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Caregiver Health Related Quality of Life and Burden When Caring for Children with Traumatic Brain Injury

A thesis

submitted in fulfilment

of the requirements for the Degree

of

Masters of Social Science in Psychology

at the

University of Waikato

by

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The University of Waikato

Te Whare Wananga O Waikato

2012

Abstract

Often family members take on the responsibility of caregiver when another family member sustains a traumatic brain injury (TBI). The caregiving role is a stressful task which may impact negatively upon caregivers' psychological and physical health. Variables which may contribute to caregiver burden include: caregiver age, educational attainment, income, gender, ethnicity, marital status, supports, time post-injury, and child clinical variables: TBI severity, behavioural functioning and adaptive functioning. The literature varies in its reporting of which areas of health are most affected, and the degree to which sociodemographic and child variables impact upon negative health related quality of life (HRQoL) and burden. To address this the current study explored health outcomes for TBI caregivers using a battery of measures (Medical Study Short Form-36, Hospital Anxiety and Depression Scale, DSM-IV Depression Diagnostic Scale, BAKAS Caregiving Outcomes Scale); questionnaires were also used to collect sociodemographic information and information relating to supports and services used in the rehabilitation of the TBI child. The Behavioural Assessment System for Children was used to collect behavioural and adaptability information from the caregivers about the child. Assessments were carried out at baseline, 1-month, 6-months and 12-months post TBI from a sample of 94 TBI caregivers and at baseline from a sample of 43 Control caregivers.

TBI caregivers experienced poorer overall health and higher levels of depression and were less likely to report positive life changes compared to Control caregivers. Older age and higher income predicted positive life changes. In addition to this higher income predicted better physical and overall health. Ethnicity was found to predict depression with the Māori/‘other ethnicity’ group suffering higher levels of depression. Children’s dysfunctional behaviour was found to predict poorer caregiver health outcomes across several domains; these include physical health, overall health, and depression; while the child’s adaptive functioning was not found to be a predictive factor in any caregiver health domains. New Zealand European and Māori TBI caregivers experienced similar health outcomes and received similar levels of support. However, Māori experienced more positive life changes than New Zealand Europeans. Caregivers’ physical and psychological well-being was found to improve over time, these changes were the greatest between the 1-month and 12-month period.

As a high percentage of children’s TBI’s occur in the home and at school, education aimed at schools and parents to inform of the effects of TBI upon children and families will bring an awareness which may encourage families to seek medical help. In doing so will offer the opportunity to receive or seek support in the initial period post TBI in the hope of reducing the burden for caregivers and producing better health outcomes. Bringing these families into contact with medical services may also help in identifying caregivers at higher risk of poorer health outcomes. Findings of more positive life changes for Māori may suggest cultural ideology is a protective factor in caregiver burden, further investigation may be necessary to understand these cultural differences and how they impact upon the caregiving role.

Acknowledgements

I would like to thank every person who contributed in any way toward my completing this thesis.

Thank you so much to my supervisors Dr Nicola Starkey and Dr Kelly Jones. Nicola, I am extremely appreciative of your time, knowledge, and particularly your patience. You were always positive and supportive which gave me the encouragement I needed to continue on to the finish. Thank you Kelly for your advice and comments which gave me the final push needed to complete my thesis.

Thank you to all the participants who had to sit through hours of testing and offered refreshments; the experiences gained from those meetings were extremely valuable.

I am so grateful to friends and family who have been supportive and understanding at times when I have been busy, in particular my husband Simon; you have been incredibly supportive, always believed in me, and tread carefully when necessary. You listened, encouraged, proof-read, smiled, cooked, gardened, grocery shopped, picked up children and more, everything that was necessary for me to get though one of my toughest years. Lots of hugs and kisses to our four gorgeous children Hannah, Maddison, Olivia and Sophia. Thank you all so much for stepping up and taking over the household duties, you were always there when I needed you with hugs, lots and lots of encouragement, cups of tea and massages!

Thanks to my friends who were always supportive and invited me on walks and shopping trips to get me away from my computer!

Lastly my mother Jenny and mother-in-law Kathlyn, thanks to you both for taking care of the children, and were only ever a phone call away when I needed you, your support was invaluable.

When we become fully aware that our success is due
in large measure to the loyalty, helpfulness,
and encouragement we have received from others,
our desire grows to pass on similar gifts.
Gratitude spurs us on to prove ourselves worthy
of what others have done for us.
The spirit of gratitude is a powerful energizer."

by Wilfred A. Peterson

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Introduction

TBI is the leading cause of death and injury for children and adolescence in New Zealand (Barker-Collo, Wilde, & Feigin, 2008). The impact of TBI upon an individual can affect the health related quality of life (HRQoL) of the TBI child but may also have far reaching effects upon those caring for them. The focus of this study is upon the caregivers of children with TBI, and how the caregiving role impacts upon their HRQoL and burden.

TBI Definition

In the past there has been difficulty in defining traumatic brain injury (TBI). Firstly the terms head injury, traumatic brain injury, and brain injury have been used interchangeably, and secondly some international definitions use criteria which excludes milder injuries, therefore the World Health Organisation (WHO) performed a systematic review of the definitions of TBI to produce a general definition, then generated specific criteria for mild TBI (The New Zealand Guidelines Group, 2006). WHO defined TBI as “an acute brain injury resulting from mechanical energy to the head from external physical forces”, and assigned the following criteria for clinical identification, partly to differentiate between head injury and TBI, and to include milder head injuries (The New Zealand Guidelines Group, 2006). Signs and symptoms may include:

- confusion or disorientation
- loss of consciousness
- post-traumatic amnesia

- other neurological abnormalities, such as focal neurological signs, seizure and/or intracranial lesion (The New Zealand Guidelines Group, 2006).

Research into the incidence and experience of TBI requires a definition and classification to determine what is and is not a TBI, and to determine the severity of the TBI which is classified as mild, moderate or severe (Bellner, Jensen, Lexell, & Romner, 2003). The Glasgow Coma Scale (GCS) is an international scale used to determine severity of head injury. This measure has three scales: eye opening (scored 0-4), verbal responses (scored 0-5), and motor responses (scored 0-6) which are scored lowest to highest on each scale according to level of consciousness and degree of dysfunction (Black's Medical Dictionary, 2010). A score of 13 and above is indicative of mild injury; between 9-12 indicates moderate injury; between 3-8 is indicative of severe injury and 0-3 is brain death (Iankova, 2006). Mild TBI can be further differentiated using Servadei, Teasdale and Merry's (2001) criterion as mild low risk; mild medium risk; and mild high risk.

Epidemiology of Traumatic Brain Injury

The impact of TBI upon the individual is far reaching, not only affecting their quality of life but also affecting friends, family and the society in which they live (Barker-Collo et al., 2008). International statistics report the incidences of TBI are estimated at 600 per 100,000 hospitalisations and non-hospitalisations per year (Carroll et al., 2004). In comparison TBI's medically attended to in Australia are approximately 135,000-160,000 (610-735 per 100,000) per year (Brain Injury Centre Australia, 2003), and 1.5-2 million (approximately 500-650 per 100,000) in America (Gary, Arango-Lasprilla, & Stevens, 2009); although the figures in

America for treated and untreated TBI’s are estimated at 7 million per year (Valente & Fisher, 2011).

New Zealand statistics reflect that of international data, reporting an estimated 100-300 injuries per 100,000 of the population per year, however these figures were drawn from incidence data identified through hospital records only, whereas much higher rates of 1000-3000 per 100,000 were reported by McKinlay et al. (2008) from hospital admissions, individuals seen by General Practitioners and at Accident and Emergency Departments. McKinlay et al’s. (2008) study used minimum inclusion criteria which allowed for the inclusion of TBI cases where the individual sustained an injury to the head but did not seek medical attention which explains the higher incidence rate reported in their study.

Accurate figures of TBI incidence may be difficult to acquire and are vulnerable to inaccuracies for several reasons. Up to 90% of TBI are classified as mild (Cassidy et al., 2004) and many mild cases of TBI go unreported due to individuals not seeking medical attention. When injuries are not medically attended to they are not referred to ACC which excludes them from being recorded in ACC statistics (The New Zealand Guidelines Group, 2006). Also TBI that are medically attended to may not be investigated or recognised as a TBI in light of other more prominent injuries (Barker-Collo et al., 2008). Many studies rely on hospital admission data which potentially misses cases of TBI that are attended to by General Practitioners or at Accident and Emergency Departments due to not being admitted (McKinlay et al., 2008; The New Zealand Guidelines Group, 2006). Also a proportion of child abuse and domestic violence cases may not be included in statistics due to many of these incidences going unreported

(Pearce, 2011) or reported but not assessed for possible TBI (Banks, 2007). Inaccuracies were also reported by McKinlay et al. (2008) due to relying on self-report and recall, however Barker-Collo et al. (2008) attempted to take all the above factors into consideration and estimated a total New Zealand figure of 22,000-33,000 new incidences of TBI per year ranging from mild through to severe.

Ethnicity

Māori and Pacific Islanders make up 19% of reported TBI cases in New Zealand which is marginally less than the proportion of Māori and Pacific Islanders (21.5%) that make up the total New Zealand population (The New Zealand Guidelines Group, 2006). Figures recorded in the National Health Database from hospital discharge records show for the period 2003-2004 approximately 520 per100,000 Māori and Pacific Islanders sustained a TBI, compared to 200 per 100,000 for the remaining New Zealand population.

Individuals of lower socioeconomic status have been identified in New Zealand and overseas as at higher risk of sustaining a TBI (Arlidge et al., 2009; Barker-Collo et al., 2008). Therefore as Māori and Pacific Island people have higher rates of unemployment, lower incomes, poorer rates of educational attainment and poorer housing conditions in comparison to Europeans (e.g., Barnett, Pearce, & Moon, 2005; Marie, Fergusson, & Boden, 2008; McNaughton, Weatherall, McPherson, Taylor, & Harwood, 2002), this places them at higher risk of sustaining a TBI than New Zealand Europeans. It is difficult to separate ethnicity and socioeconomic factors when referring to influences associated with the prevalence of TBI.

Age and Gender

International statistics show incidence of TBI are highest among teenagers and young adults (Carroll et al., 2004). This is consistent with presentations and admissions for TBI at the Christchurch Hospital Emergency Department in 2004, which offered a snapshot of age related TBI incidences within the New Zealand population (McKinlay et al., 2008). The 0-25 year age group accounted for 52% of the total presentations, with 25.9% of those being children and adolescents under the age of 18 (The New Zealand Guidelines Group, 2006). New Zealand statistical data reports males were twice as likely to sustain head injuries than their female counterparts (Barker-Collo et al., 2008; The New Zealand Guidelines Group, 2006) which is consistent with international data (Cassidy et al., 2004; Hirschberg, Weiss, & Zafonte, 2008; Langlois, Rutland-Brown, & Thomas, 2004).

TBI Severity

Mild injuries make up approximately 80-90% of reported TBI’s whereas moderate and severe TBI’s each account for approximately 5-10% of injuries. A review of international literature from United States, Europe and South Africa reported statistical information relating to severity of injury varied (Bruns & Hauser, 2003). Mild injuries were reported to account for 62%-80% of injuries; however the authors suggested typically 80% of incidences were mild, with 10% falling into the moderate category and 10% being severe.

The New Zealand Guidelines Group (2006) estimates approximately 90% of TBI’s sustained by the New Zealand population are mild, with the remaining 10% falling into the moderate to severe range. This estimation of severity in incidence data was consistent with research conducted by McKinlay et al. (2008) reporting 10% of a recruitment cohort of 458 TBI children, adolescent and young people were classified as having moderate to severe TBI.

International statistics were slightly less than that reported for the New Zealand population, however Bruns and Hauser (2003) stated multiple classification schemes were used throughout the international studies as well as the inclusion of data not intended for research, making inter-study comparisons difficult.

Mechanism of Injury

Motor vehicle accidents and falls appear consistently as prime contributors to TBI incidences (Blankfeld & Holahan, 1999; Cassidy et al., 2004; Majdan et al., 2011; The New Zealand Guidelines Group, 2006; Trudel, Scherer, & Elias, 2009), however McKinlay et al. (2008) found when researching prevalence of TBI in the New Zealand population the primary mechanism of injury was dependent upon the age of the individual. Falls accounted for 66.7% of injuries sustained by children under15-years old, while the second highest contributor was being hit with an object (10.5%). Motor vehicle accidents only accounted for 3.3% of injuries in this age group; although they were reported as a significant contributor to TBIs in the 15-25 year age group (Barker-Collo et al., 2008; McKinlay et al., 2008). Interpersonal violence and rugby incidences were found by McKinlay et al. (2008) to also be prime contributors to TBI in the 0-25 year age group. Other prominent contributors to TBI in all age groups under 25 years are sporting injuries, bicycle accidents and industrial incidents.

Consequences of TBI for the Child

The physical, cognitive and behavioural effects from sustaining a TBI may vary between individuals. This may depend upon which area of the brain is damaged and severity of the injury. Individuals with severe TBI are likely to suffer more obvious physical disabilities as well as significant changes to cognitive ability, attentional functioning, behavioural functioning and social functioning (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005). According to Anderson et al. (2005) cognitive and attentional deficits present as slowed information processing, issues with decision making and memory deficits; behavioural deficits present as poor emotional control, irritability, aggression and fatigue (Anderson et al., 2005); and social functioning pertains to communication difficulties (Stancin, Wade, Walz, Yeates, & Taylor, 2010). Brooks and McKinlay (1983) report additional behavioural deficits include childishness (reduced reasonableness and ‘being down to earth’) and dependency, however the authors noted the extent of these changes may be attributable to the pattern of the brain injury, pre-traumatic personality characteristics, and the nature of the environment the TBI individual finds themselves in post-TBI. Individuals sustaining severe injuries are also more likely than those with mild injuries to suffer clinical levels of anxiety and depression (Coetzer, Carroll, & Ruddle, 2011).

Individuals sustaining milder injuries may suffer symptoms such as headaches, tiredness, dizziness, concentration problems, blackouts and vision impairment (Petersen, Scherwath, Fink, & Koch, 2008). These issues can be expected to resolve themselves over a matter of days or weeks, although some individuals may suffer the consequences for years to come (Moreau, 2010).

Continuing problems may be due to new symptoms such as stress, anxiety, depression and insomnia developing as a result of the initial injury. Pre-existing medical conditions, personality, psychosocial stage of development, psychological states and coping behaviours were found to also influence the recovery process (Brooks & McKinlay, 1983; Moreau, 2010). This was reiterated in Taylor et al's. (2010) study which emphasised the importance of considering non-injury background characteristics when evaluating post concussive symptoms (PCS) in children with TBI. The study findings indicated these pre-injury characteristics correlated with measures of PCS.

Consequences of TBI for the Caregiver

After TBI there can be a multitude of physical, cognitive and emotional changes which may prove distressing for the TBI individual and their families, however although families play a significant role in the caring process, the primary caregiving role is often undertaken by one primary family member. This role is repeatedly reported in research to place undue strain and burden upon the caregiver, resulting in poorer physical, mental and overall health and well-being (Langlois et al., 2004; Marsh, Kersel, Havill, & Sleigh, 2002; Petersen et al., 2008; Pinquart & Sorensen, 2003; Wallace et al., 1998). These caregivers have been referred to as the "hidden patients" as up until three decades ago little attention had been paid to understanding the experiences of caregiving and researching interventions to meet their needs (Fengler & Goodrich, 1979). Now with an increased awareness of the impact caring for an individual with TBI has upon primary caregivers, more attention is being paid to their needs. Outcomes for caregivers of TBI children are generally negative (Brooks, 1991) with research comparing non-caregiver and caregiver samples finding 30% to 50% of caregivers reported poorer HRQoL (Marsh, Kersel, Havill, & Sleigh, 1998). Key health facets affected were increased emotional distress (Robertson, Zarit, Duncan, & Rovine, 2007), depression, anxiety and increased risk of pathology (Phillips, Gallagher, Hunt, Der, & Carroll, 2009).

Variables Influencing HRQoL and Burden for the Caregiver

Studies are being conducted to bring to light primary variables which are most likely to contribute to the burden of caregiving (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010; Ponsford et al., 2001). These include caregiver variables: age, educational attainment, income, gender, ethnicity, family functioning, stress appraisal and coping, supports, time post-injury; and child variables: TBI severity, behavioural functioning and adaptive functioning. Behavioural deficits are described as maladaptive changes in responding to environmental demands as a result of the TBI, and adaptive functioning pertains to cognitive, motor, perceptual, behavioural and affective disturbances that compromise adaption to the environment (Fulton, Prigatano, & Wethe, 2010).

Age and Educational Attainment

Age has often been linked to caregiver burden with studies indicating younger caregivers experience higher levels of stress (Nabors, Seacat, & Rosenthal, 2002) due to various reasons such as managing the caregiving role in conjunction with work, and caring for other young children (Fitting & Rabins, 1985). Younger caregivers with lower educational attainment were found more likely to report their needs as being unmet than that of older caregivers, this was thought due to not having the life experience to cope with adversity (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). However this also may suggest a correlation between financial situation and burden with the likelihood the younger age group participants with lower level education were also on low incomes. Nabors et al's. (2002) research supports this idea finding younger caregivers with lower educational attainment and incomes reported higher levels of burden due to restricted access to better health care facilities and supports.

Income

The effects of financial constraints were investigated by MacKenzie et al. (2009) to determine how changes in financial position affected caregivers of children with TBI. Role changes such as reducing hours of work or ceasing work altogether to accommodate the child had financial implications such as a lack of insurance to pay for health care needs and travel expenses. These constraints were found to increase burden particularly when the caregivers perceived their financial needs as being unmet. Interestingly Nabors et al. (2002) found a significant relationship between caregivers perceiving their needs as being unmet, household income and the behavioural/affective problems of the TBI child; caregivers who perceived negative behavioural and adaptive changes in their child reported the highest percentage of unmet needs, and lower incomes. This correlation may suggest the behavioural and adaptive changes in the child places more cognitive and physical strain upon the caregiver, therefore having to reduce their working hours and pay for additional health care for the child.

The extent financial burden impacts upon the caregiver may differ depending upon the country of residence and their health policies. MacKenzie et al. (2009) reported in countries where there was no free health care a significant amount of burden was endured by families due to financial costs, particularly for those without health insurance (MacKenzie et al., 2009). Health care in New Zealand may be partially funded through ACC for accidental injuries; therefore financial problems relating to the injury may not be a significant contributor to burden for New Zealand caregivers. This was evident in Marsh et al.'s (1998) study upon 123 caregivers of TBI patients enrolled in the Waikato Traumatic Brain Injury Study. Financial burden was not one of the most significant factors contributing to distress, however over 50% of participants did report financial burden as a contributing factor.

Gender

Females tend to dominate the caregiving role in both western and ethnic cultures (Navidian & Bahari, 2008; Schneider, Steele, Cadell, & Hemsworth, 2011). Although according to Russell (2008) there are increasing instances of males in caregiving roles which may be the result of more women moving into the workforce and the changing social roles of males and females. Previous research indicates spousal caregiver relationships are more emotionally distressing and disruptive than the parent-child dyad (Degeneffe, 2001; Jorgensen, Parsons, Jacobs, & Arksey, 2010); despite this female caregivers have been found to experience higher levels of anxiety, depression and burden than males regardless of the relationship to the care-receiver (Blankfeld & Holahan, 1999; Carod-Artal, Coral, Trizotto, & Moreira, 2009; Gan et al., 2010; Navidian & Bahari, 2008; Papastavrou et al., 2007; Sorensen & Pinquart, 2005). It has been suggested this inequality may be due to women being more transparent with their emotions

(Kramer & Kipnis, 1995); spending longer periods of time dedicated to the caregiving role; differing in types of care offered (help with personal cares & hands on care) (Kramer & Kipnis, 1995); being more pressured by cultural obligations; being more limited socially, and using more emotion-focused strategies (grieving, self-accusation and worrying) when under stress as opposed to problem-focused strategies (problem confrontation, information seeking and seeking of social supports) (Papastavrou et al., 2007).

