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Just part of the job:
**The experiences of parent caregivers caring for adolescents with
mild traumatic brain injury**

A thesis
submitted in fulfilment
of the requirements for the degree
of
Masters of Social Sciences
at
The University of Waikato
by
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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

2015

Abstract

Mild traumatic brain injury (mTBI) is one of the most frequently occurring injuries during adolescence. Typically care following such injuries is provided informally, by parents and close family members. The requirement for such caregiving is likely to increase as national health policies attempt to balance the growing costs of health-care provision with requirements for culturally responsive care.

While studies have shown that caregivers may experience considerable burden, it is increasingly evident that caregiving also has a positive impacts for carers. To date, few studies have evaluated the positive experiences of caregiving. Even less is known about the positive experiences of parents who care for their adolescent children following acute injury events such as mTBI. It is important to understand caregiver experiences more completely as caregiver coping and burden contribute to recovery and adaption to injury.

The aim of this study was to describe and understand the experience of caregivers of adolescents aged 10 – 18 years with mTBI. Using a mixed methods approach, existing quantitative data gathered as part of the Brain Injury Outcomes New Zealand in the Community (BIONIC) and Consequences of Brain Injury in Childhood (COBIC) studies of TBI in New Zealand were analysed (mTBI group = 54 caregiver-adolescent dyads, control group = 54 dyads). Semi-structured interviews were then completed with a sample of caregivers of adolescents with mTBI now aged 13 – 16 years recruited from the same source studies (n=10). Interview transcripts were qualitatively assessed using thematic analysis.

Quantitative analysis confirmed previous research findings that for the majority, the impacts of mTBI are minimal and typically resolve within the first year with generally positive outcomes. While carers in both groups described caring for adolescents as a predominantly positive experience, caregivers of injured adolescents reported a greater number of positive caregiving experiences. In addition, caregivers of injured adolescents reported significantly greater quality of life related to their physical health two years after injury compared with caregivers of adolescents without mTBI.

Thematic analysis of interviews uncovered five core themes underpinning caregiver experiences: initiation; impacts and attributions; accommodation and adjustment; a

valued experience; and, just part of the job. These themes revealed the importance of timely and relevant communication from schools and health providers to caregiver's feelings of competency and to their ongoing relationship with these organisations. Reflecting on their experiences, caregivers valued the opportunities a mTBI created for emotional closeness with adolescents at a challenging time in human development. They also described intrinsic benefits of being able to share wisdom and experiences with others and the practical benefit of developing transferrable skills. Carers viewed their experiences as providing a unique opportunity for personal development through the recognition of carers' capability and resilience as individuals. For all caregivers, the provision of care following mTBI was seen as an expected part of parenting – just part of the job.

In contrast to family caregiving involving other caregiver – care recipient dyads (such as adult children caring for their elderly parents, or parents caring for their children as a result of chronic illness or disability), parent caregivers in the current study viewed caregiving as a positive experience. Rather than a burdensome additional responsibility, carers viewed caring for their adolescent children following mTBI as – just part of the job - an expected and indistinguishable aspect of their existing roles as parents.

Acknowledgements

The completion of this research would not have been possible without the support and encouragement of many people.

I have been extremely fortunate to have Dr. Nicola Starkey (a supervisor supreme), supervise all my postgraduate research. I am extremely grateful for the hours she has spent guiding, inspiring and encouraging me through these processes. Also for her support in securing the Faculty of Arts and Sciences Masters Scholarship I received from the University of Waikato during the completion of this thesis. I have also benefited from the alternative perspective and pithy insights of Dr. Kathryn McPherson, which have helped (I hope) to make this a more qualitatively sound and readable document.

I have been privileged to have the opportunity to use data from the BIONIC, COBIC, and BIONIC4YOU studies. So, thank you to those many people who spent their time and energy setting up the study, recruiting participants, collecting data and compiling the database. In particular, thank you to the parents and their children who participated in these studies, graciously gave their time to be interviewed and without whom this document would not exist.

Lastly, but most certainly never least, this thesis would not have been possible without David. I am eternally appreciative of his patient support and willingness to take on more than his fair share to create a space in the chaos of our hectic family life for this thesis to take shape. To Perry, Heath and Rowan, thank you for your understanding of my frequent physical and mental absences. I look forward to now having more time to spend with you all.

Table of Contents

<i>Acknowledgements</i>	<i>iv</i>
<i>Table of Contents</i>	<i>v</i>
<i>List of Figures</i>	<i>vi</i>
<i>List of Tables</i>	<i>vii</i>
<i>Chapter One - Introduction</i>	<i>9</i>
Part One – Caregiving	<i>10</i>
Part Two - Adolescence	<i>24</i>
Part Three –Traumatic Brain Injury during Adolescence	<i>31</i>
Summary	<i>37</i>
<i>Chapter Two – Study Design</i>	<i>39</i>
Overview of Study Aims	<i>41</i>
Data Sources	<i>42</i>
Ethical Considerations.....	<i>44</i>
<i>Chapter Three – Phase One</i>	<i>45</i>
Methods	<i>45</i>
Participants	<i>47</i>
Measures.....	<i>48</i>
Procedure.....	<i>55</i>
Results	<i>58</i>
Discussion	<i>74</i>
<i>Chapter Four – Phase Two</i>	<i>88</i>
Analytic Approach	<i>88</i>
Method.....	<i>90</i>
Participant Recruitment.....	<i>92</i>
Data Collection.....	<i>95</i>
Results	<i>97</i>
Discussion	<i>115</i>
<i>Chapter Five – Study Summary</i>	<i>123</i>
Synthesis of Findings	<i>123</i>
Strengths and Limitations of the Current Studies.....	<i>126</i>
Conclusions	<i>126</i>
<i>References</i>	<i>128</i>
<i>Appendices</i>	<i>153</i>

List of Figures

<i>Figure 1.</i> Conceptual model of the caregiving process and caregiver burden among the paediatric population..	15
<i>Figure 2.</i> Conceptual framework of the positive aspects of caregiving.	19
<i>Figure 3.</i> Pathways leading to challenging behavior following TBI.	34
<i>Figure 4.</i> Relationship between data sources for the current study.	42
<i>Figure 5.</i> CONSORT diagram of participants included at baseline, 12 and 24 month time points from BIONIC and COBIC studies.	46
<i>Figure 6:</i> Summary of initial sample of eligible BIONIC4you participants included in the current study.	93
<i>Figure 7:</i> Themes of caregiver experiences and associated topic categories.	98

List of Tables

<i>Table 1.</i> Comparison of gender, ethnicity, presence of diagnosed health problems and age for adolescents with and without mTBI.	59
<i>Table 2.</i> Comparison of gender, ethnicity, relationship status, occupational group, paid working hours, highest education achieved and age for caregivers of adolescents with and without mTBI.	60
<i>Table 3.</i> Analysis of variance in self-reports of emotional, behavioural and social functioning in adolescents with and without MTBI.	62
<i>Table 4.</i> Correlations between adolescent age and self-reports of emotional, behavioural and social functioning in adolescents with and without mTBI.	64
<i>Table 5.</i> Correlations between adolescent gender and self-reports of emotional, behavioural and social functioning in adolescents with and without mTBI.	65
<i>Table 6.</i> Analysis of variance in caregiver reports of emotional, behavioural and social functioning in adolescents with and without mTBI.....	67
<i>Table 7.</i> Correlations between adolescent age and caregiver ratings of adolescent emotional, behavioural and social functioning in adolescents with and without mTBI.....	68
<i>Table 8.</i> Correlations between adolescent gender and caregiver ratings of adolescent emotional, behavioural and social functioning in adolescents with and without mTBI.....	70
<i>Table 9.</i> Analysis of variance in caregiver self-reported quality of life related to physical and mental health, symptoms of anxiety and depression and reported outcomes and impacts of caregiving for adolescents with and without mTBI.....	71
<i>Table 10.</i> Correlations between adolescent age and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety and depression and outcomes and impacts of caregiving for adolescent with and without mTBI.....	72
<i>Table 11.</i> Correlations between adolescent gender and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety	

and depression and outcomes and impacts of caregiving for adolescents with and without mTBI.....	73
<i>Table 12.</i> Correlations between caregiver outcomes (BCOS) and variables hypothesised to influence caregiver outcomes.	74
<i>Table 13.</i> Characteristics of initial sample of eligible participants approached to participate in the current study and characteristics of caregivers interviewed.....	94

Chapter One - Introduction

“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

(Rosalynn Carter, former United States First Lady).

