about your participation in the study. Please read it and then if you are still willing to participate please sign on the line that says "Signature of Person Consenting and Authorizing". Please then also fill out the following page.

The demographic questionnaire asks you basic questions about who you are, where you live, your education etc. This helps us to better understand the people who are participating in this research.

The Parenting Stress Index is a questionnaire that looks at various aspects of your childs' responses to certain situations and their behaviour. It also looks at how you feel and act as a parent. When filling this in please respond only according to the behaviour of the child who you have received this questionnaire through and not according to your other childrens behaviour. Please carefully read the instructions on how to fill this form in. If you have received an Afrikaans version you may either use the response form (which is in English) or just write your response, such as "SSS" or "OS" next to the question.

It is very important that you please answer as many questions as you can as this greatly assists the research. However if you are uncomfortable with any of the questions then please do not feel obliged to answer it.

If you have any questions or problems please feel free to to contact me on 0723484335.

Please return these questionnaires by Friday 26 June. On friday, I will leave envelopes containing your R20 reimbursement for your child to give to you. This is on condition that all of the forms have been returned and filled in. If your child cannot attend school on friday then please contact/sms me and I will give the envelope to your childs teacher on an earlier day, if the forms have been returned.

Thank you,
Deirdre Oosthuizen

University of Cape Town

UNIVERSITY OF CAPE TOWN
DEPARTMENT OF PSYCHOLOGY

Informed Consent to Participate in Research and Authorization for Collection, Use, and Disclosure of Family and Child Needs and Other Personal Data

You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your family and child needs, as well as other information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. By participating in this study you will not be penalized or lose any benefits to which you would otherwise be entitled.

University of Cape Town

1. **Name of Participant ("Study Subject")**

____

2. **Title of Research Study**

Families of children with traumatic brain injuries' experiences and needs in the context of South Africa

3. **Principal Investigator and Telephone Number(s)**

Deirdre Oosthuizen	Kevin G. F. Thomas, Ph.D.
Masters Student	Senior Lecturer
Department of Psychology	Department of Psychology
University of Cape Town	University of Cape Town
0723484335	021-650-4608

4. **Source of Funding or Other Material Support**

None

5. **What is the purpose of this research study?**

The purpose of this research study is to understand better the experiences and needs of families of children who have sustained a traumatic brain injury (TBI) compared to children with orthopedic injuries and healthy children.

6. **What will be done if you take part in this research study?**

In this study, you will be administered one questionnaires regarding your experiences of having a child with TBI and your families' needs because of it. These questionnaires look at a variety of factors including: stressors that have been brought about due to the TBI, how the family's roles and dynamic has changed, what needs the family has, and whether these needs have been met.

Your questionnaire session will be held at either the Red Cross War Memorial Hospital, Groote Schuur Hospital, Silverhurst Primary School, or the University of Cape Town. Each session will be individually conducted by either the principal investigator or a trained member of his research team.

After the questionnaire session is over, you will be informed in detail about the design of the study and the research questions we hope to answer. You will also have the opportunity to ask questions and thus learn more about psychological research.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed in #3 of this form.

University of Cape Town

- **If I choose to participate in this study, how long will I be expected to participate in the research?**

The study consists of only 1 session, which will not last longer than 90 minutes. If at any time during the experiment you find any of the procedures uncomfortable, you are free to discontinue participation without penalty.

- **How many family members are expected to participate in the research?**

125

- **What are the possible discomforts and risks?**

There are no known risks associated with participation in this study. You will be allowed to take breaks whenever requested. It is possible that some sadness or distress may come about through realisation of the magnitude of your situation and perhaps that your needs are not being met. If this happens, we will talk with you and give a referral for care.

If you wish to discuss the information above or any discomforts you or your child may experience, you may ask questions now or call the Principal Investigator.

10a. What are the possible benefits to you?

For your participation in this study you will be compensated R 50 for travel costs.

10b. What are the possible benefits to others?

The information from this study may help improve our understanding of families' experiences and needs in South Africa. Furthermore with a better understanding of families needs in South Africa, this may help in the creation of better TBI rehabilitation programmes and health services.

11. If you choose to take part in this research study, will it cost you anything?

Participating in this study will not cost you anything.

12. Will you receive compensation for taking part in this research study?

You will receive R50 travel compensation for taking part in this study.

13a. Can you withdraw from this study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty.

If you have any questions regarding your rights as a research participant, you may phone the Psychology Department offices at 021-650-3430.

13b. If you withdraw from this study, can information about you still be used and/or collected?

Information already collected may be used.

Once personal and performance information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials. Your research records will not be released without your permission unless required by law or a court order.

14. What information about you may be collected, used and shared with others?

The information gathered from you will be demographic information and records of your

University of Cape Town

families' needs and experiences. If you agree to take part in this research study, it is possible that some of the information collected might be copied into a "limited data set" to be used for other research purposes. If so, the limited data set may only include information that does not directly identify you or your child. For example, the limited data set cannot include your or your child's name, address, telephone number, ID number, or any other photographs, numbers, codes, or so forth that link you or your child to the information in the limited data set.

The results of the research will be presented as part of a Masters research project for the University of Cape Town. Also, the results may be submitted for publication in a peer-reviewed journal. In both instances neither you nor your child will be identified in any way.

10. How will the researcher(s) benefit from your being in the study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator and others attached to this research project may benefit if the results of this study are presented at scientific meetings or in scientific journals.

11. Signatures

As a representative of this study, I have explained to the parent/guardian of the participant the purpose, the procedures, the possible benefits, and the risks of this research study; and how the participant's performance and other data will be collected, used, and shared with others:

University of Cape Town

Signature of Person Obtaining Consent and Authorization Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; and how your experiences, needs, and other data will be collected, used and shared with others. You have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily consent to participate in this study. You hereby authorize the collection, use and sharing of your families' experiences, needs, and other data. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting and Authorizing Date

Please indicate below if you would like to be notified of future research projects conducted by our research group:
_____________ (initial) Yes, I would like to be added to your research participation pool and be notified of research projects in which I or my child might participate in the future.

Method of contact:

Phone number: ________________________
E-mail address: ________________________
Mailing address: ______________________________
____
____

University of Cape Town

UNIVERSITY OF CAPE TOWN

GRADUATE SCHOOL IN HUMANITIES

DECLARATION BY CANDIDATE FOR THE DEGREE OF MASTER IN THE FACULTY OF HUMANITIES

I, (*name of candidate*)

____

of (address of candidate)

____

____

do hereby declare that I empower the University of Cape Town to produce for the purpose of research either the whole or any portion of the contents of my dissertation entitled

____

____

____

in any manner whatsoever.

____________________	________________
CANDIDATE'S SIGNATURE	DATE

University of Cape Town