Ethnicity

Ethnicity has been reported in numerous studies to influence the HRQoL outcomes for caregivers (Donovan, Williams, Stajduhar, Brazil, & Marshall, 2011; Martin, 2000). One of the influential factors associated with ethnicity is familism, which like collectivism values family systems and integration rather than individual members within that system (Chun, Knight, & Youn, 2007; Sayegh & Knight, 2010). Differences were found by Haley et al. (1995) between ethnic groups immersed in familism and individualistic ethnic groups in their acceptance of caregiving duties. Caregivers immersed in familism were more likely to experience lower levels of burden (Haley et al., 1995; Robertson et al., 2007) and stronger feeling of emotional fulfilment and personal satisfaction (Scarlach et al., 2006). This may be due to expectations surrounding caring for family members being normative for this group rather than disruptive, therefore appraising their caregiving role as non-burdensome.

Cultural beliefs and values shape the caregiving experience and how they perceive the caregiving role. Some cultures are less likely to use formal supports due to familial obligations of using supports within the family environment, or finding formal services not culturally appropriate or sensitive to their needs (Dilworth-Anderson, Williams, & Gibson, 2002; Sorensen & Pinquart, 2005). The latter was found to be the case when Arlidge et al. (2009) conducted a multi-ethnic qualitative study on the experiences of Whānau from Māori and Pacific Island ethnicities, when caring for children with injuries requiring hospital treatment**.** Issues arose which undermined the social competency of Whānau members, particularly pertaining to communication, sourcing information and navigating the hospital environment. Caregivers reported feeling their culture was not being respected due to a lack of understanding and awareness of their needs, therefore shaping negative perceptions of supports and service, and restricting future access to these (Arlidge et al., 2009). If the need for support is significant for Māori and Pacific Islanders, yet they have trouble accessing culturally responsive supports as was found in Arlidge et al. (2009), this may be a contributing factor to poorer long-term health outcomes and burden for Māori and Pacific Island caregivers and their families. Although familism may be a protective factor in adapting to the caregiving role, this may not offer protection against the negative experiences of accessing support outside the family environment.

Family Functioning

Families, regardless of cultural affiliation, may be affected by the negative long term impact of TBI (Nabors et al., 2002). There is a consensus among professionals that the health and well-being of an individual rests largely upon the family (Degeneffe, 2001; Frain et al., 2007; Hocking & Lochman, 2005). Well-functioning cohesive families may bear the effects of considerable strain; however dysfunctional families are thought to be more vulnerable to the negative effects of caring for a TBI family member (Carnes & Quinn, 2005). These functional deficits include low family cohesion, marital conflict, and inflexible coping strategies (Maitz, 1990; Moore, Stambrook, & Peters, 1993). It is necessary to understand family dynamics which influence how the family as a unit manage stressors, as this impacts upon how the primary caregiver within the family will cope. Theoretical models for stress and coping provide a framework in which to understand differences in how individuals cope with life stressors.

Thompson et al's. (1994) Transactional Stress and Coping Model (see Figure 1) looks to explain the coping process and exhibits the diversity of influences that impact upon adjustment to illness within the family. This model highlights adjustment to illness is not just a function of the illness itself, but is a function of transactions between the parameters of the illness, clinical characteristics; demographic characteristics of the caregiver and child; and in particular family adaption processes (Hocking & Lochman, 2005).

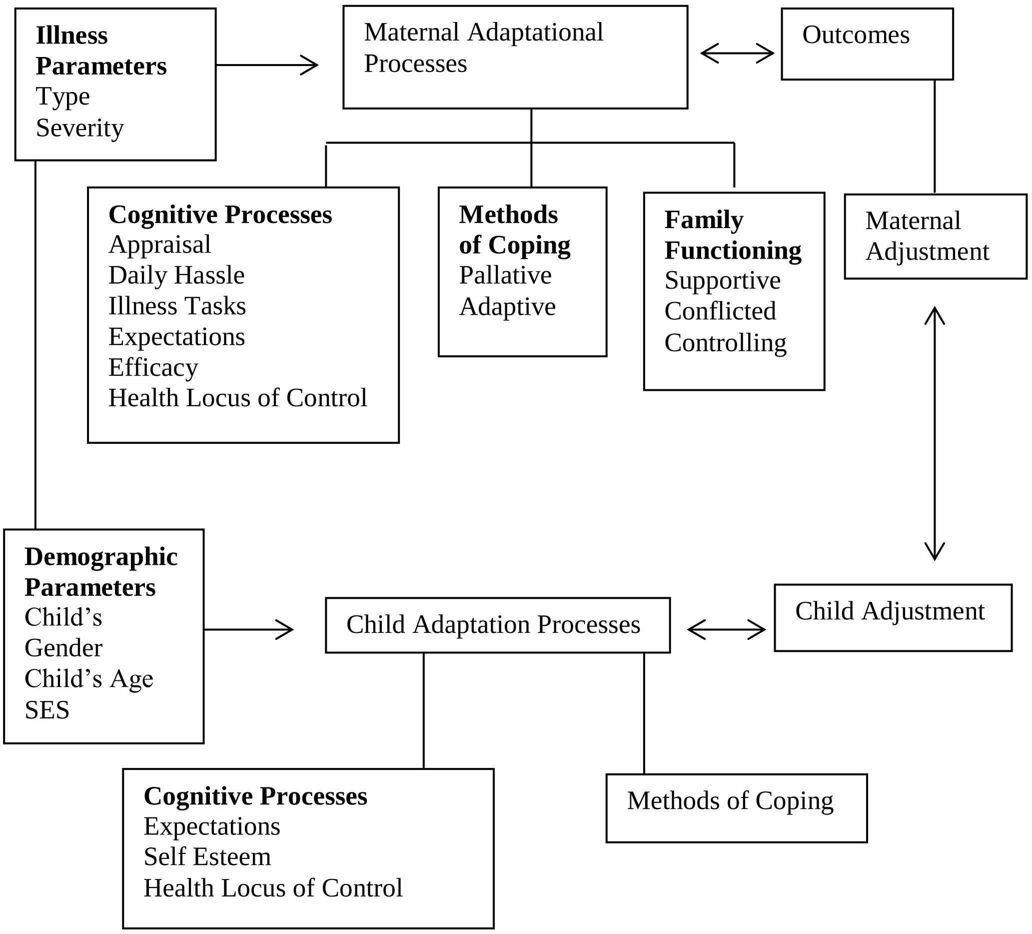

Figure 1. Transactional Stress and Coping Model of adjustment to chronic illness (Thompson et al., 1994).

The importance of understanding family adaption processes has been highlighted by Wade et al. (2001) recommending that cognitive appraisal and coping methods are a potential point of intervention in helping reduce the burden of caregiving upon families and the primary caregiver.

Stress Appraisal and Coping

Appraisal and coping are concepts which differentiate how individuals perceive and manage a situation. An individual will evaluate a situation then interpret the outcome as positive, threatening or irrelevant, using preconceived ideas; expectancies drawn from life experiences, culture and other factors. In the case of the caregiver of a child with TBI, this primary cognitive appraisal may involve harm, threat, loss, challenge, or concern (Aldwin, 2000). When one or more of the above factors are present in their appraisal, the emotional and physiological reaction known as stress occurs (Lazarus & Folkman, 1984).

Stress is a typical response to overwhelming environmental demands. Individuals are likely to experience stress when there is a mismatch between the capacity of their own resources, and the demands placed upon them by environmental forces which they perceive to overwhelm their capabilities (Lazarus, 1993). Caregivers' appraisal of a situation as stressful may be exacerbated when they have pre-existing life stressors; the more distressing a caregiver appraises their situation to be, the more stress they are likely to experience causing higher levels of anxiety and depression (Harris, Godfrey, Partridge, & Knight, 2001). This was found by Stancin et al. (2010) to be the case when researching family adaption to caregiving, revealing caregivers experienced higher levels of stress regardless of TBI related factors (e.g., severity, behavioural and adaptive problems) when perceiving their pre-injury situation (negative life events, chronic stressors, lack of resources, low levels of family functionality) as stressful. It has been demonstrated that stress, appraisal and coping behaviours impact upon caregivers' psychosocial adjustment following TBI (Anson & Ponsford, 2006). The Perceived Stress Model of Caregiver Burden developed by

Chwalisz (1996) is a good illustration of the variables and their interrelationship which are thought to influence health outcomes for the caregiver (see Figure 2).

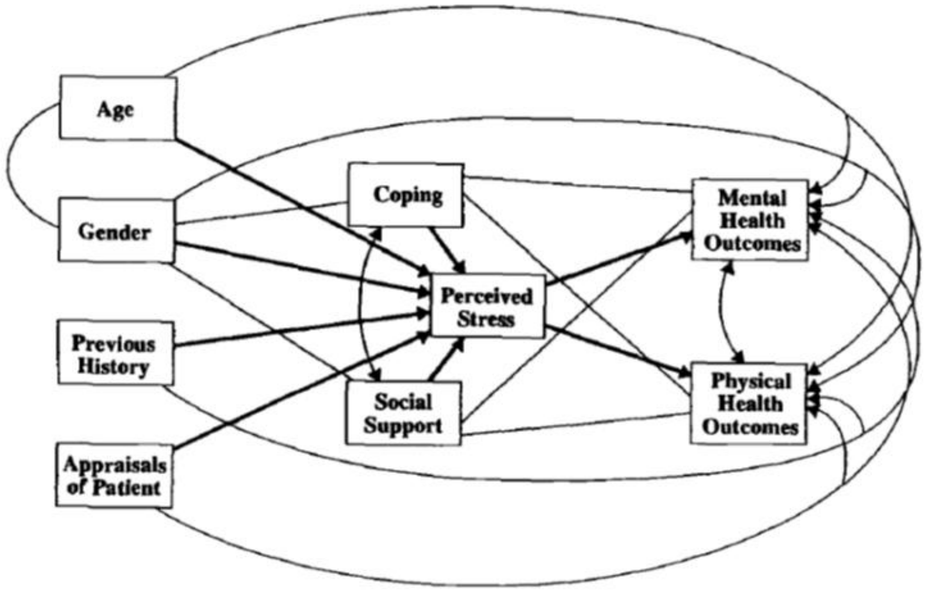

Figure 2. Perceived Stress Model of Caregiver burden (Chwalisz, 1996)

Although appraisal and coping are not the focus of this study, Lazarus and Folkman (1984) emphasise these are the two main concepts central to psychological distress which influence health outcomes. These concepts are the basis on which the Bakas Caregiving Outcomes Scale was developed, which is used in the current study to measure caregiver's perceptions of life changes. Understanding how appraisal and coping influence individuals perceptions of their situation is useful in helping explain why people experience stress, and why individuals exposed to similar adverse situations differ in their stress responses.

Caregiver Supports

Supports are an important determinant in adjustment for caregivers when assuming the new role of caring for their TBI child. Support comes in many forms and has been reported in past research to be a significant factor in the extent caregivers experience burden. Four sources of support suggested by Cohen and Wills (1985) to provide buffering effects are ‘Social support’ which involves friends, family, members of the church, sporting groups and support groups; ‘Esteem support’ which allows the caregiver to feel valued, vent their concerns and receive advice; ‘Informational support’ which offers information, guidance, and appraisal from doctors, advisors and professional support people; and ‘Instrumental support’ which offers tangible support such as from ACC grants, and free health. Social supports and Esteem supports are interrelated, so individuals who have adequate social support may find they have sufficient Esteem support.

There is a broad literature base supporting the relationship between social supports and well-being, and the buffering effects these have upon caregiver stress (Cohen & Wills, 1985; Cropley & Steptoe, 2005; Tak & McCubbin, 2002). Social support is defined by the National Institute for Health and Welfare (2008) as “the perceived availability of people whom the individual trusts, and whom makes one feel cared for and valued as a person”. Social support has been identified as a significant moderator of burden by interrupting the influence negative characteristics of the TBI child has upon the caregiver (Ergh, Rapport, Coleman, Hanks, & Zeiss, 2002; Ergh, Hank, Robin, Rapport, & Coleman, 2003; Nabors et al., 2002). Ergh and Hank (2002) suggest when caregivers perceive they are adequately supported and their needs are met they experience lower levels of psychological distress. Unmet needs are described by MacKenzie et al. (2009) as unmet healthcare needs and interference with daily routines; or better described by Nabors et al. (2002) as perceiving their support needs as being unmet in regards to their own healthcare, emotional fulfilment, professional support and involvement with care (MacKenzie et al., 2009; Nabors et al., 2002).

Cohen and Wills's (1985) 'buffering hypothesis' suggests people are less prone to succumbing to the potential adverse effects of stress if they are involved with some form of social support system. Social supports are thought to help intervene and lessen the effects of stress, particularly when one appraises the situation or event as beyond their capacity to cope, and have feelings of helplessness (Cohen & Wills, 1985). The authors explain that at two points in the process of stress appraisal, social support may be helpful in interrupting the link between stress and illness (see Figure 3).

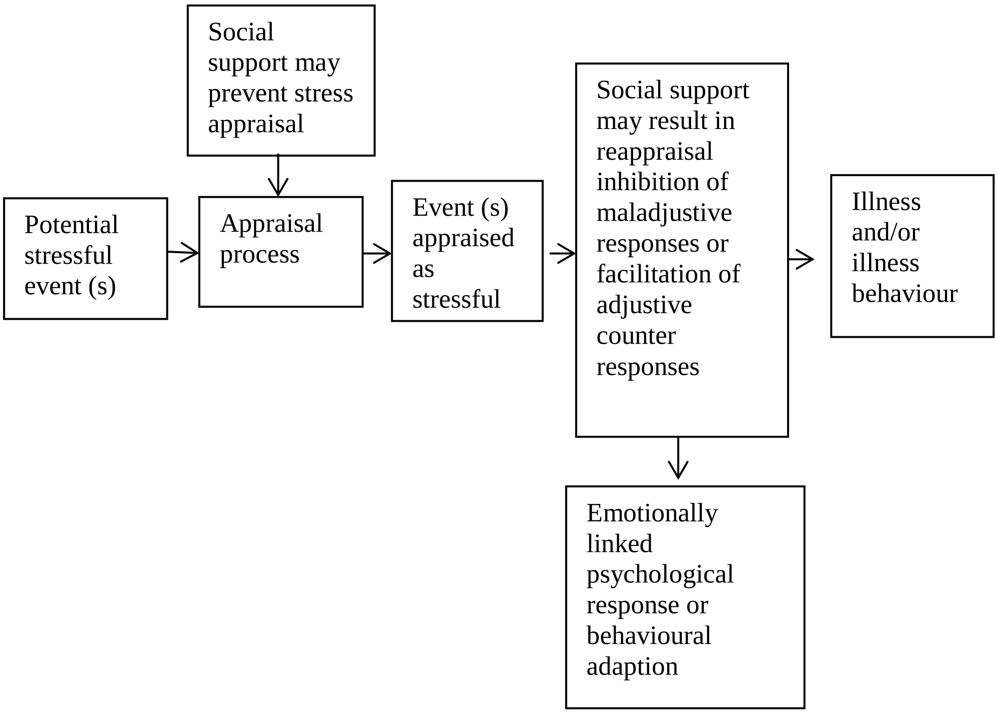

Figure 3. Two points at which social supports may interfere with the hypothesised causal link between stressful events and illness (Cohen & Wills,1985).

Understanding the relationship between supports and burden helps in explaining why social isolation is reportedly one of the more significant mitigating factors relating to caregiver distress (Pattenden, Roberts, & Lewin, 2007). Social isolation decreases the opportunity to be involved in social networks which offer regular positive socially rewarding interactions outside of the caregiving role. Positive social interactions mentioned by Cohen and Wills (1985) offer stability, predictability and self-worth, while avoiding more negative life experiences which may increase the possibility of psychological or physical health problems.

Other forms of support have been found to contribute to burden for caregivers. Informal caregivers within New Zealand reported unmet professional needs in the form of up-to-date information as being one of the most significant factors in caregiver burden. This was due to feeling unsupported in their efforts to access services, financial assistance and support to assist them in their caregiving role (Jorgensen et al., 2010).

Whether or not a caregiver perceives they are adequately supported may be partially due to personality and resilience factors. A socially competent caregiver may seek out supports and be motivated in developing stronger support systems; they may have more capacity for resilience when faced with challenges or feel adequately supported where others may not (Blankfeld & Holahan, 1999). In contrast to this, a caregiver who is less socially competent may show less resilience to adversity and perceive they are poorly supported (Cohen & Wills, 1985). It is necessary to consider actual support received and perceived supports (Nabors et al., 2002; Roth, Mittleman, Clay, Madan, & Haley, 2005) as it is suggested perceived social supports are just as significant as actual supports (Cropley & Steptoe, 2005). When an individual perceives they are receiving adequate and sufficient supports, this alone reduces the effects of the stressors by altering the way they appraise the situation, even though the degree of the stressor has not decreased (Roth et al., 2005). This is reiterated in other research with reports from Ergh et al. (2002) and MacKenzie et al. (2009) adding that burden for caregivers who perceived they were not receiving adequate supports increased over time and were still experiencing burden 12-months following the injury.

Time Post-Injury

Time post-TBI has been found both to increase and alleviate the level of burden experienced by caregivers. This is dependent upon several factors such as the sociodemographic characteristics of the caregiver and the clinical characteristic of the child (injury severity, behavioural and adaptive functioning).

Caregiver burden has been associated with deficits in physical ability and cognitive functioning of the TBI child. These deficits were found to significantly affect caregivers at 3-months and 6-months post-injury, however the stress related to these deficits was found to dissipate by 6-months post-injury (Livingston, Brooks, & Bond, 1985; Marsh et al., 1998). Cognitive and physical deficits were not the most significant stress related factors reported by caregivers. Behavioural deficits: aggression, mood changes and argumentativeness, were found to still contribute to clinical levels of anxiety, depression and social adjustment for the caregiver 12-months post-TBI (Marsh et al., 2002). Caregivers have shown evidence of adaption to TBI individuals’ functional deficits over time by learning practical ways of managing the problematic behaviour. This was found to reduce problems of social adjustment for the caregiver, however clinical levels of anxiety and depression were still evident at 12-months post TBI (Marsh et al., 2002). This may be partly due to the protective effects of supportive family relationships and well-functioning family units losing strength by 12-months post-injury (Stancin et al., 2010). Social isolation and financial strain has also been found to contribute to clinical levels of anxiety and depression at 12-months post-injury as caregivers of children with severe injuries were found more likely to reduce working hours or give up work, increasing their time at home not earning an income (Donovan et al., 2011; Marsh et al., 1998). This may suggest isolation is a stable factor as time increases and in conjunction with financial restraints maintains caregiver levels of anxiety and depression.

Children with mild TBI often suffer subtly debilitating post-concussive symptoms, particularly cognitive and somatic complaints. These tend to peak at 3-months post TBI (Taylor et al., 2010), then resolve themselves (Carroll et al., 2004). Petersen et al. (2008) found no significant changes in cognitive and behavioural functioning at 6-months post-TBI for children sustaining mild injuries, which suggests caregivers of children with mild TBI may not suffer emotional and physical disruptions to life for the same length of time as caregivers of severe TBI children.

These research findings suggest caregiver burden over time is significantly associated to injury severity and the functional deficits of the TBI child, some of which have been identified as predictors of caregiver burden. Caregivers of mild TBI children may experience a peak in stress-related burden at 3-months post TBI which decreases significantly by 12-months post TBI. Caregivers of severe TBI children are likely to suffer more long term injury-related stress and burden, which may still be evident at 12-months post TBI; this however may be dependent upon additional factors which may contribute to burden such as: sociodemographic characteristics, caregivers’ premorbid functioning, family functioning, appraisal and coping strategies, and stress management (Bakas & Champion, 1999; Gan et al., 2010; Lazarus & Folkman, 1984; Ponsford et al., 2001).