To investigate the experiences of caregivers caring for adolescents with mTBI, three areas of research literature were reviewed; caregiving by family members as a result of accident or injury; adolescence and normative cognitive, social, emotional, and behavioural development; and the characteristics and impacts of mTBI occurring during adolescence. Summaries of current understanding and relevant models for each of topic are introduced sequentially.

Part One – Caregiving

Caregiving is a ubiquitous yet complex human activity. Its provision is influenced by cultural and social expectations (Ayalong, 2004), and by the relationship between caregiver and recipient (Hermanns & Mastel-Smith, 2012; Ory, Yee, Tennstedt, & Schulz, 2000). “Family” or “informal” caregiving refers to unpaid care provided by family or friends to individuals with physical, psychological or developmental challenges, resulting in their inability to independently perform everyday tasks appropriate to their age and stage (Duxbury, Higgins, & Schroeder, 2009). In New Zealand such caregiving is frequently provided collectively by *carers*, as family, whānau or agia groups (Collins & Willson, 2008; Ministry of Social Development, 2014), with the majority of recipients living with their caregivers (Zukewich, 2003; Australian Bureau of Statistics, 2013).

The provision of caregiving within families can be viewed as adhering to “an implicit social contract” with such caring is “accepted as natural part of family life and undertaken as a familial duty” (Cabinet Social Development Committee, 2004, p. 835 as cited in Atkinson v. Ministry of Health, 2010). Indeed, less

intensive levels of caregiving may be difficult to distinguish from “parenting as usual”, rendering such activities largely invisible (Chen, Ngo, & Park, 2013; Rea, Kenealy, Sheridan, & Gorman, 2010). However, caring for children with chronic illness or disability requires the provision of care that is greater than normally expected (Goodhead & McDonald, 2007; Raina, O’Donnell, Rosenbaum, Brehaut, Water, Russell, et al., 2004). Additionally, such care is typically required without notice or respite and occurs alongside the emotional distress and vulnerability of the parent caregiver (Ylvisaker, 1998).

The incidence of chronic illness in children and young adults is increasing (Denny, de Silva, Fleming, Clark, Merry, & Ameratunga, et al., 2014; Schulz & Martire, 2004; Van Cleave, Gortmaker, & Perrin, 2010). Alongside this, pressures on healthcare resources and a focus on providing culturally relevant services have led to the active endorsement of home-based sub-acute care (Jorgensen, Askey, Parsons, & Jacobs, 2009; Medical Council of New Zealand, 2006). These shifts in the nature and prevalence of the informal care of young people highlight the porous boundary between expected parenting and the role of caregiving.

The work of caregivers. The nature of caregiving tasks varies with the degree of impairment and the duration of injury impacts. A recent study of caregiving in New Zealand found that for care recipients aged 0 – 19 years, informal carers were most frequently required to manage chronic behavioural difficulties (36%), neurological deficits (20%) and developmental disorders (16%) (Jorgensen, Parsons, Jacobs, & Arksey, 2010).

Supporting a child with chronic difficulties can become an integral part of the caregiver’s life (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005).

Caregiving may involve a full-time commitment to completing personal cares, undertaking household tasks, as well as providing on-going emotional and financial support (Nikora, Karapu, Hickey, & Te Awekotuku, 2004; Zukewich, 2003). Even with less severe impacts of injury, illness or disability, parental caregivers are likely to have increased involvement in the management of behaviour, the provision of social stimulation, as well as the supervision and organisation of daily activities of living (Goodhead, et al., 2007). Parent caregivers are also responsible for maintaining the family unit as well as their own physical and emotional well-being (Sullivan-Bolyai, Sadler, Knafel, & Gilliss, 2003).

Over time, caregiver tasks typically become a routine and accepted aspect of a changed mode of parenting for the family (Ylvisaker, 1998). With lesser physical impacts, initial levels of care gradually reduce as the young person adapts or recovers and accommodations are implemented (Sullivan-Bolyai, Sadler, Knafel, Gilliss, & Ahmann, 2004). Where behavioural impacts are evident, longer-term adaptations may be required, including changes to communication and established relationships within the family, as well as changes in the expectations of the injured individual (Shudy, de Almeida, Ly, Landon, Gorft, & Jenkins, et al., 2006). With lesser impacts, such adjustments may be unconscious and subtle. Little is currently known about the nature of these transitions.

The prevalence of caregiving. Given the indistinct boundary between caregiving and parenting, determining the prevalence of informal caregiving is problematic. Internationally, an estimated 20% of households including around 12% of the population are involved in informal caregiving activities of some kind (National Alliance for Caregiving and AARP, 2004; Australian Bureau of

Statistics, 2013), with unpaid caregivers providing an estimated 80 - 90% of all long-term sub-acute care (Institute on Medicine, 2008; Adler, & Mehta 2014).

These estimates are broadly consistent with New Zealand's experience (Department of Labour, 2011; MSD, 2014). While information specific to parent caregivers is unavailable, the most recent census identified 10% of the total population (431,649 individuals) as providing unpaid care of some kind (Statistics New Zealand (Statistics NZ), 2015). Of this group, just over half (52%) specified that they were "looking after a member of own household who [was] ill or [had] a disability" (Statistics NZ, 2015).

The profile of caregivers Consistent with international findings, informal caregivers in New Zealand are predominantly female (63%) (Statistics NZ, 2015). The majority of carers are aged between 35 and 64 years (61%) (Goodhead, et al., 2007), with the largest five-year age bracket of caregivers aged 50 – 54 years (Infometrics, 2014). Carers "looking after a child who was a member of [their] own household" are typically younger, being predominantly aged 40 – 44 years (Statistics NZ, 2015).

The greatest numbers of carers providing unpaid care to a member of their household come from New Zealand European/Pākeha backgrounds (72.3%). However, when ethnicity as percentage of population is considered, Māori (20.4%) are most likely to provide unpaid care to family members (Infometrics, 2014). Likewise, Pacific peoples frequently provide unpaid care (9.7%), typically for a member of their own household (Statistics NZ, 2015), possibly reflecting differences in household structures and cultural expectations.

The economic impacts of caregiving. Informal caregiving is typically not based on a documented agreement (Goodhead, et al., 2007), and in the case of

caregiving for children and adolescents, merges with expected parenting. Consequently, its economic value has been largely overlooked (Mmopelwa, Ngwenya, Sinha, & Sanders, 2013). A recent investigation of the economic value and impacts of informal care in general on New Zealand workforce participation and household incomes identified that around 672.2 million hours of unpaid care are provided annually, equating to around NZ\$10.8 billion or 5% of GDP (Infometrics, 2014). This suggests that, on average, 24 - 36 hours of care are provided per carer each week. Given differences in injury severity and impacts, it is likely that this average represents a broad range.

Recent analysis of income data indicates that New Zealand carer households typically earn 10.2% less than those without caregiving responsibilities (Infometrics, 2014). This was despite a similar propensity for being in paid employment, levels of qualification, and working in high skilled occupations when compared with non-carers (Department of Labour, 2011).

Models of caregiving

Caregiving as burdensome. Historically, caregiving has been viewed as a burdensome task (e.g. Chadda, Singh, & Ganguly, 2007; Koehler, Fagnano, Montes, & Halterman, 2014; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004). Accordingly, research has focused on the psychological stresses and deficits to caregiver health, well-being and quality of life. Models have largely disregarded differences in the level of support provided or the relationship between caregiver and recipient (Jorgensen, et al., 2009).

Drawing on existing health/stress models (e.g. Pearlin, Mullan, Semple, & Skaff, 1990; Schulz & Martire, 2004; Townsend, Noelker, Deimling, & Bass,

1989), Raina and colleagues' (2004) multidimensional conceptual model seeks to explain caregiver burden as a result of providing paediatric care (Raina, O'Donnell, Schwellnus, Rosenbaum, King, & Brehaut, et al., 2004). The model encapsulates five constructs that are thought to contribute to and interact with caregiver health outcomes. A significant advantage of the model is that it can be applied to caring for a variety of developmental and functional difficulties (Figure 1).

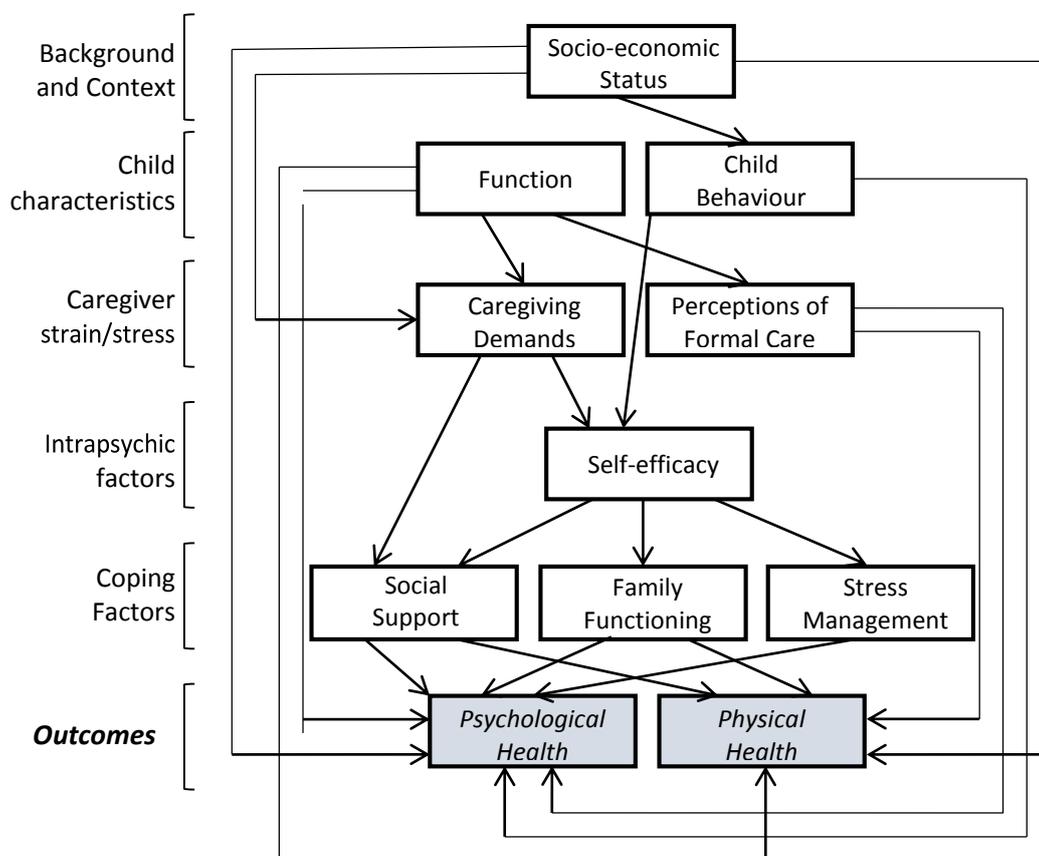


Figure 1. Conceptual model of the caregiving process and caregiver burden among the paediatric population. Reprinted from “Caregiving process and caregiver burden: conceptual models to guide research and practice”, by P. Raina, M. O’Donnell, H. Schwellnus, P. Rosenbaum, G. King, & J. Brehaut, et al., 2004, *BMC Pediatrics*, 4(1), p.10. © 2004 Raina et al; licensee BioMed Central Ltd. <http://www.biomedcentral.com/1471-2431/4/1>. Reprinted with permission.

Background and context. Carers typically work fewer hours, earn less money and may cease paid employment altogether (Bittman, Hill, & Thomson, 2007; Lilly, Laporte, & Coyte, 2007), contributing to long-term financial disadvantage. Relatedly, lower levels of caregiver education and occupation have been correlated to greater caregiver perceptions of stress and burden (Fujiura, 2014). Lower socioeconomic status (SES) has been linked to increased child behaviour problems (Propper & Rigg, 2007), greater caregiving demands (Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993), and poorer physical and psychological health in caregivers (Vitaliano, Zhang, & Scanlan, 2003).

Child characteristics. The extent of children's cognitive or motor deficits, and the presence of behaviour problems determine the level of care required (Lungley, Edgar, & Asiasiga, 1995). More severe impairments and high rates of problematic behaviours have been associated with poorer caregiver physical and psychological health (Sander, Maestats, Clark, & Havins, 2013), as well as greater demands on caregivers and negative perceptions of formal support services (Fournier, Davis, Patnaik, Elliott, Dyer, & Jasek, et al., 2010). Specific conditions associated with high levels of caregiver stress and depression include; attention deficit hyperactive disorder (ADHD), autism spectrum disorder, brain injury, and developmental problems (Jorgensen, et al., 2010).

Caregiver strain/stress. Perceptions of greater role demands and negative views of formal care arrangements are associated with decreased caregiver well-being and lower self-reports of efficacy (Bray, Moss, & Forrester, 2005). In addition, caregivers are more likely to experience poor psychological and physical health (Carpinter & Irwin, 2000; King, King, Rosenbaum, & Goffin, 1999; Pinguart & Sorensen, 2007), and express negative views about the availability of

social supports. Over 60% of caregivers caring for individuals with traumatic brain injury (TBI) describe experiencing a moderate level of stress (Sander et al., 2013).

Intrapsychic factors. Where caregivers do not identify with or accept their role as caregiver, perceptions of self-efficacy and the strength of social supports are likely to be low (Keeling, 2001). Similarly, family functioning tends to be poor (Chen, Clark, Chang, Liu, & Chang, 2014; McConnell & Savage, 2015), and caregivers are more likely to adopt ineffectual stress management strategies (Hastings & Beck, 2008).

Coping factors. Weak social support from extended family, friends and neighbours, as well as ineffective family functioning and stress management strategies have been found to lead to poor psychological and physical health in caregivers (King et al., 1999; Sander et al., 2013). Individually and collectively these health outcomes have been linked to reduced well-being and poor quality of life (Jorgensen, et al., 2009).

Caregiver health and well-being outcomes. Psychological distress and depression in caregivers has been associated with low social supports (Tsai & Wang, 2009), as well as perceptions of high caregiving demands (Canning, Harris, & Kelleher, 1995), and negative views of formal care provisions (Goodhead, et al., 2007; Reinhard, Given, Petlick, & Bernis, 2008). Similarly, physical health outcomes in caregivers are mediated by available social supports, and high caregiving demands (Hirst, 2005). Health concerns may be exacerbated by a loss of income or additional costs arising from caregiving activities (Koopman-Boyden & Wells, 1979). Carers may also experience negative impacts on family relationships (Brunton, Fouche, & Jordan, 2007).

Collectively, the constructs included in this conceptual model focus on the negative physical and psychological outcomes of caregiving, viewing caregiving as an inherently burdensome activity. More recently, the positive outcomes of caring have been highlighted.

Caregiving as a positive experience. While the body of research providing empirical evidence for the potential gains of caregiving (e.g. Cohen, Colantonio, Vernich, 2002; McIntyre, 2003; Nolan, Lunch, Grant, & Keady, 2003; Tarlow, Wisniewski, Belle, Rupert, Ory, & Gallagher-Thompson, 2004; van Groenou, de Boer, & Iedema, 2013), is comparatively small, it is steadily growing. This change in focus is consistent with increased interest in areas such as positive psychology, traumatic growth and benefit finding (e.g. Bower, Low, Moskowitz, Sepah, & Epel, 2008; Helgeson, Reynolds, & Tomich, 2006; Linley & Joseph, 2004; Tennen & Affleck, 2002).