Child Behaviour and Adaptability

Caregiving may become burdensome when the usual exchange of assistance becomes unbalanced and impairment caused by the TBI leads to increased needs of the child, and increased dependency upon the caregiver. The most frequently observed changes in TBI children reported as causing considerable stress, are to their social functioning, cognitive ability, physical ability, emotion regulation and behavioural and adaptive functioning (Marsh et al., 2002; Nabors et al., 2002; Padmini Yeleswarapu & Curran, 2010). These changes may cause a restructuring of the relationship between caregiver and child resulting in the caregiving component becoming overwhelming (Pearlin, Mullan, Semple, & Skaff, 1990). Several studies have shown children who sustain moderate to severe TBI often experience more behavioural and adaptive deficits which have been associated with longer term burden and distress for the primary caregiver (Braine, 2011; Connolly & O'Dowd, 2001; Stancin et al., 2010). Past studies report differing viewpoints as to which functional deficit causes the most burden for caregivers (Marsh et al., 2002), however adverse behavioural changes such as aggression, restlessness and antisocial behaviour appear consistently throughout studies to cause more psychological distress than cognitive (e.g., irresponsibility, memory difficulties, lack of interest) and physical deficits (e.g., dependency) (Braine, 2011; Connolly & O'Dowd, 2001; Marsh et al., 2002). It is further suggested the more active behavioural changes such as those mentioned above are more distressing for the caregiver than passive behavioural changes (e.g., lack of motivation and immaturity), as they are more emotionally charged and aimed at the caregiver (Godfrey et al., 2003). The more active behaviours are likely to be carried out in an interpersonal context involving others, and require the caregiver to develop skills to manage the behaviour (Godfrey et al., 2003). Findings from earlier research support the impact negative behaviour has upon caregiver burden. Caregivers reported stress was brought on by fear of not knowing when the TBI individual may react or act out (Marsh et al., 2008), and reported frustration when TBI individual suffered memory loss resulting in diminished progress when completing tasks (Braine, 2011). Negative behavioural changes in the TBI individual were found to be instrumental in caregivers developing a lack of confidence in their ability to control or influence the individual’s behaviour, resulting in elevated episodes of emotional distress and depression (Riley, 2007).

Stancin et al. (2010) examined 102 parent-child dyads to determine the psychological and physical effects caring for TBI children with mild to severe injuries have upon caregivers. Adaptive and behavioural deficits (e.g., communication, self-care, self-direction, social functioning and leisure) correlated significantly with poorer health outcomes, however were only evident for caregivers of children with moderate to severe TBI. Caregivers of children with mild TBI experienced minimal injury-related stress which dissipated relatively soon after the injury, whereas the more severe injury-related stress experienced by caregivers' hadn't completely resolved by 18-months. These findings indicate burden varies as a function of injury severity and child's behavioural and adaptive functioning; suggesting severe TBI's are associated with pervasive injury-related stress for the caregiver (Marsh et al., 1998).

The evidence presented above clearly demonstrates the difficulty caregivers experience adjusting to changes in the TBI individual, and the distress caregiving imposes upon them. However, people have a tendency to adapt to new situations over time regardless of the demands placed upon them

Summary

TBI has been reported in the literature as the leading cause of death and injury for young people in New Zealand (Barker-Collo et al., 2008). The effects of TBI are not only disabling for the individual but impact significantly upon the health and well-being of those who care for them. In the past, caregivers have been paid little attention; however there is now more interest in caregivers' experiences and their needs, which may encourage research into interventions to support them in their role. Caregivers' experience considerable changes to HRQoL and burden when caring for a TBI child. These have been reported in the literature as increased levels of anxiety and depression, physical strain and life changes (e.g., relationship issues, role changes and reduced income) (Brooks, 1991; Harris, Godfrey, Partridge, & Knight, 2001; Marsh, Kersel, Havill, & Sleigh, 2002; Perlin, Mullan, Semple, & Skaff, 1990).

The literature identifies many variables which contribute to and moderate the burden experienced by caregivers. These include: age, educational attainment, income, gender, ethnicity, marital status, supports, time post-TBI, stress appraisal and coping, family functioning, premorbid caregiver characteristics, TBI severity and TBI child's behavioural functioning and adaptive functioning (Donovan et al., 2011; Gan et al., 2010; Jorgensen et al., 2010; MacKenzie et al., 2009; Nabors et al., 2002; Padmini Yeleswarapu & Curran, 2010; Stancin et al., 2010). Figure.4 illustrates the relationship between variables and caregiver health outcomes explored in the current study.

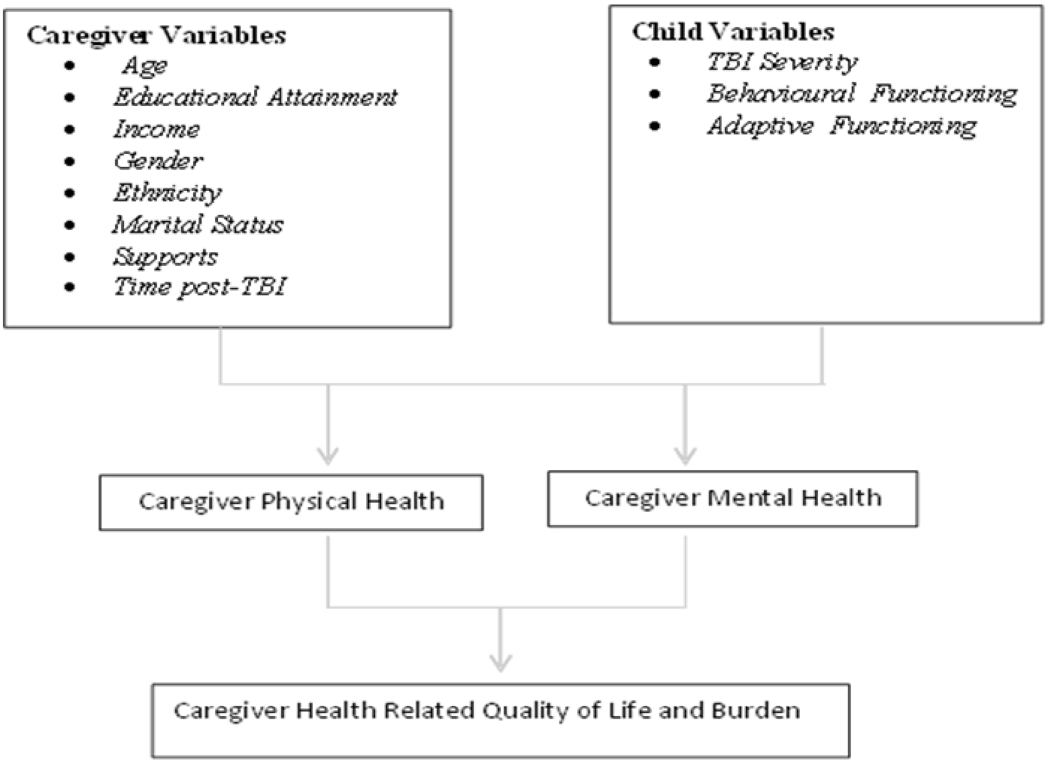

Figure 4. Model of interrelational variables contributing to health outcomes

Findings in the research are contradictory as to the extent particular variables cause health related distress for the caregiver; however the impact child’s behavioural and adaptive problems have upon caregiver’s health has been found to be two of the most significant contributing factors (Braine, 2011; Connolly & O'Dowd, 2001; Marsh et al., 2002; Stancin et al., 2010).

By considering all the variables in the model when examining the effects caregiving has upon health and well-being will enable us to pinpoint underlying mechanisms which may predict burden, and improve our understanding of the extent these variables play in caregiver HRQoL and burden.

International literature suggests there are disparities between cultures and the level of burden experienced by caregivers. Minority populations are reported to experience elevated burden (Sayegh & Knight, 2010) and poorer health outcomes due to sociodemographic factors (Arlidge et al., 2009; Barker-Collo et al., 2008), although particular cultural factors such as familism have been found to act as moderator (Robertson et al., 2007; Scarlach et al., 2006). There are no current studies to date investigating disparities between New Zealand European and Māori caregivers’ of TBI children and their caregiving experiences. Investigating the health outcomes of New Zealand European and Māori caregivers will help in identifying if the impact of caregiving upon HRQoL and burden differs between the two ethnic groups.

Caregiver burden may reduce over time however this may be partially dependent upon child clinical factors: injury severity, behavioural functioning and adaptive functioning. Severer injuries are related to more profound behavioural and adaptive deficits which have been found to have a prolonged negative impact upon caregivers' health and well-being over time (Braine, 2011; Connolly & O'Dowd, 2001; Donovan et al., 2011; Stancin et al., 2010). Time point analyses may provide an insight for caregivers into what they may expect to encounter over the following 12-months in terms of their own levels of health, well-being and quality of life.

This research will address these ideas by:

1: Examining the effects of caring for a child with TBI on caregiver health and quality of life, by comparing outcomes between a TBI caregiver group and a Control caregiver group.

2: Identifying relationships between a range of caregiver and child variables (e.g., age, educational attainment, income, gender, ethnicity, marital status, supports, TBI severity, and TBI child's behavioural functioning and adaptive functioning) and caregivers' health-related quality of life and burden.

3: Investigating caregiver health-related quality of life and burden between New Zealand European and Māori caregivers of children with TBI, and investigating caregiver satisfaction of services received pertaining to the child's injuries.

4: Examining caregivers self-reported health-related quality of life and burden at 1-month, 6-months, and 12-months following the child sustaining the TBI.

Method

The current study is part of two larger studies which originated from the HRC funded Brain Injury Outcomes New Zealand in the Community study (BIONIC). The BIONIC study aimed to identify the incidence and outcomes of traumatic brain injury (TBI) in all residents of Hamilton and Waikato Districts over a 12-month period (1st March 2010 - 28th Feb 2011) (National Institute for Stroke and Applied Neurosciences, 2011).

The Consequences of Brain Injury in the Community study (COBIC) is funded by Lottery Health Research and is a continuation of the BIONIC study which aims to look at the longer term outcomes of brain injury in childhood. The COBIC study carried out additional assessments with the BIONIC children 12-months post-injury, and also recruited a non-injured aged matched child cohort for comparison purposes (National Institute for Stroke and Applied Neurosciences, 2011).

Ethical Approval

Ethical approval to conduct the COBIC and BIONIC studies was acquired respectively from the School of Psychology Ethics Committee within the University of Waikato's Psychology Department, and from the Northern Y Regional Ethics Committee.

Participants

The current study includes two groups: caregivers of children with TBI and a Control Group of caregivers.

1) Caregivers of Children with TBI

The BIONIC study included the collection of HRQoL information from the caregivers pertaining to their own health and well-being to investigate the level of burden experienced when caring for a child with TBI. The caregivers also completed The Behavioural Assessment System for Children-2 (BASC-2) which is a measure of the TBI child's behavioural and adaptive functioning (Reynolds & Kamphaus, 2012). It was the data from these measures collected at baseline, 1-month, 6-months and 12-months that was used in the current study for the TBI caregiver group.

BIONIC child and caregiver participants were recruited via surveillance systems set up across medical services throughout the Waikato and Hamilton areas. A register was established to record every TBI in these areas. Cases were identified through Accident and Emergency Department admissions, self-referrals and Health Practitioner referrals. Checks were carried out to search for potential participants at the Waikato Hospital Trauma Unit, CT/MRI records, ACC databases, neurosurgery, medical surgery and neurological wards. Hospital discharge registers (Waikato, Taumarunui, Te Kuiti and Tokoroa) were searched along with private hospitals, Auckland public hospitals, Starship Hospital, St John Ambulance and the Waikato Concussion Clinic. Recruitment was also carried out through schools, sports centres, nurseries, IHC, Community Health Services and Care Facilities (Auckland University of Technology, 2011). All cases of TBI including cases not presented for immediate medical care or to a hospital were investigated to ascertain their eligibility for inclusion in the BIONIC study (Theadom et al., 2012).

If no formal diagnosis of TBI was made, clinical details or medical records of each potential case were reviewed by a diagnostic team to identify criteria, signs and symptoms of TBI (National Institute for Stroke and Applied Neurosciences, 2011), and participants were asked three questions of which they were required to answer yes to only one for inclusion. (1) if they had lost consciousness (or were knocked out); (2) if they had been dazed or confused or had ‘seen stars’ at the time of injury, or (3) if they could not remember the injury, or if they had experienced any memory problems. Participants were also required to have lived within the study area for at least 12-months (Theadom et al., 2012).

Figure 5 illustrates the flow of BIONIC participants at the four time points. A total of 191 caregivers of children with TBI, (children aged 5-15 years at the time of injury) consented to take part in the BIONIC study and completed the baseline assessment.

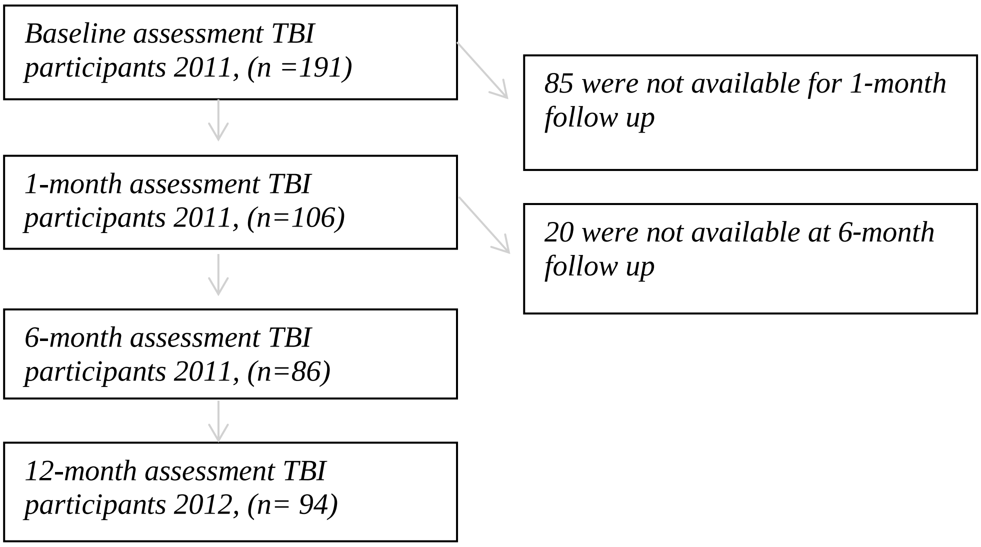

Figure 5. Flow diagram of Caregivers of 5-15 years olds with TBI in the BIONIC study

Demographic Information for TBI Participants

Of the ninety four caregivers of children with TBI, 78 (83.0%) were female and 16 (17.0%) were male, aged between 19 and 54 years (mean age = 38 years, SD = 6.95) at the time of the child's injury. Fifty two participants (55.3%) were New Zealand European; 33 (35.1%) were Māori; 9 (9.6%) were of other ethnicities.

Ninety two (97.9%) BIONIC child participants sustained a mild TBI, 1 (1.1%) was classified as having a moderate TBI, and 1 (1.1%) was classified as sustaining a severe TBI. The Glasgow Coma Scale was used to assess severity of trauma ranging from mild to severe (refer to introduction for definitions). Those who did not have GCS scores were classified as mild in severity, as someone sustaining a moderate or severe head injury would have likely been assessed in some way by the Health Services where a GCS would have been recorded (Barker-Collo et al., 2012).

2) Caregivers of Control Participants

The COBIC study included the collection of HRQoL information from the caregiver pertaining to their own health and well-being, and BASC-2 measures pertaining to the child's behavioural and adaptive functioning. This was taken at baseline and is the data used in the current study for the Control group. Control children and caregivers were recruited via the COBIC study. Pamphlets, posters and information were sent out to schools, plunkets, kindergartens, early childhood centres and colleges asking for non-head injured child volunteers and their caregivers to participate in the COBIC study.

Eligibility criteria for inclusion of Control child participants were that they had not sustained a TBI since birth and they lived in the Hamilton/Waikato region. It was also required the participants were recruited from schools with similar decile ratings to those the BIONIC children were recruited from, and the children were an age matched cohort. It was the caregivers of these children who were the participants in the current study.

A total of 43 Control caregivers completed baseline assessments for the COBIC study. Forty one (95.3%) of the Control caregivers were female and 2 (4.7%) were male. The caregivers were aged between 27 and 66 years (mean age = 43, SD = 7.70). Thirty one (72.1%) were New Zealand European; 6 (14.0%) were Māori and 4 (9.3%) were other ethnicities.

Measures

Demographic information was collected pertaining to the caregiver and child’s age and gender using questionnaires; also collected was caregiver’s educational attainment, income, ethnicity, marital status, and supports received. Information regarding supports was only collected from TBI caregivers as this related to how supported caregivers felt while caring for the TBI child.

Caregiver HRQoL outcomes were assessed using a range of measures to determine the caregivers’ level of HRQoL, and the level of burden experienced due to the caregiving role. The extensive range of measures were chosen to provide a comprehensive overview of health related issues such as physical and mental health, anxiety, depression, and life changes.

Information regarding the child's behavioural and adaptive functioning was also collected and analysed to assess the impact this had upon caregiver health outcomes.

Demographic and Background Information

Demographic and background information was determined as follows:

Age was determined as at time of injury for child, and at time of completing the baseline assessment questionnaires for the caregiver. Caregiver age bands were based upon Sheehy's (1984) transitional life stages and were grouped into ages bands (17-21,22-27, 28-32, 33-37, 38-45, 46+) for analysis.

Educational attainment information was collected from the caregivers by asking them to select what their highest level of education attainment was. For analysis purposes Primary and High School were considered low-level education, whereas Polytechnic and University were classified as high-level education.

Occupation information collected was recorded based on the Australian Standard Classification of Occupations (ASCO) Second Edition (Australian Bureau of Statistics, 1997). As this was only occupational information and not reported income, estimates have been made as to the families' incomes using the classification and coding system described by the Australian Bureau of Statistics, which classifies occupation based on skill level and whether they were one or two income families. From this families were classified as having high, medium or low income. High income earners included skill base level 1 & 2: professionals, managers, administrators and associate professionals. Medium income included skill base level 3 & 4: trades people and related workers, advanced clerical sales and service, intermediate clerical sales and service, intermediate production and transport. Low income earners included skill base level 5 & 6: elementary clerical sales and services, labourers and unemployed.

Participants could classify themselves as more than one ethnicity. If they selected New Zealand European and another ethnicity, it was the other ethnicity that was used as their classification for analysis. They were to select yes/no from: New Zealand European, Māori, Samoan, Cook Island, Māori, Tongan, Niuean, Chinese, Indian, or other ethnicity.

Marital status was determined as the caregiver's current marital status. Caregivers who stated they were married, in a civil union or defacto relationship were considered as 'married', whereas caregivers who stated they were divorced, widowed, single or unknown were classified as single. Marital status was used as a singular variable and also used as a factor in Esteem supports for support analysis.

Supports for TBI caregivers were measured using rehabilitation information gathered from the caregivers. Questions from the rehabilitation information were categorised into Esteem supports which included social supports (support from family, friends); Informational supports (Doctors and specialists advice); and Instrumental supports (ACC, DHB payments). Questions relating to Esteem supports were: had they received unpaid help from friends, family, parents and others; had they received home care (help with cooking, cleaning etc.) or personal care (help with showering, dressing, etc.). Informational support data was collected through questions enquiring if they had been spoken to regarding financial help to pay for treatment and services; if they had been spoken to about services available to them; and if they had received any services. Instrumental support data was gathered through questions enquiring about receiving a disability benefit and payments for treatment.