To date models of the positive outcomes of caregiving have primarily been applied to the informal care of the elderly with conditions such as dementia, Parkinson's disease (Habermann, Hines, & Davis, 2013), and stroke (Salminen-Tuomaala, Åstedt-Kurki, Rekiaro, & Paavvilainen, 2013).

Broadly synthesising this growing body of literature, Carbonneau, et al. (2010) propose a conceptual framework for the positive aspects of caregiving (Carbonneau, Caron, & Desrosiers, 2010). (Figure 2). While developed primarily in relation to the provision of care to the elderly, a benefit of this framework is that it captures current understanding of the positive aspects of caregiving. It presents a practical model highlighting factors that can be manipulated to enhance positive caregiver experiences in a variety of contexts.

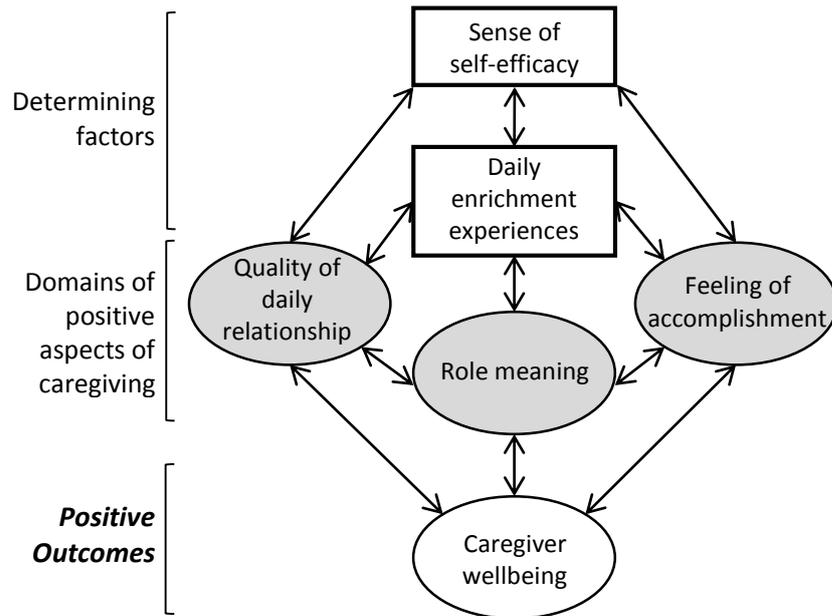


Figure 2. Conceptual framework of the positive aspects of caregiving. Reprinted from “Development of a conceptual framework of positive aspects of caregiving in dementia”, by H. Carbonneau, C. Caron, & J. Desrosiers, 2010, 9(3), p.330. Reprinted with permission.

Quality of the daily relationship. Caregiver satisfaction is a function of interactions between the quality of the previous and current relationship between the parties (Lyonette & Yardley, 2003), with a satisfying prior relationship mediating the impact of challenging behaviours (Lawrence, Tennstedt, & Assmann, 1998). Caregivers who report a strong relationship with the care recipient are more likely to report positive affect and overall psychological wellbeing (Braithwaite, 1996). Even if deterioration in the daily relationship is perceived, caregivers’ sense of filial obligation and affection may result in increased feelings of closeness to the care recipient (De Vugt, Stevens, Aalten, Lousberg, Jaspers, & Winkens, et al., 2003).

Caregivers with better relationships with care-recipients perceive their role as satisfying and enriching. The family caregiving role provides opportunities to maintain an existing relationship (Caron & Bowers, 2003; Farran, Kaene-Hagerty,

Salloway, Kupfer, & Wilken, 1991). It creates opportunities for being close to the care-recipient (Cohen et al., 2002) and may also satisfy a sense of reciprocity and mutual affection (Pinquart & Sorensen, 2003). Caregiving also provides a context for carers to strengthen their relationship with the care recipient and with others (Tarlow, et al., 2004), through expressions of appreciation.

Feelings of accomplishment. One of the most frequently cited sources of satisfaction identified by carers is “the act of giving to the cared for person” (Nolan, Grant, & Keady, 1996, p.86). Appreciation from the care-recipient, or the social recognition of others provide further reward for caregivers (Carbonneau et al., 2010; Motenko, 1989), validating their competency and efficacy. Caregiving activities benefit caregivers by making them feel “appreciated” and “proud” (Noonan, Tennstedt, & Rebelky, 1996, p. 319), enhancing their self-esteem and overall satisfaction with their role (Kramer, 1993; Braithwaite, 1996). Caregiving also provides opportunities to develop skills and personal qualities (Grant & Nolan, 1993).

Meaning of the caregivers' role. The meaning ascribed to daily caregiving activities interacts with the previous two domains and when positive, leads to feelings of usefulness and purpose (Kramer, 1997). The accompanying sense of self-worth has been found to be significantly related to caregiver self-esteem and wellbeing (Noonan, & Tennstedt, 1997). The meaning ascribed to the caregiving role also helps caregivers to put the daily challenges of caring into perspective, supporting caregivers to make sense of their experiences (Carbonneau, et al., 2010).

Determining factors. While contextual factors such as caregiver characteristics (i.e. age, gender, health status) and social and emotional support

resources have been correlated with positive caregiver experiences (e.g. Harwood, Barker, Ownby, Agüero, & Ranjan, 2000; Heru, Ryan, & Iqbal, 2004; Tarlow, et al., 2004), Carbonneau, et al., (2010) prioritise two determinants which enable or limit positive caregiving experiences.

Enrichment events in daily life – “events that make one feel joyful or satisfied” - reinforce the positive aspects of caregiving and bring balance to perceptions of the task of caregiving (Stephens, Kinney, Franks, & Norris, 1990 as cited in Jensen, Ferrari, & Cavanaugh, 2004, p. 96). Shared enrichment events have also been found to be beneficial to the continuity of the caregiver / care-recipient relationship (Motenko, 1989; Voelkl, 1998), and enhance caregivers’ feelings of accomplishment (Kinney & Stephens, 1989).

Caregiver’s who have a greater sense of self-efficacy in their role, tend to focus on the positive aspects of the caregiving experience (Steffen, et al., 2002) and are less likely to be overwhelmed by their responsibilities (Farran, Loukissa, Perraud, & Paun, 2004). This helps in ensuring that caregivers are motivated to act and to be consistently involved with care recipients (Carbonneau, et al., 2010). Additionally, possessing a strong sense of self-efficacy leads to caregivers more frequently incorporating coping strategies into their life (Steffen, et al., 2002). This is associated with lower levels of perceived stress (Pearlin, et al., 1990) and reported depressive symptoms (Fortinsky, Kercher, & Burant, 2002).

To date, the literature exploring caregiving has focussed predominantly on burdens and the potential for negative outcomes. A smaller body of research has considered the positive outcomes and potential gains of caregiving. This research has primarily investigated the experiences of those caring for the elderly, with the

experiences of other caregiver and care recipient groups less well understood.

The resulting imbalance skews perceptions of caregiver experiences, providing an incomplete understanding on which to base interventions and supports intended to enhance positive caregiving outcomes.

Exploring the specific experiences of parents caring for their adolescent children promises to facilitate an increased understanding of how their perspectives of may differ from other caregiver-care recipient cohorts. To introduce a more balanced perspective to the understanding of caregiver experiences, specific analysis is needed to clarify the nature of any gains attributed to their caregiving role. In order to adequately consider the nature and scope of the roles of those caring for their adolescent children, it is important to first appreciate the cognitive, social, emotional, behavioural changes of adolescence which may contribute to the demands placed on caregivers.

“At no time of life is the love of excitement so strong as during the season of the accelerated development of adolescence, which craves strong feelings and new sensations, when monotony, routine, and detail are intolerable.”

(G. Stanley Hall, 1904, vol. 1, p. 368).

Part Two - Adolescence

Like caregiving, adolescence is both universal and culturally constructed. Consequently, there are varying views about its defining characteristics (Newman, & Newman, 2011). The World Health Organisation (WHO) broadly defines adolescence as occurring between the ages of 10 and 19 years (WHO, 2014). This period is generally seen as a time of transition from childhood to adulthood, associated with rapid physical, cognitive and emotional change (Bailey, & Bradbury-Bailey, 2013).

Domains of development during adolescence. Biologically, the beginning of adolescence is anchored to the onset of puberty (Blakemore, Burnett, & Dahl, 2010). Puberty refers to the genetically determined processes of hypothalamic-pituitary-gonadal hormone activation leading to changes in physical characteristics, psychological functioning and social experiences (Cameron, 2004). This hormonal cascade also influences the process of neuronal remodelling and activation responsible for adolescent cognitive, behavioural, and social development (Sisk, & Foster, 2004; Ladouceur, Peper, Crone, & Dahl, 2012). The goal of these processes is to facilitate independence (Blakemore, et al., 2010). Consequently, these processes have a significant impact on adolescents' relationship with caregivers.

Brain development. During adolescence, the speed of communication within the brain progressively increases (Imperati, Colcombe, Kelly, Di Martino, Zhou, & Castellanos, et al., 2011). Development commences in the sensory and motor areas of the occipital lobe, concluding in structures of the prefrontal cortex responsible for emotional, behavioural and cognitive control, planning and

attention (Blakemore, & Choudhury, 2006). Males have significantly faster increases in white matter volume during adolescence, concentrated in different brain regions than for females (Schmithorst, 2009).

Brain connectivity follows a similar back-to-front trajectory (Jetha, & Segalowitz, 2012), with steady increases in the complexity of structures until the onset of puberty (Lenroot, & Giedd, 2006). From this point, approximately 40% of less-used synapses are progressively pruned to enhance the efficiency of neuronal processing (Tau, & Peterson, 2010). Hormonal differences result in this process commencing approximately one year earlier in girls (Giedd, Raznahan, Mills, & Lenroot, 2012; Schmithorst, 2009).

Cognitive development. Enhancements in connectivity and the maturation of the prefrontal cortex enable the more consistent use and flexible synthesis of cognitive abilities (Shaw, Greenstein, Lerch, Clasen, Lenroot, & Gogtay, et al., 2006). This supports progressive increases in logical thinking and problem solving abilities (Casey, Trainor, Giedd, Vauss, Vaituzis, & Hamburger, 1997), as well as improvements in memory (Mabbott, Rovet, Noseworthy, Smith, & Rockel, 2010), visuospatial capabilities (Fryer, Frank, Spandoni, Theilmann, Nagel, Schweinsburg, & Tarpel, 2008), language receptivity and processing (Ashtari, Cervellione, Hasan, Wu, McIlree, Kester, et al., 2007).

Much of the brain development occurs in regions and systems responsible for the regulation of behaviour, emotion and the perception of risk and reward (Steinberg, 2005). Simultaneously, pubertal hormones generate changes in socio-emotional arousal and motivation (Smith, Chein, & Steinberg, 2013). This disjunction is thought to be responsible for the increased appeal of novelty and

learning through reward during adolescence (Steinberg, 2004; Steinberg, 2008; Wahlstrom, Collins, White, & Luciana, 2010).

Behaviour during adolescence. Experience is necessary to support the refinement of higher-order cognitive processes such as attention, working memory and self-regulation (Steinberg, 2010; Zatorre, Fields, & Johansen-Berg, 2012). While the adolescent brain is “primed to learn” (Giedd, 2009, p. 1), a lack of opportunities to engage in novel adult behaviours limit the brain’s ability to adapt to environmental influences (Janacsek, Fiser, & Nimeth, 2012).

Hormonal changes motivate adolescents to engage in sensation-seeking and impulsive behaviour at a time when their cognitive capacity may provide inadequate assessment and control (Steinberg, 2007). Additionally, changing hormones typically result in more intense emotions that fluctuate more often and are more subject to extremes (Jetha, & Segalowitz, 2012). This combination results in an increase in risky decision-making and sensation seeking behaviour (see Romer, 2010; WHO, 2014), intensifying the possibility of injury and accident (Monahan, Steinberg, Cauffman, & Mulvey, 2009). Globally, New Zealand adolescents have the highest rate of injury leading to death (Bland, Shepherd, Ameratunga, Carter, Chambers, & Hassall, et al., 2011).

Due to increases in testosterone concentrations, males are more likely to engage in risk-taking behaviours (NZ Mortality Review Data Group, 2014), or exhibit instinctual reactions such aggression (Asato, Terwilliger, Woo, & Luna, 2010). Conversely, greater densities in frontal lobe structures linked to a greater propensity for internalising behaviours and affective disorders in females (Ruigrok, Salimi-Khorshidi, Lai, Baron-Cohen, Lombardo, & Tait, et al., 2014).

Social development. An increasing drive for peer affiliation and the greater influence of peer attitudes and behaviours during adolescence has been identified across cultures (Nelson, Libenluft, McClure, & Pine, 2005). At the same time; as adolescents are seeking to develop their social skills and independence, there is an increasing need for self-regulation as the externally derived guidance and constraints put in place by parents and caregivers during childhood lessen (Jetha, & Segalowitz, 2012).

The parent - adolescent relationship. The relationship between adolescents and their parents/caregivers is bi-directional, with parent and adolescent attitudes and behaviours simultaneously interacting to determine the nature of the relationship (Kerr, Stattin, & Özdemir, 2012).

Parenting style refers to the combination of overtly and implicitly conveyed attitudes behaviours and interaction comprising the emotional climate within which caregiving interactions occur (Darling, & Steinberg, 1993). The style most beneficial for adolescent development in a range of areas is an authoritative style, which balances high responsivity with high demands (Baumrind, 1966; Steinberg, Lamborn, Dornbusch, & Darling, 1992). Each pattern of parenting is associated with different behavioural, social and emotional development and outcomes (see De la Torre-Cruz, García-Linares, & Casanova-Arias, 2014; Durbin, Darling, Steinberg, & Brown, 1993; Hoffmann, & Bahr, 2014; Uji, Sakamoto, Adachi, & Kitamura, 2014).

Emotionally responsive and respectfully directive caregiving creates an environment that supports healthy adolescent development (Steinberg, 2001). Parenting has been found to account for more variance in problematic behaviours than any other single factor (Crosswhite, & Kerpelman, 2009; Dekovic, Janssens,

& van As, 2003). In particular, inadequate nurturance and guidance during adolescence is associated with increased rates of externalising behaviours and mental health difficulties in both genders (Bailey, & Bailey-Bradbury, 2013; Copeland, Adair, Smetanin, Stiff, Briante, Colman, et al., 2013).

During adolescence parenting style can change in response to adolescent adjustment, familial stressors and shifts in socioeconomic status (Kerr, et al, 2012; Schroeder, & Mowen, 2014). Of particular relevance during adolescence is an increased potential for conflict arising from the adolescents' expanding cognitive skills and their drive to establish their identity as an autonomous entity outside the family (Bailey, & Bailey-Bradbury, 2013). Escalating rates of conflict may be most evident during early adolescence. This most frequently involves first-born children (Shannahan, McHale, Osgood, & Crouter, 2007) and occurs between mothers and sons (Collins, & Steinberg, 2006), placing strain on existing family relationships and dynamics. More positively, some parenting behaviours (e.g. caring and warmth) have been found to remain stable over time (Forehand, & Jones, 2002).

Adolescence is a developmental transition characterised by substantial physical, psychological, and behavioural change. At a lifetime peak in physical health, strength, and mental capacity, maturing cognitive capabilities and the adolescent drive for independence combine. This synthesis creates an environment where adolescents seek, and require, novel experiences in order to stretch their developing capacities for problem-solving and cognitive control. Alongside reducing levels of caregiver oversight, peers play an increasingly important role in shaping adolescent perspectives. Consequently, adolescence can

be a hazardous period, with increasing rates of injury. However, little is currently known about the interaction between adolescent development, sub-acute injury during adolescence, and the nature and scope of subsequent caregiving.