TBI caregivers were asked for information regarding satisfaction of services received. Satisfaction was rated on a scale of 1-10 (1 being very unsatisfied and 10 being very satisfied) relating to services received at out-patient clinics, professionals offices, at home, residential homes, hospitals or other places of care. Caregivers were asked a second question if the services received were culturally appropriate, this was measured using a rating scale from 1 = 'very satisfied' to 4 = 'not at all satisfied', if they felt the services received were not acceptable to their culture.

Health Related Quality of Life

Health related Quality of Life was measured by The Medical Study Short Form (SF-36). SF-36 is a 36-item self-report assessment with 8 scales which generate a profile of functional health and well-being (Total Score), along with summary measures of mental and physical health (see Appendix A). The SF-36 is a measure of one's perceived level of health and well-being and has been used extensively with a variety of populations for a wide range of medical conditions (Ware, 2006). The 8 scales consist of four physical health scales and four mental health scales Physical health includes subscales: physical functioning (ten items in which a high score would indicate no difficulty with physical functioning, and a low score would indicate some difficulty with physical ability); role physical (four items which indicate whether or not difficulty is experienced with work or daily activities); bodily pain (two items which indicate limitations to health and well-being due to bodily pain; lastly, general health incudes five items which indicate how the participant perceives their general health to be now and in the future.

Mental health scales include: vitality (four items which indicate whether the participants feels tired or full of energy most of the time; social functioning, has two items indicating whether or not physical and emotional problems interfere with daily social activities; role emotion includes three items measuring difficulty with work or daily activities due to emotional problems; lastly, mental health includes five items measuring feelings of nervousness, depression, calm and happiness.

Scores from these eight scales are calculated to yield scores from 0-100 (100 representing the highest level of functioning), producing a physical component summary score, a mental component summary score and a total overall health summary score (Ware, 2006). All questions either have a yes/no format or a Likert format requiring the participant to indicate whether or not health or emotional issues limit them in any way physically or socially, also how they perceive their current and future health status. Reliability of these two summary measures and 8 scales using internal consistency and test-retest methods were rated by Ware (2005) via a literature review. Cronbach’s coefficient alpha were found to equal or exceed .80 showing good internal consistency and adequate test-retest reliability. Validity was rated using the same process showing good correlation with other measures (r =.40 or greater), and has been supported in many studies. The scales: mental health, role emotional and social functioning have had specificity of 81% when identifying people with depression and have shown to be responsive to changes in depression and changes in individuals before and after suffering depression (Ware, 2006).

The SF-36 has been used internationally and translated into many languages to be utilised with non-English speaking populations (Ware, 2005). The SF-36 has been used in a number of caregiver outcomes studies (McPherson, Pentland, & McNaughton, 2000; Tsai-Chung Li, Yih-Dar Lee, Cheng-Chieh Lin, & Amidon, 2004) and has been reported by Scott, Sarfati, Tobias, and Haslett (2000) as the most widely used instrument designed to measure HRQoL; declaring it as making an important contribution to measuring burden in society. Scoring the SF-36 uses the method of standardised SF-36 algorithms and summated ratings which assumes items shown in the same scale can be combined without score standardisation or item weighting (Ware, 2005). Scoring for this study was carried out using a Microsoft Excel 97 programme developed by Kalantar-Zadeh, Jopple, Block, and Humphreys (2001). The programme was developed using well-defined SF-36 guidelines and uploaded to the internet for public use (www.nephrology.rei.edu/qol.htm).

Anxiety and Depression

Depression was assessed using both the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and set of questions from the DSM-IV Depression Diagnostic Scale (National Institute for Stroke and Applied Neurosciences, 2011). HADS was also used to measure anxiety in the caregiver samples. HADS is a brief measure designed to recognise emotional disorders while distinguishing between anxiety and depression (see Appendix B). The 14-item questionnaire scores each item on a 4-point Likert Scale, with scores 0-3 assigned to each of the four responses. This instrument was originally designed to measure anxiety and depression in non-psychiatric patients (Bjelland, Dahl, Tangen Haug, & Neckelmann, 2002), and consists of two subscales (anxiety and depression) each consisting of seven items resulting in a score of between 0-21 (Skilbeck, Holm, Slatyer, Thomas, & Bell, 2011). A score on either subscale of 0-7 is in the normal range; a score of 8-10 is suggestive of possible mood disorder; whereas a score of 11 or more is an indication of the probable presence of mood disorder (Snaith, 2003). A literature review conducted by Bjelland et al. (2002) consisting of 747 papers using the HADS, established the instrument showed good internal consistency with a Cronbach coefficient alpha of .83 on the anxiety subscale and .82 on the depression subscale. Concurrent validity was also found to be between .60 and .80 when compared to instruments such as Becks Depression Inventory (BDI), Speilberger's State-Trait Anxiety Inventory (STAI), General Health Questionnaire (GHQ-28) and the Clinical Anxiety Scale (CAS) (Bjelland et al., 2002).

The function of the HADS is to assess levels of depression and anxiety in populations as a result of illness (Martin, Lewin, & Thompson, 2003) and has been used in a number of TBI studies (e.g., (Draper, Ponsford, & Schönberger, 2007; Powell, Heslin, & Greenwood, 2002; Whelan-Goodinson, Ponsford, & Schönberger, 2009). Research has consistently found the HADS to have good reliability and validity within individuals with somatic disease and in the general population, with most studies reporting a Cronbach's alpha between .80 and .90 for both the anxiety and depression subscales (Bjelland et al., 2002).

The set of questions from the Structured Clinical Interviews for the DSM-IV (SCID) (First, Williams, Spitzer, & Gibbon, 2007) were selected by the primary researchers of the BIONIC study to develop the DSM-IV Depression Diagnostic Scale. This was designed to identify people at risk of developing (or are currently suffering) depression (see Appendix C). The scoring is based on there being a specific number of symptoms present before being assessed as at risk of, or currently experiencing depression, and needing a referral to a General Practitioner (National Institute for Stroke and Applied Neurosciences, 2011).

Life Changes.

The revised 15-Item Bakas Caregiving Outcomes Scale (BCOS) was used to measure life changes for those who undertake the role of caregiver (Bakas & Champion, 1999). This scale was developed based on Lazarus's model of 'Stress, Appraisal and Coping', which suggests a person's antecedent personality and environmental factors mediated by their cognitive appraisal of a situation and coping methods, determine emotional outcomes which are specific to the situation or event (Bakas & Champion, 1999). This scale was used to measure changes in outcomes for caregivers of the stroke population and was found to have the ability to detect important changes that were relevant to caregivers of stroke victims. According to Visser-Meily, Post, Riphagen, & Linderman (2004) this sensitivity is missing from other measures. The 15-Item Instrument Scale is rated on a 7-point Likert scale from (-3) "changed for the worst"; (0) "did not change", to (+3) "changed for the best". The questions in the BCOS were designed to measure social functioning (e.g., my time for social activities with friends); subjective well-being (e.g., my future outlook); and somatic health (e.g., my physical functioning). The BCOS has shown good internal consistency reliability and satisfactory test-retest reliability when used upon a sample of 147 family caregivers of stroke victims. Internal consistency was measured at .90 and test-retest showed an intraclass coefficient of .66 and confidence interval of 95% (Bakas, Champion, Perkins, Farran, & Williams, 2006). Criterion-related validity was supported by making correlations with the 36-item Short Form (SF-36) subscales ‘general health’ and ‘overall change in caregivers lives’. A 16th item in the scale is, “In general how has your life changed?” this is measured as a single item designed to assess criterion related validity. The score from this single item is not added to the total score (Bakas et al., 2006). The BCOS is scored by recoding the -3 to +3 ratings to scores of 1-7 (e.g.,-3 = 1; -2 = 2; -1 = 3; 0 = 4; 1=5; 2=6; 3=7). The higher the total score for the 15-Items is an indicator of more positive outcomes for the caregiver (Bakas et al., (2006). For the current study a score of 15-59 on the 15-item scale indicated life had changed for the worse, a score of 60-74 indicated life had not changed, and a score of 75-105 indicated the caregiver felt life had changed for the better. Question-16 was scored as 1-3 indicating life had changed for the worse, 4 indicated life had not changed, and 5-7 indicated caregivers felt life had changed for the better.

TBI Severity.

TBI severity was classified according to the Glasgow Coma Scale, however for the current study, mild head injury was separated into three categories using Servadei, Teasdale and Merry’s (2001) criterion: mild low risk; mild medium risk; and mild high risk. Mild low risk is described as having a GCS of 15 with no loss of consciousness, amnesia, diffuse headache or vomiting. Mild medium risk includes a GCS of 15 while experiencing one or more of the following criteria: amnesia, loss of consciousness, diffuse headache or vomiting. Mild high risk criteria are a GCS of 14-15 with a fractured skull or neurological deficits. This criterion was included due to the high percentage of head injuries presenting as mild causing difficulty comparing outcomes in studies (Servadei et al., 2001).

Behavioural and Adaptive Functioning.

The Behavioural Assessment System for Children-2 (BASC-2) was used as a measure of the TB child’s behavioural and adaptive functioning. The BASC Parent Rating Scale is a rating scale completed by the parent/caregiver of the child, and is a measure of the parents perceptions of the child’s problematic behaviour and adaptive deficits at home and in the community (Reynolds & Kamphaus, 2012). BASC-2 (Reynolds & Kamphaus, 2004) is a multidimensional approach to assessing children and adolescents’ observable behaviours and emotions, to give a comprehensive picture of the child’s behaviour and personality. The BASC-2 parent rating scale consists of 16-primary measures that load onto the behavioural scale: (attention problems, aggression, atypicality, hyperactivity, depression, withdrawal) and adaptability scale: (activities of daily living, functional communication, study skills, adaptability, leadership, social skills). Somatization, anxiety and depression sub scales load onto the internalising problems scale, while conduct disorder, hyperactivity and aggression load onto the externalising scale. These primary measures are gathered using 134-160 items; the number of items used is dependent upon the age of the child being assessed. These are answered using a four-point Likert response scale format, indicating the frequency of a particular behaviour from never through to almost-always. The specified items are loaded onto the 16 primary measurement scales which are then analysed to inform whether the test taker is high, average, or low on each primary measure. This then indicates problematic or typical behaviours and adaptive functioning (Reynolds & Kamphaus, 2004). The BASC Parent Rating Scale shows high internal consistency reliabilities with all scales over all age groups, and general and clinical normed samples. A coefficient alpha of between .80 and .87 and t-test reliability of .77 and .90 was found over all age groups when parents of 254 sample children completed the assessments with an interval of between 9 to 70 days between undertaking the tests (Reynolds & Kamphaus, 2004). Evidence of convergent validity was found between the BASC-2 and the Social Skills Rating System (SSRS) when a sample of 53 participants were rated using the parent and teachers rating scales. Correlations of between .50 and .60 were found between the hyperactivity, aggression and externalising scales (Flanagan, Alfonso, Primavera, Povall, & Higgins, 1996). Discriminant validity was demonstrated by Schoff (2003) when using the parent rating scales to distinguish between two cohorts of children; one suffering recurrent abdominal pain and the other a matched control cohort. The two groups were distinguishable from each other particularly on the somatization, depression and anxiety scales which load onto the behavioural symptoms index subscale.

Procedure

TBI Caregiver Participants

Once child participants were identified the caregivers were phoned to confirm eligibility and confirm theirs and their child’s interest in taking part in the study (see Appendix D). They were emailed or posted information explaining the study (see Appendix E); for children who were unable to complete the assessments a proxy was appointed. Caregivers were then contacted by the researcher to confirm if they had received and read the information and some further contact information was collected over the phone. An appointment was made at this stage to meet and carry out the caregiver assessments. One caregiver of each child participant was asked to complete assessments providing personal information regarding their own health and well-being, and also information regarding their child's health and well-being.

During the first face to face meeting the limits of confidentiality were discussed with the caregiver and a consent form was signed which was required to consent to the release of a summary of results for the purpose of the study (see Appendix F). Most assessments were conducted in the participant's home or work place, although some were conducted at Waikato University and Waikato Hospital. Each battery of caregiver assessments took approximately 2 hours to complete and was the caregiver data used in the current study.

Control Caregiver Participants

Once potential COBIC participants made contact with the researchers, information was posted or emailed to further inform them of the purpose of the study. The participants (parents and children) were phoned and asked if they were still interested in participating in the study; if they were the researcher checked they met the studies eligibility criteria (i.e., the child has been TBI free since birth and that they are a resident of the Hamilton/Waikato region). Once eligibility was confirmed contact details and verbal consent were obtained along with some basic demographic information (e.g., age of child, gender, ethnicity, school attended).

Finally an appointment was made to meet with caregivers to complete the assessments. The assessments were usually carried out in the participant's home or place of work. Prior to the assessment the limits of confidentiality were explained and written consent was obtained; the primary researchers contact details were made available and the participants were asked if they had any questions pertaining to the study. The battery of assessments were then completed taking between 1-1.5 hours. Assessments were also completed with the children, but as they are not the focus of this study these findings are reported elsewhere.

Once the data from both BIONIC and COBIC caregivers was collected it was entered into the central database for subsequent analysis to obtain the caregiver HRQoL data for this study.

Data Analyses

Data analyses were carried out using SPSS (version 20), using an alpha level of .05 (two tailed); effect size was reported using Cohen's guidelines (.01 = small, .06 = moderate, .14 = large) (Cohen, 1988).

Descriptive statistics were used to compare the demographic characteristics of the two groups of caregiver participants.

Analyses were conducted to determine differences in reported quality of life outcomes for caregivers of TBI and Control children. One-Way ANOVA's were carried out comparing SF-36, HADS and BCOS data from the 12-month assessments of the TBI caregiver group, to the baseline data from the Control caregiver group. Differences between groups for behavioural and adaptive functioning of the child were also explored using One-Way ANOVA's.

Analyses were carried out to explore the relationship between caregiver and child variables, and caregiver HRQoL and burden. Spearman’s non-parametric correlations were chosen as normality could not be assumed due to most of the variables being non-linear and not normally distributed.

Variables that correlated significantly were included in multiple regression analysis to further explore if the variables were predictive of poorer health outcomes for the caregiver. A series of Standard Multiple Forced Entry regression analyses were used to carry this out.

Analyses than shifted to focus upon differences between ethnic groups. Chi-square analyses were used to indicate if there were significant differences in demographic variables between New Zealand European and Māori caregiver groups. Fisher’s exact test statistic was reported due to some variables having less than the required minimum value of 5. Next, One-Way ANOVA’S were conducted on health and well-being scales to examine differences in caregiver health outcomes between the two caregiver groups.

The final part of the analyses focused on change of caregiver burden over time for the TBI caregivers. One-Way Repeated Measures ANOVA was used to test for significance of effect of time on caregiver health outcomes, between the 1-month, 6-month and 12-month time points. To further investigate significant results, pairwise comparisons using the bonferroni multi-comparison correction were carried out to detect significant differences between each time point.

Results

The first part of the results section presents age, gender and injury data relating to the TBI child participants. Sociodemographic information relating to the caregiver participant samples is presented for each analysis in the relevant sections. Secondly, analyses results are presented which examine differences in quality of life for caregivers of children with TBI and Control caregivers. The next section highlights caregiver and child variables found to have a relationship with caregiver health outcomes, and variables found to predict the HRQoL and burden for caregivers. Results are then presented from a series of analyses which were conducted to examine if there are differences between New Zealand European and Māori TBI child caregivers in terms of HRQoL and burden. The final set of analyses presented investigates HRQoL over time between 1-month, 6-months and 12-months post injury.

TBI Child Participants Demographic Information

The following four figures present information regarding injury characteristics of the children with TBI.

The total number of participants varied in each age group. A higher number of incidences were recorded for the 10-15 year olds, and more males than female's sustained TBI injuries in each age group (see Figure 6).

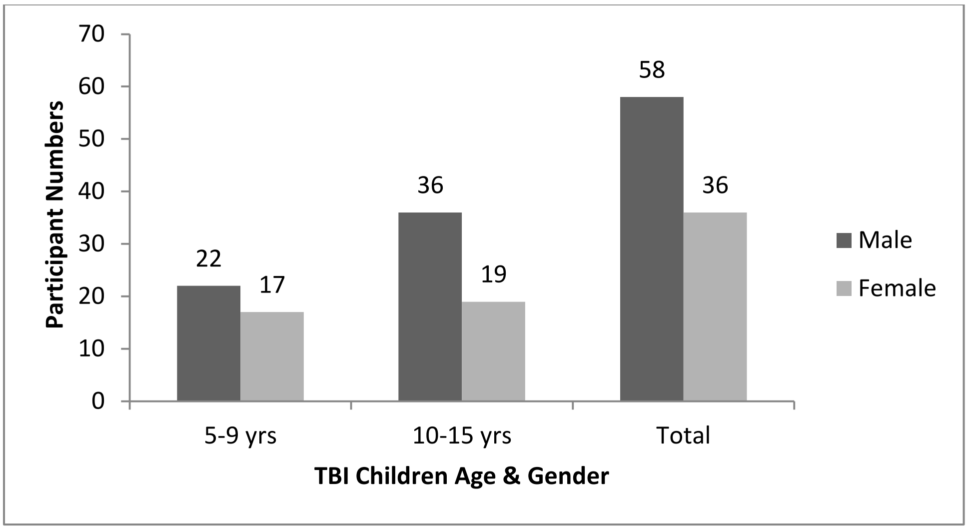

Figure 6. Age and gender distribution of TBI children

Brain injury severity was classified into five categories as shown in Figure 7. Over 50% of the injuries were classified as mild high risk, with the majority overall falling in the mild range (n = 92, 97.9%).

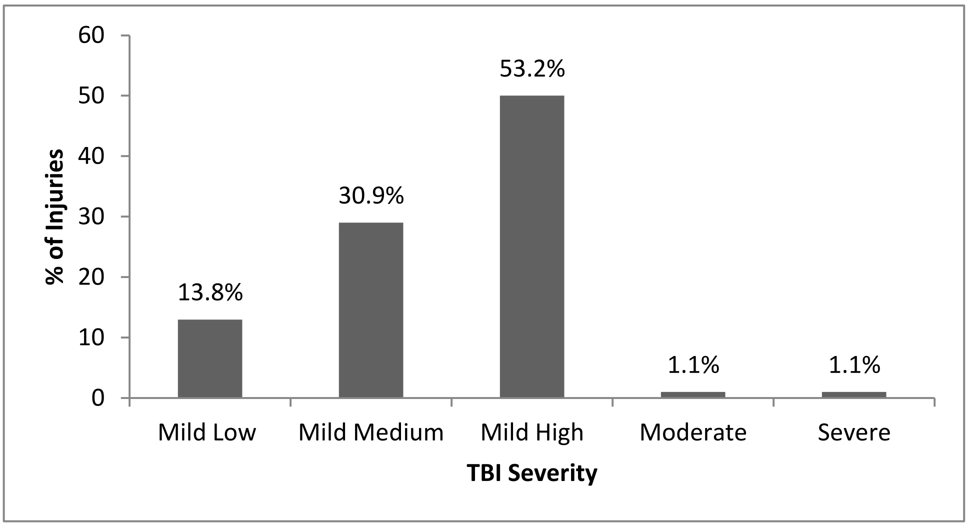

Figure 7. Injury severity distribution

Recreational activities appeared to be the highest cause of injury closely followed by falls (Figure 8). Injuries sustained by traffic incidences accounted for the least number of injuries.