As a frequently occurring injury during adolescence, care following mTBI is typically provided by parents and close family members. To appreciate how such injuries may shape the roles of those providing care, it is important to consider what is currently known about the cognitive, behavioural and social sequelae of mTBI during adolescence. Also relevant are the interactions between the impacts of mTBI and adolescents' subsequent relationship with their caregivers.

“When it comes to adolescents, it’s hard because a lot of the aspects of being an adolescent or teen, look like symptoms of brain injury – impulsivity, moodiness, feeling very sad one moment and angry another moment, wanting to be independent and wanting to be close, experimentation, sexual expression...A lot of the symptoms of brain injury look like adolescence.”

(Unnamed counsellor reflecting on working with adolescents with brain injury, 2014).

Part Three –Traumatic Brain Injury during Adolescence

A traumatic brain injury (TBI) is “an acute brain injury resulting from mechanical energy to the head from external physical forces” (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004, p.115). When compared with other age groups, adolescents are at the highest risk of TBI, which represents a major cause of morbidity and mortality during this period (McKinlay, Grace, Horwood, Fergusson, Ridder, & MacFarlane, 2008). Approximately 95% of all TBI sustained during adolescence are classified as mild (Feigin, Theadom, Barker-Collo, Starkey, McPherson, & Kahan, et al., 2013). Despite the high rate of incidence among adolescents, little is currently known about the long-term outcomes arising from a single mTBI (Keightly, Sinopali, Davis, Mikulis, Wennberg, & Tartaglia, et al., 2014).

Mild traumatic brain injuries (mTBI) are defined by a loss of consciousness of no longer than 30 minutes accompanied by a Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) score no higher than 13 – 15 after this time. Where measures of Post-Traumatic Amnesia (PTA) are used, the period of PTA should be no longer than 24 hours (New Zealand Guidelines Group, 2007; The Management of Concussion/MTBI Workgroup, 2009). The term “concussion” is sometimes used interchangeably with mTBI to describe such injuries (Gordon, Dooley, Fitzpatrick, Wren, & Wood, 2010).

The causes of mTBI during adolescence. While research into the causes of TBI by injury severity is limited, for individuals aged 5–14 years unintentional falls (37%) and being hit by an object (30%) account for the majority of TBI (Feigin, et al., 2013). From around 15 years of age, the causes of injury for males

change. Assaults (28%) become the most common cause of TBI, followed being struck by an external force (25%), and motor vehicle accidents (24%) (Browne, & Lam, 2006; Feigin, et al., 2013; McKinlay, et al., 2008). While unintentional falls and exposure to mechanical force remain frequent causes of mTBI for females, from 15 years, assault becomes an increasing cause of injury (Feigin, et al., 2013).

The profile of adolescents experiencing mTBI. Perhaps unsurprisingly given their hormonally driven propensity for greater levels of aggression, adolescent males experience mTBI more frequently than females, with peaks evident at 10 – 13 and 18 – 23 years (Winqvist, Lehtilahti, Jokelainen, Luukinen, & Hillbom, 2007). Males are also more likely to sustain injuries of greater severity (Feigin, et al., 2013).

Consistent with international studies of ethnic communities, individuals identifying as Māori or of Pacific heritage carry a disproportionate burden with regard to incidence and possibly adverse outcome (New Zealand Guidelines Group, 2006; Elder, 2013; Lagolago, Theadom, Fairburn-Dunlop, Ameratunga, Dowell, & McPherson, et al., 2015). Conversely, European/Pākeha adolescents have been found to experience TBI less frequently (58 - 63%) (Feigin, et al., 2013). Finally, socioeconomic status has been negatively correlated with the risk of TBI (WHO, 2014).

Sequelae of mTBI. The majority of individuals experiencing mTBI do not experience any on-going difficulties (Cassidy, et al., 2004) and rapidly resume an appropriate developmental trajectory (Babikian & Asarnow, 2009). However, 10 – 15% of adolescents sustaining a single mTBI experience residual cognitive, behavioural or social consequences (Anderson, et al., 2009; Anderson & Yeates, 2010; Hessen, Anderson, & Nestvold, 2007; McKinlay, Dalrymple-Alford,

Horwood, & Fergusson, 2002). Possibly as a result of hormonal differences combined with a greater propensity to describe symptoms, females are significantly more likely to report poor outcomes following mTBI (Bazarian, Blyth, Mookerjee, He, & McDermott, 2010)

Cognitive functioning. Initially, mTBI is frequently accompanied by confusion or disorientation, which may be followed by other transient physiological effects such as headaches, fatigue, noise sensitivity, difficulties with attention, concentration, or memory (Catroppa, & Anderson, 2006; Schwartz, Taylor, Drotar, Yeates, Wade, & Stancin, 2003; Landon, Shepherd, Stuart, Theadom, & Freundlich, 2012). Headaches and impaired attention are the most commonly experienced difficulties (Babikian, et al, 2009). Cognitive problems typically resolve within 3 months (Hessen, 2010), leaving few long-term cognitive impacts (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012).

Behaviour. Changes in behaviour immediately following mTBI are common (Li, & Liu, 2012), generally diminishing as recovery progresses (Prigatano, Fulton, & Wethe, 2010). Externalising behaviours such as arguing with adults, aggressive outbursts, deliberately annoying others, blaming others for own mistakes and bullying increase modestly (Max, Robertson, & Lansing, 2001). Similarly, adolescents are at elevated risk for internalising difficulties, and depressive symptoms may also be evident (Peterson, Kirkwood, Taylor, Stancin, Brown, & Wade, 2013; Max, Keatley, Wilde, Bigler, Schachar, & Saunders, et al., 2012). Research suggests that such difficulties may be predictive of reduced quality of life (QoL) long-term (Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014). Likewise, adolescents injured at younger ages are at greater risk for

anxiety difficulties (e.g. phobias, generalized anxiety) six months post-injury (Li, et al., 2013; Max, et al., 2012).

The propensity for developing internalising and externalising behaviours can be conceptualised as an interaction between adolescent, injury characteristics, parent-family and environmental factors (Taylor, Yeates, Wade, Drotar, Stancin, & Burant, 2001; Woods, Catroppa, Eren, Godfrey, & Anderson, 2013) (Figure 3).

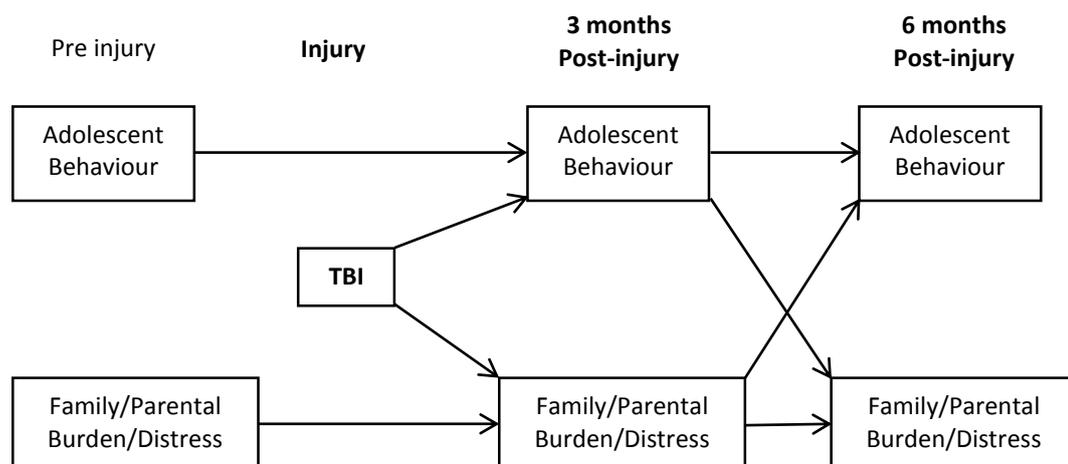


Figure 3. Pathways leading to challenging behavior following TBI. Reprinted from “Helping families to manage challenging behaviour after paediatric traumatic brain injury (TBI): a model approach and review of the literature”, by D.T. Woods, C. Catroppa, S. Eren, C. Godfrey, & V.A. Anderson, 2013, *Social Care and Neurodisability*, 4(3/4), p. 95. Reprinted with permission.