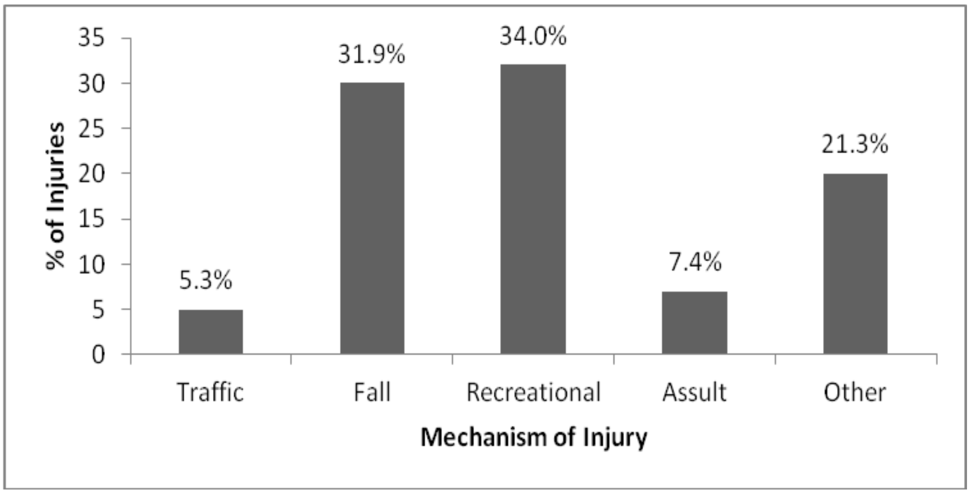

Figure 8. Mechanism as cause of injury over all age groups

The most common place for injuries to occur was at school which accounted for over a third of reported injuries closely followed by injuries sustained in private homes (see Figure 9).

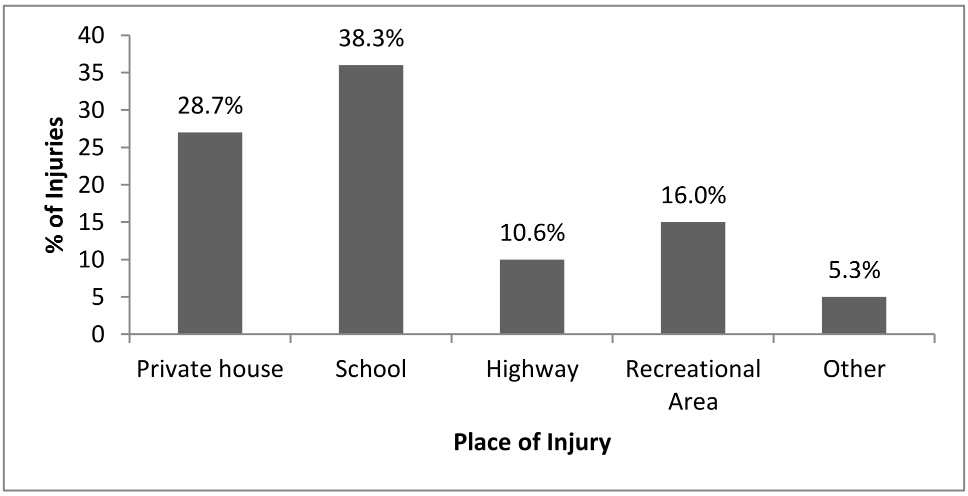

Figure 9. Place of injury

To summarise the children's injury data, 10-15 year olds sustained a higher number of injuries than the 5-9 year age group, with nearly double the total number of participants being male. Ninety seven percent of participant's injuries were mild while most injuries involved recreational activities and falls. School and home were the most likely places for injuries to occur.

Demographic Characteristics of TBI and Control Caregivers

Chi-square analyses were conducted to indicate if there were significant differences between the two groups for the frequency data. Fisher’s exact test statistic was reported due to some variables having less than the required minimum value of 5. Table 1 presents the distribution of sociodemographic information for caregivers of TBI children who completed assessments at 12-months post child’s injury, and the Control group.

The age range for TBI caregivers was 19-54 years $(X = 38.3, SD = 6.95)$; Control caregivers were aged 27-66 years $(X = 42.5, SD = 7.70)$. One-Way ANOVA indicated a moderately significant difference in age between groups $(F (1,127) = 9.38, p < .05, p\eta^2 = .069)$ revealing TBI caregivers were younger than Control caregivers. A significant association between caregiver groups and educational attainment was indicated by the chi-square test $X^2(3, N = 137) = 19.46, p<.001)$. This suggested a larger portion of TBI caregivers only reached High School level education as opposed to the majority of Control participants entering into University level education. Chi-square analysis also indicated a significant association between groups and income level $X^2(3, N = 137) = 8.40, p<.05)$ revealing income levels differed between groups. More TBI caregivers earned lower incomes than that of Control caregivers, while over half the Control caregivers were on high incomes. A chi-square test was performed on caregivers and hours worked, a significant association was found $X^2(3,N =137) = 22.01, p<.00)$ indicating TBI caregivers worked less hours per week than the Control caregiver group (although there was a large amount of missing information from the caregivers of the TBI group). A chi-square statistic of $X^2 (1,N = 137) = 3.95$, $p<.05$) revealed a significant difference between groups and gender. This result indicated a higher proportion of male caregivers in the TBI group. A chi-square Fisher’s Exact test statistic of $X^2 (3,N = 137) = 9.24$, $p<.05$) identified an association between ethnicity and caregiver group, demonstrating there was a significantly higher proportion of Māori in the TBI group than the Control group.

Proportions of participants were similar in each group pertaining to marital status with the majority of caregivers in both groups having a partner. This was confirmed as there was no significant association found using chi-square analysis between groups.

In summary of the previous results; TBI caregivers were younger and attained a lower level of education than that of Control caregivers. TBI caregivers earned lower incomes and worked less hours than the Control group, while having a higher proportion of male participants within the group. There were more Māori caregivers in the TBI group while both groups were similar in marital status, with majority of caregivers having a partner.

Table 1. Distribution of Demographic Information between TBI and Control Caregivers

	TBI Group		**Control Group**	
	n	***(%)***	***n***	***(%)***
	94		**43**	
Educational Attainment				
Primary	2	(2.1)	-	-
High school	34	(36.2)	5	(11.6)
Polytechnic	29	(30.9)	11	(25.6)
University	23	(24.5)	26	(60.5)
Unknown	6	(6.4)	1	(2.3)
Estimated Income Level				
High	37	(39.4)	24	(55.8)
Moderate	25	(26.6)	14	(32.6)
Low	29	(30.9)	5	(11.6)
Unknown	3	(3.2)	-	-
Hours Worked				
Full Time	27	(28.7)	15	(34.9)
20-24 Hours	14	(14.9)	20	(46.5)
< 20 Hours	15	(16.0)	2	(4.7)
Not Employed	-	-	-	-
Unknown	38	(40.4)	6	(14.0)
Gender				
Male	16	(17.0)	2	(4.7)
Female	78	(83.0)	41	(95.3)
Ethnicity				
New Zealand European	52	(55.3)	31	(72.1)
Māori	33	(35.1)	6	(14.0)
Other	9	(9.6)	4	(9.3)
Unknown	-	-	2	(4.7)
Marital Status				
Married/Civil Union	55	(58.5)	35	(81.4)
Separated/Divorced	14	(14.9)	3	(7.0)
Never Married	17	(18.1)	4	(9.3)
Unknown	8	(8.5)	1	(2.3)

Comparative Health Outcomes for TBI and Control Caregivers

One-Way ANOVA’s were conducted to explore differences in Health outcomes between the TBI and Control caregiver groups. The 12-month data from the SF-36 (physical, mental and overall health subscales) and HADS (anxiety and depression) were used.

With regards to overall health, analysis indicated a significant difference between groups on the SF-36 overall health subscale, suggesting TBI caregivers perceived their overall health as poorer than that of the Control caregivers. HADS anxiety scores were similar across both groups, however a significant difference was revealed for scores on the HADS depression scale, suggesting TBI caregivers were more depressed than Control caregivers (see Table 2).

Table 2. One-Way ANOVA Comparing Health Related Outcomes on the SF-36 and HADS Subscales between TBI and Control Groups

	TBI Group		**Control Group**					
	x	***sd***	***x***	***sd***	***F***	***df***	***sig.***	***partial n^2***
SF-36 *(n)*	*(93)*		*(43)*					
Physical Health	76.90	21.26	83.21	9.64	3.45	1,134	.06	.025
Mental Health	76.59	21.16	82.00	9.18	2.58	1,134	.11	.019
Overall Health	78.85	21.22	85.98	7.76	4.55	1,134	.03*	.033
HADS								
Anxiety	4.00	3.73	2.31	.47	.51	1,135	.47	.004
Depression	2.05	2.63	1.02	1.44	5.79	1,135	.01**	.041

Note: *p<0.05;**p<0.01

Further exploration was undertaken to determine if in fact the TBI caregivers depression scores were in the range for a clinical diagnosis of depression (score >7). Table 3 presents descriptive statistics which show the proportions of TBI and Control participants in each of the clinical categories for depression. The majority of TBI caregivers presented in the normal range while 100% of Controls fell into this category. A very small number of TBI caregiver participants were reported as experiencing mild and moderate depression, therefore although the previous analysis indicated TBI caregivers were more depressed than Controls the majority of TBI caregivers were not in the clinical range for depression.

Table 3. Distribution of Caregiver Participants Reporting in the Clinical Range for HADS Depression

	TBI Group		**Control Group**	
	Depression		Depression	
Clinical Range	***n***	***(%)***	***n***	***(%)***
Normal	88	(93.6)	43	(100)
Mild	5	(5.3)	-	
Moderate	1	(1.1)	-	
Severe	-		-	
Total	94	(100)	43	(100)

The DSM-IV Depression Diagnostic Scale was included to identify caregivers at risk of developing depression and if they had received treatment for depression in the past year. Table 4 shows descriptive statistics for three of the main questions within the DSM-IV Depression Diagnostic Scale. More TBI caregivers than Controls reported feeling sad or depressed, and were currently receiving treatment for depression. Across both groups, a similar percentage of participants had received treatment for depression in the last year (~12%). Chi-square analyses were conducted to examine between group frequency of reported depressive symptoms and current receipt of treatment. Fisher's exact test statistic was reported due to some variables having less than the required value of 5. No significant associations were found indicating the groups were similar in their experiences of depression and reported treatment *($X^2 = 2.081$, $p>.05$.).*

Table 4. Distribution for Depression Symptoms and Treatment Received by TBI and Control Caregiver Groups

	TBI Group				**Control Group**			
	Yes		No		Yes		No	
DSM-IV Questions	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***
Received treatment in last year	11	(12.0)	81	(88.0)	5	(11.9)	37	(88.1)
Do you often feel sad or depressed	13	(14.1)	79	(85.9)	2	(4.8)	40	(95.2)
Currently receiving treatment	15	(16.3)	77	(83.7)	3	(7.1)	39	(92.9)

One-Way ANOVA's were carried out upon the BCOS 15-Items and Question-16 to determine if there were differences between groups on their perceived life changes over the previous 12-months. A significant difference was detected upon both BCOS subscales each showing a moderate effect size, this indicating Control caregivers perceived their life had changed for the better, more so than TBI caregivers (see Table 5).

Table 5. One-Way ANOVA Comparing BCOS Life Changes Between TBI and Control Caregivers

	TBI Group		**Control Group**					
	x	***sd***	***x***	***sd***	***F***	***df***	***sig.***	**partial η^2**
BCOS ***(n)***	*(93)*		*(42)*					
Total 15-Items	61.59	9.43	68.83	9.71	16.75	1,133	.00**	.112
Question-16	4.27	.99	4.90	1.30	9.73	1,133	.00**	.068

Note: *$p<0.05$;**$p<0.01$

Further exploration was carried out upon the BCOS subscales to determine to what extent the TBI and Control caregiver groups experienced life changes. Descriptive statistics indicated a similar percentage of caregivers in each group reported changes for the worse on the BCOS Total 15-Items, although more Control caregivers indicated life had changed for the better than TBI caregivers. A slightly higher percentage of TBI caregivers reported life had changed for the worse on Question-16 compared to Control caregivers. A higher percentage of Control caregivers than TBI caregviers reported life had changed for the better. This suggests although differences were detected between groups, and more TBI caregivers reported worse life changes, the majority of TBI caregivers reported life hadn’t changed at all (see Table 6).

Table 6. Descriptive Statistics for BCOS Total 15-Items and Question-16 for TBI and Control Caregiver Groups.

	TBI Group		**Control Group**	
	n 93	***(%)***	***n 42***	***(%)***
Total 15-Items				
Changed for Worse	17	(18.3)	7	(16.7)
Did not Change	67	(72.0)	26	(61.9)
Changed for Better	9	(9.7)	9	(21.4)
Question-16				
Changed for Worse	6	(6.5)	1	(2.4)
Did not Change	70	(75.3)	25	(59.5)
Changed for Better	17	(18.2)	16	(38.1)

Child Behavioural and Adaptive Scales for TBI and Control Children

One-Way ANOVAS were used to explore if there were significant differences in mean scores between TBI and Control children on the BASC Behavioural Symptoms Index and Adaptive Skills Composite. The clinical range for low-average is 20-59 while high clinical range is 60+. The range of scores for the TBI group sat in the average to high clinical range, indicating typical to problematic behaviour, while the Controls range of scores sat in the average clinical range indicating typical behaviour. This suggests that overall levels of problematic behaviour are higher in the TBI sample. Adaptive Skills composite (mean T score) is an indication of how the child expresses appropriate emotional expression/control, daily living skills, organisational skills, social and communication skills at home and away from home (Reynolds & Kamphaus, 2012). Mean scores differed significantly between groups with a moderate effect size. Clinical cut-off scores for the Adaptability scale are: low to average range is

10-40, average to high range is 41+. The TBI children's range of scores sat in the low-average range, while the Control children's scores fell into the average to high range. These differences suggest TBI children have problems with adaptability where Control children present with better adaptive functioning (see Table 7).

Table 7. One-Way ANOVA of Behavioural and Adaptive Functioning between TBI and Control Children

	TBI Group		**Control Group**					
	x	***sd***	***x***	***sd***	***F***	***df***	***sig.***	***partial η^2***
BASC *(n)*	*(94)*		*(43)*					
Mean T-Score BSI	52.81	9.24	48.12	8.10	8.21	1,135	.00**	.057
Mean T-Score Adaptability	47.98	10.39	53.70	8.51	10.00	1,135	.00**	.069

Note: *p<0.05;**p<0.01

In summary of the previous findings for TBI and Control caregivers health outcomes; due to the caregiving role TBI caregivers at 12-months post TBI experienced poorer overall health and were more depressed, however most TBI caregivers weren't clinically depressed. Control caregivers experienced more positive life changes than TBI caregivers, although this was not to say TBI caregiver's lives had changed for the worse. This just indicated life had not changed at all over the past year.

TBI children had more behavioural problems and greater difficulty with adaptive skills than the Control children group.

Caregiver and Child Variables Influencing Caregiver Outcomes

The objective of the following correlational analyses was to determine which caregiver and child variables influence health outcomes for the TBI caregiver. Given the study aims and the previous findings of differences in health outcomes and life changes between groups, this part of the analysis pertains to the TBI group only.

Identifying Potential Predictors of TBI Caregiver Outcomes Through Exploring Caregiver Variables

Several caregiver sociodemographic variables were analysed to investigate if a relationship exists between these and reported levels of physical, mental and overall health and well-being, anxiety and depression, and life changes. The variables used in the analysis were: caregiver age, educational attainment, income, gender, ethnicity, marital status, Esteem, Instrumental and Informational supports.

Spearman's non-parametric correlations were chosen for this analysis as most of the variables were non-linear and not normally distributed.

Caregiver age was found to correlate with both subscales on the BCOS (Total 15-Items and Question-16), which may suggest as age increases so too does the likelihood of the caregiver reporting more positive life changes pertaining to social functioning, subjective well-being and somatic health. Correlations were found between caregiver income and the SF-36 subscales physical health and overall health; also BCOS Total 15-Items. This suggests caregivers on higher incomes reported better physical and overall health, and positive life changes.

A positive correlation was found between ethnicity and depression with a medium effect size; this implies depression was higher in the Māori/‘other’ ethnic group than in the New Zealand European group. Marital status and Esteem supports both showed correlations with the BCOS subscale Question-16. This suggests caregivers in a relationship, and who perceived they were supported, were more likely to report more positive life changes (see Table 8).

In summary of the previous results; older caregivers’ experienced more positive life changes and those with higher incomes had better physical health, overall health, and positive life changes. Māori/‘other ethnicity’ were more likely to suffer depression; also caregivers who had partners and felt supported experienced more positive life changes.

Table 8. Spearman’s Non-Parametric Correlations for Caregiver Variables and Health Outcomes on the SF-36, HADS and BCOS Subscales

	SF-36						**HADS**				**BCOS**			
	Physical		Mental		Overall Health		Anxiety		Depression		Total 15-Items		Question-16	
	r (n)	***p***	***r***	***p***	***r***	***p***	***r (n)***	***p***	***r***	***p***	***r(n)***	***p***	***r***	***p***
Caregiver Age	.11 *(92)*	.26	.11	.27	.12	.22	-.09 *(93)*	.37	.00	.93	.22 *(88)*	.03*	.25	.01*
Educational Attainment	.09 *(88)*	.37	.06	.57	.08	.45	.00 *(89)*	.94	-.04	.71	-.10 *(84)*	.35	-.11	.30
Income	.25 *(92)*	.01*	-.14	.17	.21	.04*	-.20 *(91)*	.06	.04	.67	.28 *(86)*	.00**	.20	.05
Caregiver Gender	.02 *(92)*	.80	-.00	.96	.02	.82	-.07 *(93)*	.47	.04	.68	-.03 *(93)*	.74	.05	.63
Ethnicity	.01 *(92)*	.78	-.08	.40	-.04	.67	.02 *(93)*	.79	.21	.03*	.25 *(93)*	.25	.19	.06
Marital Status	-.10 *(87)*	.32	-.10	.35	.15	.16	.00 *(89)*	.94	-.04	.71	.13 *(82)*	.23	.25	.02*
Esteem Supports	.00 *(92)*	.96	.03	.76	.03	.72	-.12 *(94)*	.21	.09	.36	-.15 *(93)*	.14	-.21	.03*
Instrumental Supports	.04 *(92)*	.66	.06	.55	.04	.64	-.15 *(94)*	.14	.07	.48	-.15 *(93)*	.15	-.03	.77
Information Supports	-.07 *(92)*	.48	-.06	.52	-.07	.47	.03 *(94)*	.70	.07	.46	-.12 *(93)*	.22	.06	.56

Note: Ethnicity defined as New Zealand European, Māori/Other Ethnicity
*Correlation is significant at the .05 level (2-tailed)**Correlation is significant at the .01 level (2-tailed)

Identifying Potential Predictors of TBI Caregiver Outcomes Through Exploring Child Variables

BASC BSI T-scores indicated a strong correlation with all three measures on the SF-36 subscales. BASC BSI T-scores negatively correlated with SF-36 mental health, physical health and overall health. This suggests caregivers who reported their children as having more behavioural problems at 12-months post-TBI also reported poorer physical, mental and overall health and well-being. BASC BSI T-scores showed a positive correlation with the two HADS subscales anxiety and depression. This suggests caregivers who reported their children had higher levels of behavioural problems at 12-months post TBI, experienced higher levels of anxiety and depression. BASC Adaptability T-scores positively correlated with all three SF-36 measures, indicating the child's ability to express appropriate adaptive skills related to caregivers experiencing better physical, mental, and overall health and well-being. Adaptability T-scores showed no correlation with HADS anxiety and depression, or BCOS overall life changes. The severity of the child's TBI showed no relationship to any of the three measures; SF-36, HADS and BCOS (see Table 9). In summary of these results, caregivers who reported more problematic behaviour in the child experienced poorer mental and physical health; and higher levels of anxiety and depression. Caregivers who reported higher adaptive functioning in the child experienced better physical, mental and overall health and well-being. There were no correlations found between TBI severity on any of the SF-36 or HADS subscales, or on either of the BCOS subscales.

Table 9. Spearman's Non-Parametric Correlations for Child Variables and Caregiver Health Outcomes on the SF-36, HADS and BCOS Subscales.

	SF-36						**HADS**				**BCOS**			
	Physical		Mental		Overall Health		**Anxiety**		**Depression**		**Total 15-Items**		**Question-16**	
	r (n)	***p***	***r***	***p***	***r***	***p***	***r (n)***	***p***	***r***	***p***	***r(n)***	***p***	***r***	***p***
TBI Severity	-.15*(92)*	.14	-.13	.18	-.16	.12	.00 *(94)*	.99	.13	.19	.05*(93)*	.62	.12	.22
BASC BSI T-Scores	-.47*(91)*	.00**	-.49	.00**	-.52	.00**	.34 *(91)*	.00**	.26	.00**	.03*(93)*	.72	.09	.38
BASC Adaptability T-Score	.36*(91)*	.00**	.42	.00**	.41	.00**	-.14 *(91)*	.15	-.13	.20	-.08*(93)*	.44	-.09	.37

*Correlation is significant at the .05 level (2-tailed)
**Correlation is significant at the .01 level (2-tailed)

Multiple Regression Analyses for Caregiver and Child Variables, and Caregiver Health Outcomes and Life Changes

Due to the significant relationship between caregiver health outcomes and caregiver and child variables, a series of Standard Multiple Forced Entry Regression analyses were carried out to examine if caregiver variables: age, income, ethnicity, marital status and Esteem supports, and child variables: behaviour and adaptability, significantly predicted caregiver self-ratings of physical health, mental health, overall health, anxiety, depression and life changes.

Income, BSI mean scores and Adaptability mean scores were entered into the regression analysis to determine if these variables could predict caregiver's physical health. The results indicated these variables accounted for 25.2% of the variance in physical health ($r^2 = .252, F(3,86) = 9.66, p < .01$). Income ($\beta = -.236, p < .05$), and child's behaviour ($\beta = .549, p < .05$) significantly predicted caregiver's physical health; however child's adaptability could not predict physical health outcomes. Next income, BSI T-scores and adaptability T-scores were entered into the regression analysis to determine if these were predictors for overall health and well-being. These variables accounted for 25.4% of the variance in overall health and well-being ($r^2 = .254, F(3,86) = 9.77, p < .01$). Caregiver's income ($\beta = -.219, p < .05$) and child's behaviour ($\beta = .511, p < .05$) were found to be the only predictors for overall health and well-being. Ethnicity, BSI T-scores and Adaptability T-scores were entered next to investigate if these could predict depression. Sixteen percent of the variance was explained by these variables ($r^2 = .160, F(3,89) = 5.96, p < .01$). Both behaviour ($\beta = .327, p < .05$) and ethnicity *($\beta = .278, p<.01$)* were found to be significant predictors of caregiver depression. Age and income were entered with BCOS 15-Items, these variables explained 10.1% of the variance in life changes on the 15-Item subscale *($r^2 =.101, F(2,83) = 4.67, p<.05$).* Income was found to be the only predictor variable for caregiver life changes *($\beta = .262, p<.05$).* Age, marital status and Esteem supports were the last variables to be entered into the regression analysis; this was to determine if these variables could predict the BCOS subscale Question-16 overall life changes. These variable explained 13.9% of the variance *($r^2 =.139, F(3,78) = 4.21, p<.01$),* however age was the only variable found to be a significant predictor for life changes *($\beta = .284, p<.05$).*

A summary of the regression analyses tells us income predicts physical health and overall health, as well as life changes. This suggests caregivers on higher incomes can expect better physical and overall health and more positive life changes. Age was found to predict life changes suggesting older caregivers could expect more positive life changes. Ethnicity was found to predict depression, suggesting the caregivers from ethnicities other than New Zealand European were more likely to experience depression. Child behaviour was found to predict poorer caregiver health outcomes across several health domains, spanning physical health, overall health and well-being, and depression; while TBI severity and child’s adaptive functioning were not predictive factors for any caregiver health outcomes.

Exploring the Health Outcomes of New Zealand European and Māori Caregivers

To determine if there were differences in caregiver health outcomes between New Zealand European and Māori, the data from these groups who completed assessments at 12-months were examined. Table 10 presents the demographic data for the participants included in the analyses. Chi-square analyses were carried out to determine if there were differences between the two samples. Fisher’s exact statistic was reported due to some variables having less than the required minimum value of 5. Both groups reported similar educational attainment, income level, hours worked and marital status ($p=>.05$). The majority of participants in both groups were female although there were more Māori male caregivers than New Zealand European ($X^2 = 1.60, p>.05$). The age range for New Zealand European was 26-54 years ($X = 39.5, SD = 6.19$), and Māori 19-50 years ($X = 36.6, SD = 8.07$). One-Way ANOVA’s indicated no significant difference in ages between the two groups, $F(1,81) = 3.55, p > .05$). Considering all demographic variables, no significant differences were found between the New Zealand European and Māori groups.

Table 10. Distribution of Demographic Information between New Zealand European and Māori TBI Groups

	New Zealand European		**Māori**	
	***n* 52**	***(%)***	***n* 31**	***(%)***
Educational Attainment				
Primary	-	-	1	(3.2)
High school	18	(34.6)	13	(41.9)
Polytechnic	16	(30.8)	11	(35.5)
University	14	(26.9)	5	(16.1)
Unknown	4	(7.7)	1	(3.2)
Estimated Income Level				
High	24	(46.2)	9	(29.0)
Moderate	12	(23.1)	9	(29.0)
Low	15	(28.8)	12	(38.7)
Unknown	1	(1.9)	1	(3.2)
Hours Worked				
Full Time	13	(25.0)	6	(19.4)
20-24 Hours	10	(19.2)	4	(12.9)
< 20 Hours	9	(17.3)	5	(16.1)
Unknown	20	(38.5)	16	(51.6)
Gender				
Male	5	(9.6)	6	(19.4)
Female	47	(90.4)	25	(80.6)
Marital Status				
Married/Civil Union	34	(65.4)	17	(54.8)
Separated/Divorced	7	(13.5)	5	(16.1)
Never Married	7	(13.5)	9	(29.0)
Unknown	4	(7.7)	-	-

Comparative Analysis for New Zealand European and Māori Caregivers

To examine differences in caregiver outcomes between New Zealand European and Māori participants, One-Way ANOVA's were conducted on caregiver outcome scales from the SF-36, HADS, BCOS, and the three support measures: Esteem, Instrumental and Informational.

There were no significant differences found between groups in relation to the SF-36 subscales (physical, mental and overall health and well-being), HADS subscales (anxiety and depression), and supports (Esteem, Instrumental and Informational). However, a significant difference was detected for BCOS Total 15-Items *($p=.02$)* and Question-16 *($p=.00$),* both with a moderate effect size (*partial η^2 =.05 and .09).* This is an indication that when considering specific and overall life changes over the last year post child's injury, New Zealand European participants reported quality of life hadn't changed due to their caregiving role, whereas Māori indicated life had changed slightly for the better (see Table 11).

Table 11. One-Way ANOVA’s Comparing New Zealand European and Māori Caregiver HRQoL 12-months Post Child’s TBI

	New Zealand European		**Māori**					
	x	***sd***	***x***	***sd***	***F***	***df***	***p.***	***partial*** η^2
SF-36 ***(N)***	*(52)*		*(31)*					
Physical	77.67	20.23	76.42	19.27	.077	1,81	.78	.001
Mental	79.38	18.94	73.61	20.70	1.67	1,81	.19	.020
Overall Health	80.73	19.34	77.00	20.46	.692	1,81	.40	.008
HADS ***(N)***	*(52)*		*(31)*					
Anxiety	3.75	3.36	4.26	3.79	.404	1,81	.60	.005
Depression	1.50	2.22	2.39	2.64	2.69	1,81	.10	.032
BCOS ***(N)***	*(52)*		*(31)*					
Total 15-Items	60.04	7.22	64.65	11.56	5.01	1,81	.02*	.058
Question-16	4.08	.621	4.68	1.30	8.05	1,81	.00*	.090
SUPPORTS ***(N)***	*(54)*		*(32)*					
Esteem Supports	0.74	.442	0.69	.471	.277	1,84	.60	.003
Instrumental Supports	0.26	.442	0.28	.457	.048	1,84	.82	.001
Informational Supports	0.35	.482	0.44	.504	1,84	.613	.43	.007

Table 12 presents the frequency counts for New Zealand European and Māori caregivers for the three main questions within the DSM-IV Depression Diagnostic Scale. A greater proportion of Māori than New Zealand European reported receiving treatment over the past 12-months for depression; this was also the case regarding the second question “Do you often feel sad or depressed”. A quarter of Māori caregivers reported currently receiving treatment for depression as opposed to only 13.5% of New Zealand Europeans. However, a chi-square analysis found no significant association between treatment for depression and ethnicity suggesting both groups reported similar levels of treatment for depression.

Table 12. Frequency Data for the Three Main Questions within the DSM-IV Depression Diagnostic Scale for New Zealand European and Māori Caregivers

	New Zealand European				**Māori**			
	Yes		No		Yes		No	
DSM-IV Questions	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***
Received treatment in last year	6	(11.5)	46	(88.5)	5	(16.1)	26	(83.9)
Do you often feel sad or depressed	6	(11.5)	46	(88.5)	5	(16.1)	26	(83.9)
Currently receiving treatment	7	(13.5)	45	(86.5)	8	(25.8)	23	(74.2)

New Zealand European and Māori Caregivers' Reported Level of Satisfaction of Services

The caregiver participants were asked to rate on a scale of 1-10 how satisfied they were with the services they had received over the 12-months post TBI (1 = very unsatisfied, 10 = very satisfied). Ratings for the New Zealand European and Māori sample were calculated to give an overall rating of satisfaction for each participant over the 12-month period. The average level of satisfaction reported by New Zealand European participants *(n = 17, x = 8.1, sd = 2.08)* and Māori participants *(n = 13,.x = 8.0, sd = 2.14)* indicated a relatively high level of satisfaction for both groups. Chi-square analysis reported no significant difference between the two groups *($X^2 = 10.09, p>.05$).* Of those New Zealand European who reported dissatisfaction the following comments were made specifying reasons for their dissatisfaction: “service took too long”, “financial barriers”, “staff un-contactable”, “no services offered’, and “not listened too”.

Comments from Māori who reported dissatisfaction were: “cost”, “long wait time”, “not enough information”, “they made me feel like I didn’t know what I was doing”, “unable to contact professional to query injury”, “sent unwell child home only to have to re-admit them the following day”, “no additional services were suggested”, “staff attitude”, and “not listened too”.

Caregivers were also asked to rate from 1 = ‘very satisfied’ to 4 = ‘not at all satisfied’, if they felt the services received were acceptable to their culture. The average level of satisfaction for New Zealand Europeans was *($n = 16, x = 3.5, SD = .855$),* and Māori *($n = 13, x = 3.2, SD =.958$).* Chi-squared analysis indicated no significant differences between groups on reported satisfaction of services ($X^2 = 6.56, p>.05$)*.* Some comments surrounding reported dissatisfaction were “services not accessed” and “no services received” (New Zealand European participants) and ‘not understanding about Whānau” and ‘not receiving the services needed” (Māori participants).

In summary of the previous results; Māori and New Zealand European TBI caregivers experienced similar health outcomes and received similar levels of support in all three categories; however Māori experienced more positive life changes than New Zealand European *($p<.00$).* Both caregiver groups were also similar in their subjective experiences with services they were involved with due to their child sustaining a TBI.

Caregivers Health Outcomes Over Time

The last area of investigation was to determine if there were differences in caregiver's reported health outcomes due to their caregiving role from 1-month post-injury to 12-months post injury. Measures used for these analyses were SF-36: mental, physical, and overall health scales; HADS anxiety and depression Scales and BCOS Total 15-Items and Question-16. Scores from each measure were calculated at three time points: 1-month, 6-months and 12-months.

A series of One-Way Repeated Measures ANOVA was used to test for significance of effect of time on caregiver health outcomes between the 1-month, 6-month and 12-month time points. Results were reported using alpha level of .05. The means and standard deviations, and inferential statistics are presented in Table 13. To further investigate significant results, pairwise comparisons using the bonferroni multi-comparison correction were carried out to detect significant differences between each time point for each scale as appropriate.

The results from the Wilks' Lambda tests revealed a significant difference over time for the SF-36 physical scale, which had a large effect size. Pairwise comparisons revealed a significant difference in physical health mean scores between time points 1-month and 12-months revealing caregivers physical health improved over the 12-month period. Significant effects for time were found for SF-36 mental health scale, the effect size was large. Pairwise comparisons were undertaken revealing a significant difference between time point's 1-month and

12-months thus concluding mental health improved for the caregiver over the 12-month period. SF-36 overall health outcomes scale reported a significant difference, this also showed a large effect size and significant difference in means between time points 1-month and 12-months revealing caregivers overall health and well-being improved over the 12-month period. These results suggest time has an effect upon physical, mental and overall reported health.

One-Way Repeated Measures ANOVA were also conducted upon the HAD's anxiety and depression subscales. A significance effect for time was found for anxiety, which showed a large effect size. A significant effect for time was also found on the depression subscale which indicated a moderate effect size. These results suggest caregiver-reported anxiety and depression lessened over time. Pairwise comparisons between time points showed significant differences in anxiety scores between time point's 6-months and 12-months, and 1-month and 12-months. This revealed anxiety not only decreased significantly for the caregiver over the 12-month period but also showed a significant decrease between 6- and 12-months post TBI. For depression there was a significant difference noted only between 1- and 12-months indicating depression decreased progressively for the caregiver over the 12-month period.

BCOS Total 15-Items showed no significant difference in changes over the entire 12-month period although a significant difference was noted for Question-16 between 6- and 12-months indicating that for this period of time life changed for the better.

In summary of the previous findings; mental, physical and overall health improved significantly for TBI caregivers over the 12-months post-injury. This was also the case for anxiety and depression levels. These changes were the greatest between the 1-month and 12-month period, although anxiety levels also improved significantly over the 6-month to 12-month period. Caregivers experienced the most positive life changes between 6- and 12-months post TBI (see Table 13).

Table 13. One-Way Repeated Measures ANOVA for SF-36, HADS and BCOS Subscales Measured at 1-Month, 6-Months and 12-Months Post-TBI

		1-Month		**6-Months**		**12-Months**						*Sig. (pairwise comparison)*		
	n	***x***	***sd***	***x***	***sd***	***x***	***sd***	***F***	***df***	***sig***	***partial*** η^2	**1-6 mont**	**6-12 months**	**1-12 month**
SF-36 Physical	54	75.39	20.79	76.70	20.74	80.87	17.39	7.26	2,52	.00**	.218	1.0	.08	.00**
SF-36 Mental	54	73.67	20.20	77.11	19.22	80.14	17.15	8.85	2,52	.00**	.254	.48	.09	.00**
SF-36 Overall Health	54	76.23	19.91	78.94	19.49	82.79	16.48	11.50	2,52	.00**	.307	.67	.06	.00**
HADS Anxiety	54	4.95	4.02	4.79	3.86	3.43	3.21	7.91	2,52	.00**	.227	1.0	.00**	.00**
HADS Depression	54	2.71	3.01	2.21	2.76	1.64	2.23	3.75	2,52	.03*	.122	.45	.29	.02*
BCOS 15-Items	54	61.57	7.25	62.52	8.14	63.07	9.06	1.67	2,52	.19	.060	1.0	1.0	.22
BCOS Question-16	54	4.20	.810	4.20	.959	4.37	.938	2.33	2,52	.10	.082	1.0	.03*	.16

Note: *p<0.05;**p<0.01

Discussion

This study explored aspects of caregiver HRQoL and burden when caring for a child with TBI. Findings in the frequency data for the TBI children showed similarities between the current study and those published in the literature pertaining to the New Zealand population. This suggests the TBI sample in this study is a realistic representative sample of the New Zealand TBI population. The higher incidence of injuries in ethnic groups per population was evident within the current sample, with Māori sustaining a higher number of injuries per population than New Zealand Europeans; this confirms previous finding of ethnic disparities in TBI rates (The New Zealand Guidelines Group, 2006). The current sample also showed a higher number of injuries in the 10-15 year old age group than in the 5-9 year old group, which is in line with McKinlay et al's. (2006) study upon the prevalence of injury in children, adolescence and adults. Nearly twice as many male children had a TBI compare to females which mirrors local and international literature (Barker-Collo et al., 2008; Cassidy et al., 2004; Hirschberg et al., 2008; Langlois et al., 2004). Barker-Collo (2008) estimate 70-90% of TBI cases are mild which is slightly lower than rates of mild TBI observed in the current study, however Barker-Collo's figures are estimates so the actual number of mild TBI cases are unknown. Similarities were also found for mechanism of injury in which falls and recreational activities were found to be the most common reason for injuries (McKinlay et al., 2008).

Findings relating to each of the four study aims are now discussed.

Comparative Health Outcomes for TBI and Control Caregivers

The main focus of this study was to investigate health outcomes for caregivers of children with TBI to determine if their physical and psychological health was worse than that of caregivers of children without a TBI.

Study findings suggest caregivers of children with TBI were more likely to experience depression than caregivers in the Control group, although levels were not clinically significant (Snaith, 2003). This subtle elevation in depression may be indicative of this group experiencing higher levels of distress due to their caregiving role. Higher levels of self-reported depression were also indicated for TBI caregivers in the DSM-IV Depression Diagnostic Scale. A similar percentage of TBI and Control caregivers had received treatment for depression in the past year, however double the percentage of TBI caregivers reported currently receiving treatment for depression, and four times as many TBI participants reported often feeling sad and depressed. These results reflect findings in the literature which suggest caregiving significantly increases the likelihood of psychological stress (Marsh et al., 1998), with depression being one of the leading symptoms associated with the caregiving role (Ruff et al., 2009). In contrast to TBI caregivers experiencing higher levels of depression, anxiety levels were similar in the two groups. This was surprising considering anxiety is also reported as a prominent symptom associated with the caregiving role; more so than depression due to its immediacy in affect response to stressful situations (Pinquart & Sorensen, 2003). However Demirrtepe-Saygih and Bozo (2011) found levels of anxiety and depression were not necessarily experienced in conjunction with one another, as there were other variables which influenced these levels such as educational attainment and other sociodemographic variables (this will be discussed in more detail later in the chapter). Furthermore, given that the data for the current study was obtained 12-months post TBI any initial anxiety experienced by the caregiver may have diminished. These findings link with previous research which suggests time is in integral factor in the reduction of caregiver burden and anxiety (MacKenzie et al., 2009). In addition, as the majority of TBI participant's sustained mild injuries this may not have stretched the caregivers capacity of personal resources, therefore not placing excessive demands upon them resulting only in low level anxiety. This explanation sits well with Lazarus's (1993) model of stress and coping which suggests stress is an adverse response to overwhelming environmental demands.

In terms of specific life changes (BCOS 15-Items) as a result of caregiving, there were no significant differences between the two groups, and the majority of both groups reported no change. This is in line with research by Pinquart and Sorenson (2003) who found the three aspects of health and well-being measured by the BCOS (social functioning, subjective well-being and somatic health) to be less sensitive to change due to their disruption being less situation specific; unlike anxiety and stress which is more likely to be associated to a specific situation or event.