The level of challenging behaviour prior to injury contributes to the risk for incurring a TBI (Light, Asarnow, Satz, Zaucha, McLeary, & Lewis, 1998). While the direct physiological effects of the injury itself can exacerbate post-injury adolescent behaviour. Post-injury behaviour is also influenced by the ability to regulate emotions, including frustration at deficits or other impairments (Max, Levin, Schacher, Landis, Saunders, & Ewing-Cobbs, et al., 2006). Long-term, individuals sustaining mTBI in childhood or adolescence are at a moderately

increased risk for developing subsequent behavioural impairments (Li, et al., 2013).

Parent and family functioning pre and post injury as well as symptoms of anxiety and depression in family members also contribute to behavioural and mood changes in the injured individual (Raj, Wade, Cassidy, Taylor, Stancin, & Brown, et al., 2014). Poorer caregiver psychological functioning contributes to greater adolescent externalising behaviours. Conversely, effective parent communication styles have been associated with reduced adolescent externalising behaviour 3 months post-injury (Raj, et al., 2014). Similarly, providing adequate supports to prevent academic and social failure as well as sensitive management and supports at home contributes to better behavioural outcomes for adolescents (Ylvisaker, & Feeney, 1996).

Social functioning. MTBI has few social consequences during adolescence (Rosema, Crowe, & Anderson, 2012). However, the acute effects of injury may make it difficult for adolescents to maintain a sense of competency (Ylvisaker, 1998), particularly if accompanied by reduced cognitive control or increased irritability. Such a constellation of factors may lead to reductions in self-esteem, social participation and increased loneliness and reduced quality of life (Anderson, et al., 2010, Van Tol, et al., 2011).

Impacts on the family. Moderated by injury severity, brain injuries can generate substantial disruption and distress within the family unit (Aitken, McCarthy, Slomine, Ding, Durbin, Jaffe, et al., 2009). This may include changes in the relationship between the injured individual with any siblings (Bugel, 2014).

Family members play an important role in optimising recovery and adaption outcomes (Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2005;

Braga, Da Paz Junior & Ylvisaker, 2005; Saltapidas, & Ponsford, 2008). The ability to adapt is related to the families' intrinsic coping skills as well as the type and severity of injuries. These elements interact with factors such as adolescent age, the quality of marital relationship, the nature of any competing demands on caregivers, along with the extent and nature of external supports to determine injury outcomes (Max, Castillo, Robin, Lindgren, Smith, & Sato, et al., 1998).

In response to the traumatic event, family functioning typically decreases in the short-term, before stabilising in the longer-term (Testa, Malec, Moessner, & Brown, 2006). Families appear to move through a process, analogous to the model of loss and grief proposed by Elisabeth Kübler-Ross (Kübler-Ross, 1997). The intensity and speed of progression through these stages is again determined by the severity of injury impacts.

Overall, changes in behavioural control (Ponsford, Olver, Ponsford, & Nelms, 2003), and cognitive difficulties in (Testa et al., 2006) have been found to be most predictive of recovery outcomes. Other contributing factors include, the injured individual's emotional state (Ponsford et al., 2003; Testa et al., 2006), the presence and level of physical impairment as well as the injured person's participation in their community and social integration (Marsh, Kersel, Havill, & Sleigh, et al., 1998; Ponsford et al., 2003). Informed adults sensitive to the possible developmental problems arising from injury and with sufficient flexibility to adjust supports over time also contribute to positive outcomes (Ylvisaker, 1998).

Little is currently known about the long-term impacts of a single mTBI during adolescence. While injuries are generally considered to have few impacts,

a proportion of adolescents experience difficulties. Regardless of the nature and duration of any impacts, changes in adolescent behaviours following mTBI are likely to interact with the social, emotional and behavioural development during adolescence. It is important to more fully understand the outcomes of these interactions and their consequences because of their influence on the experiences of those providing care.

Summary

Current research into caregiving highlights the negative outcomes for caregivers. This includes literature exploring the experiences of parent caregivers caring for children as a result of chronic health or disability. To date research considering positive caregiving experiences has focussed on those caring for the elderly, with other caregiver and care recipient groups less studied. Despite the comparatively high rates of brain injury among youth, little is currently known the long-term outcomes of a single mTBI during this important developmental period. Even less is understood about the positive experiences of parents caring for their adolescent children following abrupt injury events such as mTBI. This imbalance skews perceptions of caregiver experiences, providing an incomplete understanding on which to base interventions or supports intended to enhance positive caregiving outcomes.

The development of a more complete understanding of caregiver experiences is important given caregivers' contribution to adolescent adaption and recovery following injury. Such knowledge may help inform caregivers and families of ways they can contribute to improved outcomes for adolescents following traumatic brain injury. The current study sought to fill this gap by

identifying how providing care for adolescents following mTBI was associated with caregivers' perceptions and experiences of caregiving burden and gain.

Chapter Two – Study Design

The opportunity to use data from established studies (i.e. BIONIC: Brain Injury Outcomes New Zealand in the Community, COBIC: Consequences of Brain Injury in Childhood, and BIONIC4you: Brain Injury Outcomes in New Zealand 4 Year Outcomes), was fortuitous. However, the use of a combination of quantitative and qualitative approaches to explore the experiences of caregivers of adolescents with mTBI was entirely intentional.

Studies combining quantitative and qualitative approaches have been found to “enhance the scope, depth and consistency of research findings” (Flick, 2002, p. 227), by facilitating the exploration and description of complex and divergent aspects of human experience (Tashakkori, & Teddlie, 2008). Their application to the “complexities and contexts of social experience” benefit research outcomes by “enhancing the capacity for social explanation and generalisation” (Mason, 2006, p.10). Used in combination, qualitative and quantitative research methods complement each other; consolidating strengths, mitigating limitations, ultimately facilitating robust analysis (Greene, Caracelli, & Graham, 1989).

The current study, employed an explanatory sequential mixed-methods design (Creswell, Plano-Clark, Gutmann, & Hanson, 2003), involving the collection of quantitative data (phase one), followed by the compilation of qualitative information (phase two). Each phase played an equally important role in addressing research questions, with findings mixed during a final interpretation. This multi-stage model was selected because the structure facilitated a comprehensive explanation of caregiver experiences, with the second phase

enhancing contextual understanding of phase one findings. Further benefits were that it capitalised on the initial opportunity to access quantitative data while permitting further investigation of the research topic, and that the sequential structure could be achieved by a single researcher.

Mixed-methods research designs raise a number of methodological issues (Creswell, 2014). Specifically, divergent paradigms, length of time to complete, and the feasibility of analysing and synthesising both qualitative and quantitative data (Bazeley, 2002; Creswell, et al., 2003). In order to manage these inherent challenges, the current study adopted a universally pragmatic theoretical framework. This paradigm placed research questions centrally, focussing on utilising the research methods best suited to answer the specific research questions being investigated (Feilzer, 2010).

As the time-frame for completion of the study was prescribed, the scope of investigation was targeted to a previously understudied group (parent caregivers of adolescents with mTBI), generating a manageable, yet meaningful participant cohort. The length of time taken to complete the study was also assisted by the prior collection of much of the data analysed in phase one and the ability to recruit a subset of already identified participants in phase two. Finally, analysis was simplified by the selection of an explanatory design, which allowed the findings of each phase to be analysed and discussed sequentially before the findings of both phases were synthesised.

As appropriate, the specific techniques employed in each phase were discussed in subsequent sections as part of the explanation of their respective methodologies.