Considering overall life changes (BCOS Question-16), Control caregiver's experienced better life changes than TBI caregivers. This was not to say TBI caregivers reported life had changed for the worse; just that they were more likely to report no life changes. Reporting of life changes in caregiver and non-caregiver samples is varied and may depend upon factors such as whether the participant is specifically focusing upon life changes in conjunction to their caregiving role, or whether they are focusing upon life changes in the general sense. It would seem reasonable to think the TBI caregivers would have reported positive life changes in conjunction with improved health outcomes over the 12-months post TBI; however this was not the case suggesting other factors may have played a part in this outcome. Although the caregivers' health improved, there were still elevated levels of depression at 12-months post TBI which may have influenced this result. This however does not explain why the Control group reported better life changes. An explanation may be that these caregivers were in a better position in regards to sociodemographic factors, health and well-being than the TBI caregivers, therefore may have experienced life more positively.

Measuring HRQoL allows us to determine how physical and mental stress impact upon ones' life (Arostegui, Nunez-Anton, & Quintana, 2007). The SF-36 reports ones' perceived level of well-being in accordance with their current health status. Findings from the current study revealed TBI caregiver's experienced poorer overall health compared to the Control caregiver group. A finding within the current study which may help in explaining this outcome was the TBI children were found to display higher levels of problematic behaviour than Control children. Previous studies have reported on-going cognitive, behavioural and emotional effects from the TBI continued to cause disruption to normal functioning of the TBI individual 12-months post TBI, therefore continuing to have an adverse effect upon caregiver's physical and psychological health (Marsh, 1998). Although these findings were based on a sample of severe TBI children; it was the on-going dysfunctional behaviour of the child which was one of the main variables contributing to caregiver burden at 12-months post TBI, which was also confirmed in the current study. Problematic behaviour in the TBI individual is reportedly the most common disruption for the caregiver (Braine, 2011) due to its emotionally charged nature and often being aimed at the caregiver (Godfrey et al., 2003).

Surprisingly, there were no significant differences between the groups on the physical health and mental health subscales of the SF-36. These findings may appear unusual considering the difference in overall health outcomes were significant between the groups, although research by Pinquart & Sorenson (2003) indicated physical restrictions may be less inhibiting than other health issues relating to caregiving. The caregiving role is repeatedly reported in the literature to exert physical pressure upon caregivers; there may be several reasons why this wasn’t the case in the current study. The majority of TBI children had mild injuries therefore the physical exertion may not have necessarily increased significantly for the caregiver. Also Pinquart and Sorenson (2003) suggest physical health may be less situation specific than stress and anxiety, and have a more indirect effect upon caregivers, therefore the level of physical health may not be directly linked to caregiver burden.

These explanations may in part explain the lack of between group differences in caregiver physical health outcomes, although it is puzzling when considering the DSM-IV(American Psychiatric Association, 1994) proposes physical health declines due to depressive symptoms, and the current study findings of elevated depression in conjunction with subsequent normal physical well-being. It may be necessary to consider the caregiver’s depression levels were elevated and the assessments were self-report, therefore it may be questionable as to whether these caregivers were making clear judgement concerning their well-being. Or it may simply be explained that the caregivers depression scores, although elevated, were not in the clinical range so may not have been severe enough to affect physical well-being.

There were differences in sociodemographic data between caregiver groups. The Control caregivers were older, worked more hours, had higher educational attainment and higher incomes; therefore it was not unexpected to find they experienced better physical health, overall health, lower levels of depression and more positive life changes. Previous research recognises sociodemographic variables impact significantly upon health outcomes in many caregiving domains. It was however slightly surprising to find similarities between groups in reported anxiety, and mental health. As the data was 12- month post TBI data it is understandable that anxiety levels may have reduced resulting in similar between groups outcomes, however the similarities in mental health (SF-36) remains unexplained.

Caregiver and Child Characteristics Influencing Caregiver Outcomes

Based on previous research (Nabors et al., 2002), an attempt was made to identify specific caregiver characteristics, TBI severity, and aspects of child behaviour and adaptability contributing to caregivers' physical and psychological health outcomes. Many studies have identified factors which are thought to influence health outcomes. Thompson et al's. (1994) Transactional Stress and Coping Model provides a framework to help in explaining the interaction by suggesting adjustment for individuals to an illness is a combination of factors such as the illness, sociodemographic variables, personal characteristics and adaption processes. Although the current study doesn't focus upon adaption processes in the form of coping strategies, it set out to determine if sociodemographic variables impacted upon caregiver's health and well-being as reported by the caregivers at 12-months post TBI. Variables found to make significant independent contributions to caregiver's health and well-being were caregiver age, family income, ethnicity, marital status, supports and child's behavioural functioning and adaptive functioning.

Caregiver Variables and Health Outcomes

Older caregivers reported more positive life changes, which is in line with previous research suggesting older caregivers have more life experience and manage adversity better than younger caregivers (Papastavrou et al., 2007). Caregivers with higher incomes had better physical and overall health and more positive life changes than those on lower incomes. Income as a predictor of health outcomes varies in significance from study to study, which is interesting as income is strongly associated with better health outcomes worldwide (Case, 2000). In fact income is reported by The New Zealand Guidelines Group (2006) as the key contributor to overall quality of life due to income determining access to healthcare, food, housing, clothing and goods and services. Nabours (2002) found caregivers on lower incomes experience higher levels of burden, however suggests there isn't a lot of direct focus in the literature upon the relationship between income and access to resources, and the impact this has upon caregivers. The significance of income may differ between studies conducted in different countries due to some countries offering free access to health care, while in many countries insurance is a requirement to receiving health care. Mackenzie et al. (2009) recognised the existence of higher burden among countries that do not offer free medical care, leaving families to endure the financial costs or not seek medical intervention. Although income was identified in the current study as a significant contributor to physical and overall health outcomes, income was not correlated with caregiver mental health, anxiety or depression. This may suggest caregivers on higher incomes have the expenditure to maintain their physical well-being and enjoy a better lifestyle. In addition to this, the cost of health care in New Zealand pertaining to accidents is covered by the Accident Compensation Corporation (ACC), therefore may not financially burden the caregiver and cause psychological distress. Relationships between income and caregiver health outcomes in the TBI population are clearly complex and require further examination.

Unexpectedly, no significant relationship was found between caregiver educational attainment and health outcomes, yet income was a significant predictor of overall health (SF-36 subscale). This is despite the strong association between higher educational attainment and greater income reported in the literature (Ministry of Education, 2012). A factor which may have been influential in this outcome was the household income in many cases was that of two people whereas the educational level was recorded as that of the primary caregiver. Therefore the primary caregiver’s educational attainment may not have been closely associated with the total household income.

Ethnicity was found to predict depression although this appeared to be influenced by the ‘other ethnicities’ within the study which were grouped together with Māori for these analyses. Māori made up 35.1% of the total study population while Asian, Indian, Pacific and other ethnicities made up 9.6% of the ‘other’ ethnic group. When the ‘other’ ethnic group was removed for the analysis of health outcomes between New Zealand European and Māori, no significant association was detected for depression, indicating the ‘other’ ethnic group influenced this outcome.

Lack of support in the form of unmet needs is reported to be a significant contributor to caregiver burden (Marsh et al., 2002; Nabors et al., 2002). The current study identified supports as: Esteem (which included social supports), Informational and Instrumental, which attempted to identify whether caregivers felt their support needs were met. Results showed Esteem supports were associated with positive life changes reported by caregivers. This relationship was expected due to evidence of significant associations reported in the literature linking unmet needs in the form of lack of social supports to poorer health outcomes (Jorgensen et al., 2010; Marsh et al., 2002; Nabors et al., 2002). The Esteem supports may have interputed the link between stress and illness as suggested by Cohen & Wills (1985) avoiding negative experiences and adjusting appraisal and coping strategies, contributing to more positive life changes. Esteem supports may also encompass family functioning as family assistance was included as an Esteem support. This may suggest positive life changes associated with Esteem supports were an indication of positive family adaption processes which are found to assist in adjustment to the injury (Hocking & Lochman, 2005).

Marital status (with partner) was also associated with more positive life changes. Marital status was considered as an individual variable in the analysis and was included as an Esteem support; therefore these findings were not unusual. Informational and Instrumental supports did not contribute to health outcomes, despite lack of Informational supports being reported by New Zealand caregivers as one of the most significant factors contributing to burden (Jorgensen et al., 2010). An explanation for this may be that the data used for this analysis was 12-month post-injury data, therefore the need for Informational and Instrumental supports may have not been necessary that long after the TBI occurred.

Child Variables and Caregiver Health Outcomes

Studies differ in their findings regarding the priority in which variables impact upon the caregiver, although the TBI individual’s behaviour appears in several studies to be one of the more significant predictors of caregiver burden (Connolly & O'Dowd, 2001; Marsh et al., 1998; Nabors et al., 2002). The present findings supported this by revealing behavioural problems in the TBI child were predicative of health outcomes in several areas of caregiver HRQoL measured within this study. Caregivers who perceived their child to have behavioural problems experienced poorer physical health, overall health and well-being, and higher levels of depression. This is in accordance with previous research which suggests behavioural deficits in the TBI individual is the most significant contributing factor to burden, and is explained by Harris et al. (2001) as a common finding among studies due to the TBI individuals’ behaviour predicting emotional adjustment in the caregiver. Marsh et al. (1998) recognised the impact of behavioural problems upon the caregiver by suggesting although severity is often implicated as a predictive factor in caregiver health, burden was more likely related to how the injury impacted upon the individual’s behaviour and adaptability. Connolly and O’Dowd (2001) suggested that behaviour deficits in the TBI individual are unpredictable in nature and therefore difficult for the caregiver to pre-empt, resulting in loss of control and feelings of incompetence, which ultimately impact upon health. Marsh et al. (1998) found caregivers who appraised problematic behaviour (more so than physical and cognitive impairment) as the most significant change in the TBI individual, experienced higher levels of distress. They emphasised behavioural problems provide a challenge not only for the caregiver but extend to other relationships and family members which may indirectly contribute to the intensity of impact upon the caregiver’s health and well-being.

It must be stated the behavioural problems reported in this study were solely based on the subjective perceptions of the caregivers, who had elevated levels of depression. It may be important in future studies to also assess the child’s measures from another’s perspective due to studies finding caregivers mental health impacts upon how they perceive their children’s behaviour and adaptability (MacKenzie et al., 2009). The depression levels of the caregivers within the current study may have influenced how they tolerated and perceived the child’s functioning in these areas. Another consideration regarding the children’s problematic behaviour is the children’s behavioural and adaptability data was collected at the 12-month time point, therefore post concussive symptoms from mild injuries should have subsided by this time. This suggests the children’s behavioural and adaptive problems were possibly premorbid.

The current study found better physical, mental and overall health and well-being correlated with higher adaptive functioning of the TBI child, although regression analysis found adaptive functioning was not a predictor of caregiver health outcomes. Adaptive functioning has been reported in studies to be an issue for caregivers (Braine, 2011; Godfrey et al., 2003) impacting upon emotional, physical, cognitive and behavioural domains of functioning. Relationship between caregiver and care receiver, when it is a spousal relationship, has also been found to be more difficult when there are apparent adaptive deficits (Degeneffe, 2001). Given the current study sample consisted mostly of children with mild TBI, and the relationship was a child/parent dyad, this may have lessened the effects of adaptive deficits upon caregiver health outcomes and burden.

In contrast to findings from other studies no relationship was found between caregiver characteristics: educational attainment, gender, Instrumental and Informational supports, and caregiver health outcomes. A possibility for this may be due to the relatively small sample size within this study reducing the opportunity for significant statistical relationships to be detected. Another feasible explanation may be due to the sociodemographic characteristics of the TBI sample population being favourable when pertaining to caregivers’ income and educational attainment in comparison to previous studies, which associate poorer sociodemographic outcomes as predictors of poorer health (Donovan et al., 2011; Livingston et al., 1985; MacKenzie et al., 2009; Nabors et al., 2002; Papastavrou et al., 2007). Other considerations which may be taken into account are appraisal and coping strategies which were not explored within this study, but impact upon how one conceptualises their situation. Aldwin (2000) suggests we cognitively appraise situations using preconceived ideas, expectations, culture and life experiences, which then leads to emotional and physiological reactions. Keeping this concept in mind may individualise how the role of caregiving affects the caregiver despite the sociodemographic variables involved. This may go partway in explaining how individuals experiencing similar situations differ in their responses.

Lastly, TBI severity was not predictive of caregiver health in any of the domains explored. This finding was expected and may explain many of the outcomes within this study, as caring for a child with mild injuries is associated with considerably less disruption to the caregiver than caring for a child with moderate to severe injuries. This finding also supports the suggestion that behavioural deficits may have been premorbid as they are closely associate with TBI severity which showed no relationship to health outcomes for the caregiver.

Health Outcomes of New Zealand European and Māori Caregivers

An investigation into differences in health outcomes between New Zealand European and Māori caregivers found both groups experienced similar health outcomes in regards to physical, mental, overall health, anxiety and depression. This was not surprising considering there were no significant differences between the two groups pertaining to sociodemographic variables, and no difference in levels of support received. Age, educational attainment, income and supports are variables often identified in international literature as key influences for ethnic minority groups experiencing poorer health; not only due to caregiving but in general (Barker-Collo et al., 2008; Haley et al., 1995; Pinquart & Sörensen, 2005; Sanders et al., 2007; Sayegh & Knight, 2010; The New Zealand Guidelines Group, 2006).

Lack of support is a key predictor of burden when caregivers perceive their needs as unmet (Jorgensen et al., 2010; Nabors et al., 2002). This was not the case for the New Zealand European and Māori caregiver groups when answering questions focusing upon injury-related supports and services. Both groups perceived their needs to have been met regarding satisfaction of services and culturally appropriate services, reporting moderately high levels of satisfaction, which may have influenced the non-clinical health outcomes for both groups. Only a small number of participants responded to this section of the rehabilitation questionnaire, and although most were satisfied with culturally appropriate services, some negative comments were recorded which differed between groups. New Zealand European caregivers were more focused upon access to services and receiving services; whereas Māori were focused on lack of Whānau understanding and miscommunication. The comments from Māori caregivers were in line with Arlidge et al's. (2009) qualitative study surrounding Whānau experience with children in hospital, which indicated miscommunication, lack of understanding cultural needs, and sourcing information, as some of the more salient issues undermining Whānau confidence. Due to the small number of responses obtained for this section generalizability of the results to the wider population is limited.

Māori were found to experience more positive life changes than New Zealand European. This may be conceptualised in part by considering the following ideas from the literature. Firstly a model by Pinquart and Sorensen (2005), and Chun, Knight and Youn (2007) suggests appraisal of burden is a key mediator/predictor to stress and burden; and secondly literature suggests ethnic minority groups are less likely to appraise the caregiving situation as burdensome due to traditional ideology, values and beliefs (Chun et al., 2007; Sanders et al., 2007). By taking these ideas into consideration it may be concluded that although initially the new role of caregiving results in greater stress, traditional ideology may influence their appraisal and use of coping strategies, which contributes to lessening the perceived level of burden to a level lower than that of the majority culture individuals (Haley et al., 1995). This concept fits with Lazarus's Stress and Coping Model (Bakas & Champion, 1999) which suggests emotional outcomes are determined by antecedent personality and environmental factors, coupled with cognitive appraisal and coping methods. Coping was also suggested by Pearlin, Mullan, Semple and Skaff (1990) as a primary mediator of caregiver burden. Pinquart and Sorensen's (2005) study found minority culture caregivers had higher levels of subjective well-being and lower levels of perceived burden. This was largely due the concept of familism (Sayegh & Knight, 2010) which values family systems and integration rather than individuality; this may indicate higher levels of family support within these groups. It is however uncertain whether this concept is transferrable into Māori culture and applicable to this study; although Māori traditional beliefs as a collectivist culture are similar to those in the aforementioned studies. So when considering sociodemographic variables were similar between groups, and the moderating effects of traditional ideology and familism; this may place Māori in a better position than New Zealand Europeans with regard to positive life changes.

The Impact of Time upon Caregiver Health Outcomes

Lastly, this study explored if health outcomes for caregivers changed over time. The present study confirmed health and wellbeing improved significantly between 1- and 12-months post TBI, with participants reporting improvement to physical, mental and overall health on the SF-36 subscales, and anxiety and depression levels on the HADS subscales. It was found there were also significant improvements in anxiety levels between 6- and 12-months, although most significant changes in health and well-being were between the 1- and 12-month time-points.

There are several ideas when considering the impact of caregiving on health and well-being over time; however literature is limited pertaining to the health consequences for caregivers of mild TBI children. It is suggested improvement to caregiver burden occurs over time regardless of caregiver and child variables, due to humans' propensity to adapt to adversity (Harris et al., 2001; Stancin et al., 2010). This may apply to the current caregiver participants' health improvements as only two variables (age and income) were found to predict positive health outcomes, which alone may not be responsible for these findings. This is supported by Josie et al. (2008) whom suggests it is often a combination of moderating variables and time which contribute to reducing burden.

The relationship between care-receiver and caregiver may influence the lack of clinical health problems contributing to burden, due to it being a parent-child dyad as opposed to a spousal relationship. Spousal caregivers experience higher levels of distress as a result of role changes and financial difficulties (Degeneffe, 2001; Jorgensen, Parsons, Jacobs, & Arksey, 2010). It must also be noted that caregivers' health outcome scores although elevated were not in the clinical range at 1-month post TBI therefore improvement in HRQoL may simply be attributed to an accumulation of positive life factors unrelated directly to the child's TBI.

Associations have been made between individuals with moderate to severe TBI’s and deficits in their cognitive, behavioural, adaptive, emotional, and physical functioning (Marsh et al., 1998). Individuals with mild TBI have been found to present no significant changes to these areas of functioning over time (Peterson, Scherwath, Fink & Koch, 2008). These findings may offer an explanation to why health outcomes for caregivers within the current study didn’t deteriorate over time, however doesn’t explain improvement in health outcomes. It appears injury severity associates with functional deficits in several domains for the TBI individual, which elevates adjustment issues for the caregiver resulting in a lack of improvement in health and well-being. To assess whether behavioural and adaptability directly associates with health improvements over time, further examination could be undertaken by analysing the TBI child participants 1- and 6-month behavioural and adaptability data from the BASC parent rating scales. This may help in determining if in fact the improvement in health outcomes correlate with improvement in the child’s behavioural and adaptive functioning. Unfortunately this data was not available for analysis at the time of conducting the current study.

Taking into consideration the link between caregivers’ health improvement over time, and supports being an important moderator (Cohen, 1988; Cropley & Steptoe, 2005; Pearlin et al., 1990; Tak & McCubbin, 2002), it may be considered that sufficient supports were in place to alleviate associated factors contributing to burden (Nabors, et al., 2002; Pattenden et al., 2007). The current study may have benefited from a more extensive exploration of supports, using specific support based assessment measures at individual time points. This would help in determining if the level of support received after the child's TBI were in any way related to the improvement in caregiver health outcomes.

Caregivers' positive life changes were significant between 6- and 12-months according the BCOS. This is in line with Taylor et al's. (2008) study which suggests the effects from mild injuries tend to peak at 3-months then resolve themselves thereafter. This may suggest any interference to daily living caused by the child's TBI may have been in the initial months post injury; with positive life changes being reported after this time as was indicated in the current study.

Interestingly the analysis undertaken between TBI and Control caregivers revealed no significant life changes for the better for TBI caregivers; this was in contrast to the findings within the time-point analysis which indicated significant improvements in many areas of health and well-being over the 12-month period. A possible explanation may be the participants had the shorter time frame of three months in which to think about changes that may have occurred when doing the assessments, as opposed to trying to remember and report changes over the entire 12-month period as was required by the BCOS. This may suggest utilising time-point analysis is more accurate than assessments relying on caregiver recall over an extended period of time.

Strengths and Limitations

Several strengths are identified in the current study. The inclusion of a non-TBI caregiver cohort allowed for comparison between groups, highlighting the differences in health related outcomes unique to TBI caregivers. Also the Waikato catchment area used to recruit the participants offered the diversity representative of the New Zealand population (Statistics New Zealand, 2006).

Little is known of the recovery of children with mild TBI as the majority of research is conducted upon moderate to severe TBI. As the sample for the current study included mostly children with mild TBI, this allowed for health outcomes for these caregivers to be studied as little is also known about the caregivers of this population. The inclusion of non-hospitalised TBI children captured a wider range of children and caregivers; many of these individuals are not included in research due to not coming to the attention of medical-based services, which is often where research participants are recruited from.

Lastly an extensive range of well validated measures were used to examine important outcome domains of caregiver HRQoL and burden.

Several limitations have been considered in this research. The parent study to the current study (COBIC) generated an age and gender matched Control cohort to the TBI children. This was not a matched caregiver cohort and these differences were highlighted in the comparative analysis between Control caregivers and those of the TBI group. Significant differences between the two groups were detected on several demographic variables and these differences were not statistically controlled for in the current study. The TBI group had lower incomes, lower educational attainment and higher ethnic minority participants, therefore it may be difficult to determine if the caregiving role is the causal factor in poorer health outcomes or if in fact the demographic differences, play a more significant role.

The current study used data at 1, 6 and 12-months post-injury, and although baseline data was collected in the BIONIC study only the demographic information was used in the current study. The exclusion of baseline assessment data may have omitted caregiver pre-injury health and well-being information, making it difficult to determine if health deficits were pre-existing or due to the caregiving role. Also omitted was baseline behavioural and adaptive data for the TBI children, which may have helped in identifying if the behavioural and adaptive problems detected in the analysis were premorbid or injury-related.

At the time of data analysis there were significantly less Control caregiver participants than TBI caregivers. A more evenly matched sample size would be more useful in future so as not to reduce the opportunity for a more accurate comparison between the group’s health data and sociodemographic variables. A consideration when using a smaller sample size, is the reduced effects of detectability (Pinquart & Sorensen, 2003), and the limiting effect this has upon utilising regression analysis when correlational significance is reduced. While the current study highlights specific caregiver characteristics and child factors of interest in terms of caregiver health outcomes, the small sample size may have lessened the opportunity to explore the significance of variables upon caregiver health outcomes in more detail.

Another sampling issue may have been the lack of child TBI participants with moderate and severe injuries. A more representative TBI sample in terms of injury severity would have provided a more complete insight into the health outcomes for caregivers. However it may have been more difficult to recruit children with moderate and severe injuries due to the distress experienced by the caregiver at the time of injury and the commitment involved in participating in the research.

Conclusions

Findings from this study indicate HRQoL is poorer for TBI caregivers than Control caregivers, although mental and physical health domains including depression and overall health and well-being were not clinically affected. This suggests as the children's' TBI's were mild this may not have placed excessive demands upon the caregivers resulting in non-clinical levels of health deficits. Caregivers reported life hadn't changed despite health improvements over the 12-months post TBI. This may suggest a combination of low level health deficits still apparent at 12-months post injury; child's behavioural deficits apparent at 12-months post injury, and the possibility of other life factors influencing caregivers' perceptions of life. Despite the subtly negative health outcomes there were no differences in anxiety problems between TBI and Control caregivers which may suggest anxiety related symptoms associated with the caregiving role had dissipated by 12-months post injury.

Several variables were found to be predictors in the health outcomes for caregivers. Older caregivers and those on higher incomes experienced better health outcomes which may indicate an association between the two factors contributing to better quality of life. Supports also had positive effects upon health outcomes. This reinforces the need for caregivers to receive appropriate and timely supports from friends, family and others to interrupt the link between stress and illness, assisting the caregiver to adjust to the caregiving role. Ethnicity predicted depression when Māori and 'other ethnicities' were analysed as one group, however when the ‘other ethnicities’ were removed from the analysis of outcomes between Māori and New Zealand Europeans, depression levels were similar. This suggests the ‘other ethnicities’ may have influenced the negative results for depression. These findings may suggest other ethnic groups are at risk of poorer heath outcome than New Zealand European and Māori.

Children’s problematic behaviour as perceived by their caregivers predicted poorer physical and overall health, and higher levels of depression. The behavioural deficits were possibly premorbid due to their still being apparent at 12-months post injury, and the reporting of problematic behaviour may have been influenced by the caregivers’ elevated depression levels reducing their tolerance of the children’s behaviour.

Differences between groups were limited when investigating the health outcomes between New Zealand Europeans and Māori. Ethnicity had no effect upon health outcomes; however Māori experienced more positive life changes. This may suggest collectivist cultural values and beliefs influence how Māori appraise their role of caregiving when finding themselves in a situation where caring for relatives is necessary.

As demonstrated by the outcomes of the time-point analyses, caregiver’s health and well-being on all domains improved between the 1- and 12-month period post-injury. These findings suggest health outcomes were worse in the initial months post TBI. The resulting improvements in health outcomes may be due to a combination of moderating variables and time, or may simply be attributed to positive life events unrelated to the TBI.

Implications of the Research

Results from this study provide evidence that the HRQoL and burden among caregivers of children with mild TBI is affected. Worse health outcomes were experienced in the initial months post-injury as was found in the time-point analysis; however there was a significant improvement in caregiver health 12-months post-TBI. A large percentage of injuries go unreported and over half of injuries are sustained at school and home, therefore to improve outcomes for caregivers and offer appropriate support interventions, initial intervention may include education aimed at schools and parents to inform of the effects of mild TBI. This awareness may encourage caregivers to seek medical attention for the child; this may not only benefit the child but also offer the opportunity for caregivers to receive adequate support/ask for support in the hope of producing better health outcomes for them. Although caregiver support and the effects this has upon caregiver burden has been considered in many studies, outcomes from the intervention of support resources has not (Roth et al., 2005), therefore it is important to note the implications support related interventions may have upon the reduction of caregiver burden for future research.

Bringing caregivers in contact with medical services may also assist in the early identification of caregivers at elevated risk for poorer health outcomes by identifying inequalities in outcomes related to caregiver and child variables. Although at the present time, only injury-related details are collected from individuals and caregivers receiving medical help for mild TBI, therefore realising these inequalities in variables may be difficult. It also may be impractical to suggest the collection of such sociodemographic information be carried out upon individuals seeking treatment, although collection of this information may be worthy of further consideration as to how this could be included in the initial assessment of the TBI child

Also, further investigation may look more closely at the complex interplay between caregiver and child variables and other factors such as appraisal and coping, and family functioning. This may continue to help better inform the research into how these affect the health outcomes of the caregiver.

Findings provided evidence that Māori caregivers experienced more positive life changes than New Zealand European caregivers. Traditional ideology, values, beliefs and methods of coping may be worthy of further examination in relation to caregiver burden, not only to help in understanding cultural differences, but also to help in understanding if these differences are moderating factors for caregiver HRQoL and burden.

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Appendices

Appendix A

Medical Study Short Form (SF-36) (Australia/New Zealand, version 1.0)

This questionnaire asks for your views about **your own** health, how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

Q#	**Label**	**Field format**
5.1	In general would you say your health is:	Excellent Very good Good Fair Poor
5.2	Compared to one year ago, how would you rate your health in general now?	Much better now than one year ago Somewhat better now than one year ago About the same as one year ago Somewhat worse than one year ago Much worse now than one year ago

5.3 The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much? (tick one circle on each line)

Q#	**Label**	**Field format**		
		Yes, limited a lot	Yes, limited a little	No, not limited as all
5.3.1	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
5.3.2	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	○	○	○
5.3.3	Lifting or carrying groceries	○	○	○
5.3.4	Climbing several flights of stairs	○	○	○
5.3.5	Climbing one flight of stairs	○	○	○
5.3.6	Bending, kneeling or stooping	○	○	○

5.3.7	Walking more than one kilometre	○	○	○
5.3.8	Walking half a kilometre	○	○	○
5.3.9	Walking 100 meters	○	○	○
5.3.10	Bathing or dressing yourself	○	○	○

5.4 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (tick one circle on each line)

Q#	**Label**	**Field format**	
		Yes	No
5.4.1	Cut down on the amount of time you spent on work or other activities	○	○
5.4.2	Accomplished less than you would like	○	○
5.4.3	Were limited in the kind of work or other activities	○	○
5.4.4	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

5.5 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (tick one circle on each line)

Q#	**Label**	**Field format**	
		Yes	No
5.5.1	Cut down on the amount of time you spent on work or other activities	○	○
5.5.2	Accomplished less than you would like	○	○
5.5.3	Didn’t do work or other activities as carefully as usual	○	○

Q#	Label	Field format
5.6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	Not at all Slightly Moderately Quite a bit Extremely
5.7	How much bodily pain have you had during the past 4 weeks?	No bodily pain Very mild Mild Moderate Severe Very severe
5.8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	Not at all A little bit Moderately Quite a bit Extremely

5.9 These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks (tick one circle on each line)

Q#	Label	Field format					
		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
5.9.1	Did you feel full of life?	○	○	○	○	○	○
5.9.2	Have you been a nervous person?	○	○	○	○	○	○
5.9.3	Have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○	○
5.9.4	Have you felt calm and peaceful?	○	○	○	○	○	○
5.9.5	Did you have a lot of energy?	○	○	○	○	○	○
5.9.6	Have you felt worn down?	○	○	○	○	○	○

5.9.7	Did you feel worn out?	○	○	○	○	○	○
5.9.8	Have you been a happy person?	○	○	○	○	○	○
5.9.9	Did you feel tired?	○	○	○	○	○	○

Q#	**Label**	**Field format**
5.10	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (circle one)	All of the time Most of the time Some of the time A little of the time None of the time

5.11 How TRUE or FALSE is each of the following statements for you? (tick one circle on each line)

Q#	**Label**	**Field format**				
		Definitely true	Mostly true	Don’t know	Mostly false	Definitely false
5.11.1	I seem to get sick a little easier than other people	○	○	○	○	○
5.11.2	I am as healthy as anybody I know	○	○	○	○	○
5.11.3	I expect my health to get worse	○	○	○	○	○
5.11.4	My health is excellent	○	○	○	○	○

Appendix B

Hospital Anxiety Depression Scale (HADS)

These questions are about how you have been feeling **in the last two weeks:**

Q#	**Label**	**Field Format**
1	I feel tense or 'would up' (tick only one)	Most of the time [3] A lot of the time [2] From time to time, occasionally [1] Not at all [0]
2	I still enjoy the things I used to enjoy (tick one only)	Definitely as much [0] Not quite as much [1] Only a little [2] Hardly at all [3]
3	I get a sort of frightened feeling as if something awful is about to happen (tick only one)	Very definitely and quite badly [3] Yes, but not too badly [2] A little but it doesn't worry me [1] Not at all [0]
4	I can laugh and see the funny side of things (tick only one)	As much as I always could [0] Not quite so much now [1] Definitely not as much now [2] Not at all [3]
5	Worrying thoughts go through my mind (tick only one)	A great deal of the time [3] A lot of the time [2] From time to time, but not too often [1] Only occasionally [0]
6	I feel cheerful (tick only one)	Not at all [3] Not often [2] Sometimes [1] Most of the time [0]
7	I can sit at ease and feel relaxed (tick only one)	Definitely [0] Usually [1] Not often [2] Not at all [3]
8	I feel as if I am slowed down (tick only one)	Nearly all the time [3] Very often [2] Sometimes [1] Not at all [0]
9	I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all [0] Occasionally [1] Quite often [2] Very often [3]

	(tick only one)	
10	I have lost interest in my appearance (tick only one)	Definitely [3] I don’t take as much care as I should [2] I may not take quite as much care [1] I take just as much care as ever [0]
11	I feel restless as if I have to be on the move (tick only one)	Very much indeed [3] Quite a lot [2] Not very much [1] Not at all [0]
12	I look forward with enjoyment to things (tick only one)	As much as I ever did [0] Rather less than I used to [1] Definitely less than I used to [2] Hardly at all [3]
13	I get sudden feelings of panic (tick only one)	Very often indeed [3] Quite often [2] Not very often [1] Not at all [0]
14	I can enjoy a good book or TV programme* (tick only one)	Often [0] Sometimes[1] Not often [2] Very seldom [3]
	Complete after the assessment HADS-Anxiety score (0-21) [1+3+5+7+9+11+13] *If participant scores >11 refer to their GP*	2 digits
	Complete after the assessment HADS-Depression score (0-21) [2+4+6+8+10+12+14] *If participant scores >11 refer to their GP*	2 digits

Appendix C

DSM-IV Depression Diagnostic Scale

Depression		
8.1	Since the child's injury/In the last year have **you** received any treatments for **depression**?	Yes No
	If Yes:	
8.1.1	Saw a doctor, psychologist or counsellor	Yes No
8.1.2	Medication	Yes No
8.1.3	Admitted to hospital	Yes No
8.1.4	Shock treatment/ECT	Yes No
8.2	Do you cry more now, (not just feel like it, actually cry) than you used to?	Yes No
8.2.1	If yes, Is it in situations (places/people) you wouldn't have cried in before?	Yes No
8.2.2	Do you get any warning?	Yes No
8.2.3	Does the crying just come 'out of the blue' with only seconds warning?	Yes No
8.2.4	Do you know what sort of things make you cry?	Yes No
8.3	Do you often feel sad or depressed?	Yes No
8.4	Are you currently receiving any treatment for depression?	Yes No
8.4.1	If yes, what type? (tick as many as apply)	Counsellor Pastor Psychologist Psychiatrist Medications Other
8.4.2	If other, please specify:	Text

Appendix D

BIONIC
Brain Injury Outcomes New Zealand in the Community

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

The Consequences of Brain Injury In Childhood (COBIC)

FORM CE: Case Ascertainment/Eligibility - For ALL Participants (Phone)

Information to be obtained from phone or face to face

Registration Number ☐☐☐☐☐☐ Participant initials ☐☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

General Questions – Section 1

Q#	Label	Field format
1.1	NIH Number	
1.2	Gender	Male Female
1.3	Date of Birth	ddmmyyy
1.4.1	TBI between 1 March 2010 and 28 Feb 2011 and registered in BIONIC?	Yes – go to 1.4.4 No – go to 1.4.2
1.4.2	TBI free since birth?	Yes – go to 1.4.3 No – ineligible for study, go to 1.4.5
1.4.3	Are they age/gender matched to TBI participant?	Yes – go to 1.4.4 No – ineligible for study, go to 1.4.5
1.4.4	Are they a resident of Hamilton /Waikato District	Yes - go to 1.5 No – ineligible for the study, go to 1.4.5
1.4.5	Can we keep your contact details for future studies?	Yes - stop here, sign and date form No - stop here, sign and date form
1.5	Area of Residence	Resident of Hamilton Resident of Waikato

1.6	Ethnicity (tick one on each line) New Zealand European Maori Samoan Cook Island Maori Tongan Niuean Chinese Indian Other (such as Dutch, Japanese, Tokelauan)	Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No
1.6.1	If other, please specify	Text

Now complete Contact details form (CC) if eligible or if happy for future contact.

Teacher	
Does the participant attend school or preschool?	No, Yes (If yes or baseline, fill in the details)
Name of School:	
Teacher's name:	
Teacher's role (class teacher, subject teacher etc)	
School Street Address:	
Suburb:	
Town	
City	
Post code	
School telephone number	Area ☐☐☐ Number ☐☐☐☐☐☐☐
Mobile telephone number	
Email address (if known)	

Study Researcher to complete

	Label	**Field format**
	Signature	Text
	Printed name	Text
	Date	ddmm20yy

Appendix E

The Consequences of Brain Injury In Childhood (COBIC)

Child and Adolescent Participant Information Sheet (under 16)

Who are we?

We are a team of people who work in universities and health care services in New Zealand. We would like to help people who have had a head injury and to find out information that will make treatment better.

What is the study about?

To help us to do this we would like to ask people who have had a head injury about any problems they have (such as finding it difficult to remember things) and to see how quickly they get better. We also want to talk to people who haven't had a head injury so we can find out more about how a head injury affects people.

We are asking every child who had a head injury and took part in the BIONIC study to take part in this study as well. We also want children who are under 16 years of age and have not had a head injury to take part. You do not have to be involved in the study and you can stop taking part any time you want to. You can ask us any questions you like before you say that you would like to take part.

What will happen if I want to take part?

We would like to ask your parent or a person who looks after you some questions and if you have had another head injury we would like to look through what the doctors have written about your injury. If you would like us to stop talking to your parent or person who looks after you at any point, that's okay, please just tell us you want us to stop talking to them.

Having a head injury can sometimes effect how well people can remember things, how they think and how they behave. We would like to compare people who have had a head injury and people who haven't had a head injury to find out more about how a head injury effects how people remember, how they think and also how they get on at school. So if it's ok with you and your parents we would also like to talk to your school teacher to find out about how you are getting on at school.

A researcher will come to visit you (where you live, or somewhere easy for you) and bring some activities that will help us to look how you remember things and how you think. We hope that you find these activities enjoyable. The activities last for about 4 hours, but we will split these activities up so that you can do them on at least two different days. We will also ask you some questions about things you like doing and how you are feeling. This is not a test so we don’t usually tell you how you did.

To help us to see how quickly people get better, we will ask you to answer the same questions and to do the same activities now, and in 1 year and 2 years time. At each time point we will come to see you twice, for about 90 minutes each time. In total this will take about 1.5 days of your time over 2 years.

Do I have to take part?

No, it is up to you. If you would like to help us with the study, a researcher will ask you to sign a form to say that you are happy to take part.

You are free to stop your part the study at any time and you do not have to give us a reason. If you have had a head injury and you are still receiving treatment, this will not change whether you take part in this study or not. If you have any worries or questions about the study you can come and talk to us. We will keep everything private but if we think that you might not be safe we might have to tell some other adults who can help us to keep you safe.

How many people will be in the study?

We think there will be about 690 children and young people from New Zealand taking part in this study. Around half of them will have had a head injury.

How long does the study go on for?

We will be starting the study in April 2011 and will continue until the end of October 2014.

What will happen afterwards?

When we look at what everyone has told us, we will write about what we have found. We won’t write your name anywhere, so people won’t know that what you have said was from you.

After the study has finished we will keep all your information locked in a cupboard at the University. Only the people working on this study will be able to look at this information.

We will keep everything private but if we think that you might not be safe we might have to tell some other adults who can help us to keep you safe.

How will the study affect me?

We cannot promise that the study will help you, but the information that we find out will help us to treat people better in the future.

To say thank you, we will give you a gift or voucher ($20) after you have finished the activities now, and when you do the activities in 1 and 2 years' time (3 gifts or $60 vouchers in total).

Has this study been approved by anybody?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This study has been checked and approved by the Northern Region Y Ethics Committee (Ref NTY/11/02/016).

What if I have any questions?

If you would like to contact someone about the study or if you have any worries, you can talk to any member of the team or you can phone;

Nicola Starkey who runs the study; Telephone: 07 8384466 ext 6472

Appendix F

BiONiC
Brain Injury Outcomes New Zealand in the Community

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

The Consequences of Brain Injury In Childhood (COBIC)

Child Participant Consent Form

I know that;
I have read the information about the study (version 3 dated 31/5/2011) and/or had the information about the study explained to me
I have had the opportunity to ask questions about the study and I am happy with the answers I have been given.
I understand that it is my choice to take part in the study and I do not have to take part if I do not want to.
I understand that I can pull out of the project if I want to at any time.
If I have an injury I am happy for the team to look at what the doctors have written about my injury.
I am happy for the team to contact my school teacher
I understand that when the team write about the study they will not use my name.
I understand that if the researchers are worried that I might not be safe, they may contact other adults who can help me.
If I have any worries I can talk to the study manager or any member of the team.
I understand that my GP may be told that I am taking part in this study.
I agree to take part in this research study.

I ____ (Name of child) agree to take part in this study.

Signature of child____

Date: ______________________

Project explained by……………Project role ……………………………………

Signature.. Date
…………………………………………