Overview of Study Aims

Phase one of the current study sought to identify how providing care for adolescents (aged 10 to 18 years), with prior mTBI was associated with caregivers' perceptions of their quality of life (physical and mental health), mood (anxiety and depressive symptoms), and experiences of caregiving burden and gain at 12 and 24 months post injury. The relationships between caregiving outcomes and the existence of injury, increasing adolescent age (as an indicator of adolescent cognitive, behavioural and social development), gender and functioning along with caregiver quality of life and mood were also explored to determine how these variables were associated with caregiving outcomes in the current cohort. Given the unique comprehensiveness of the source studies and the access this gave to a previously understudied cohort, analysis was largely exploratory. Quantitative analysis of these data allowed for greater accuracy and objectivity while enhancing the generalisability of results (Bernard, 2008).

Following quantitative analysis, with the aim of expanding on and contextualising findings, a qualitative approach was used to explore the experiences of a selection of caregivers of adolescents with prior mTBI now aged 13 – 16 years. Interviews were conducted approximately four years following the adolescent's mTBI.

Phase two explored the question “what are the experiences of caregivers caring for adolescents following mild traumatic brain injury?” This question sought to understand caregivers' lived experiences and the realities of their daily lives as carers. A qualitative approach was used to elicit greater depth and detail about individuals' thoughts and perspectives while allowing for aspects of experience not previously considered to be revealed (Berg, & Lune, 2011).

Data Sources

Phase one. Data for phase one was drawn from a prospective, population-based epidemiological study of TBI in New Zealand (BIONIC: Brain Injury Outcomes New Zealand in the Community) and a related sub-study (COBIC: Consequences of Brain Injury in Childhood) (Figure 4).

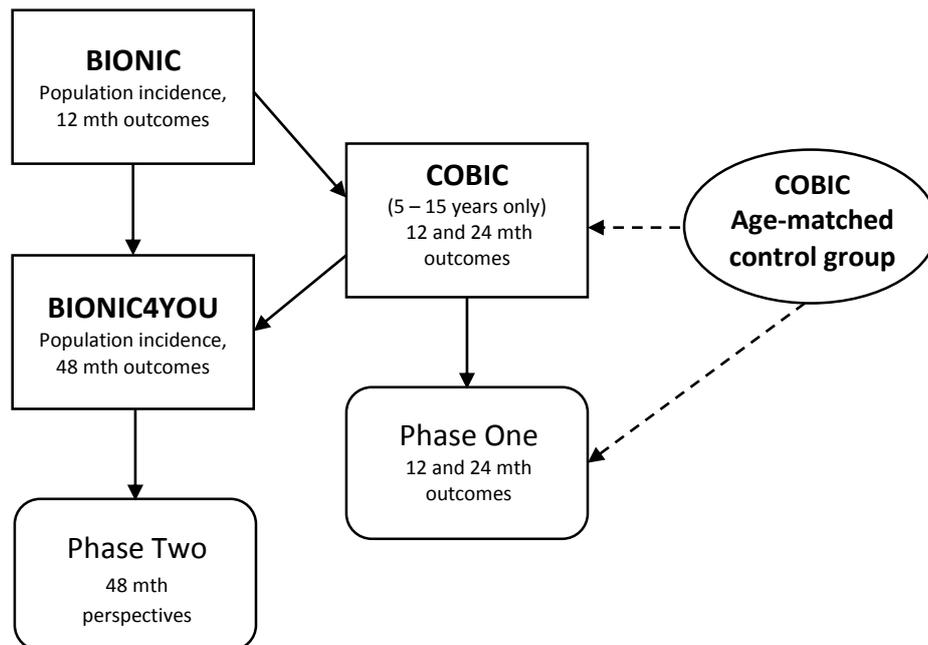


Figure 4. Relationship between data sources for the current study.

The BIONIC study investigated the incidence and 12 month outcomes of all cases of TBI occurring in the Hamilton and Waikato districts between 1st March 2010 and 28th February 2011 (Feigin, et al., 2013). The sample region captured a general population of 173,208 urban and rural residents considered representative of New Zealand as a whole (Statistics New Zealand, 2012).

A total of 1369 cases of TBI were identified and consenting participants were assessed at baseline, and at 1, 6 and 12 months post-injury. (Feigin, et al., 2013). A comprehensive description of the study's methodology is provided by Theadom and colleagues (Theadom, Barker-Collo, Feigin, Starkey, Jones, & Jones, et al., 2012).

Following the completion of the 12-month BIONIC assessments, participating families with children aged 5 to 15 years at the time of injury were invited to join the COBIC study: a longer term follow-up of children and adolescents with TBI. COBIC replicated and supplemented the information previously gathered in the BIONIC study. Measures were collected at 12 and 24 months post injury, incorporating a wider range of child and adolescent academic and behavioural outcomes.

The COBIC study also recruited a non-injured, age-matched control group with information obtained at 12 and 24-month post-injury equivalent time points. Each brain-injured individual was age-matched (to within 3 months of age where possible), with a non-injured adolescent and their nominated caregiver (see Wacholder, Silverman, McLaughlin, & Mandel, 1992). The method of age matching used recognised the rapid development occurring in childhood and accommodated the normative age bands of psychometric measures used in the COBIC study (Wechsler, 2004). Children and adolescents were eligible for inclusion if they had no lifetime incidence of TBI and lived in Hamilton or the Waikato region at the time of recruitment.

Comparison participants were sourced using pamphlets, posters and flyers, which were distributed through Plunket rooms, Kindergartens, and early childhood centres as well as primary and secondary schools. Participants were also recruited by word of mouth and directly approached to ensure as many TBI participants as possible were paired with age-matched comparisons. Additionally, current BIONIC participants were asked to pass on information to friends and acquaintances that may be interested in participating in the study. Overall the group had the same gender balance and similar average school decile ratings.

Phase two. Participants in phase two were recruited from the BIONIC4you (Brain Injury Outcomes New Zealand in the Community: 4 Year Outcomes) study (Figure 4). This research followed-up consenting participants from the BIONIC study four years post-injury. BIONIC4you sought to investigate the long-term impacts of initial and recurrent TBI in New Zealand.

In all source studies (BIONIC, COBIC, BIONIC4you), the World Health Organisation (WHO) criteria were used to determine the presence of TBI (Carroll, et al., 2004). Injury severity was assessed using the Glasgow Coma Scale (GCS) as mild, moderate or severe (Teasdale, et al., 1974). MTBI was further classified into high, medium and low risk categories (Servadei, Teasdale, & Merry, 2001).

Ethical Considerations

The research study received approval from the University of Waikato, School of Psychology Ethics Committee and the Northern Y Regional Ethics Committee.

To facilitate the unfolding of the findings of the current study in a logical manner, a detailed account and analysis of each phase is presented sequentially. An overall discussion then summarises and synthesises findings from both phases.

Chapter Three – Phase One

Phase one sought to identify how providing care for adolescents with prior mTBI was associated with caregivers' perceptions of their quality of life, mood, and experiences of caregiving burden and gain. It was hypothesised that (a) the caregiving experiences of parent caregivers of adolescents with mild traumatic brain injuries would be largely positive; with (b) similar perceptions quality of life (related to their mental and physical health), mood (symptoms of anxiety and depression), and caregiving outcomes (caregiver burden or gain, and the impact of change), to those of caregivers of adolescents in a matched non-injured comparison group.

The relationships between caregiving outcomes and the existence of injury, increasing adolescent age (as an indicator of adolescent cognitive, behavioural and social development), gender and functioning along with caregiver quality of life and mood were also explored to determine how these variables were associated with caregiving outcomes in the current cohort. Based on current understanding of caregiving, adolescent development and the impacts of mTBI during adolescence, it was hypothesised that the existence of injury, adolescent age and adolescent behaviour would have the strongest relationship with caregiver outcomes. However, given the unique comprehensiveness of the source studies and the access this gave to a previously understudied cohort, analysis was largely exploratory.

Methods

Following a review of study records, the caregivers of all adolescent participants in the BIONIC/COBIC cohort with TBI, aged between 10.0 years and

16.11 years (inclusive) at the 12-month COBIC assessment were identified for inclusion. The age-range sampled was consistent with the WHO definition of adolescence while allowing for variations in the onset to and transition from adolescence. The derivation of this initial sample is outlined in Figure 5.

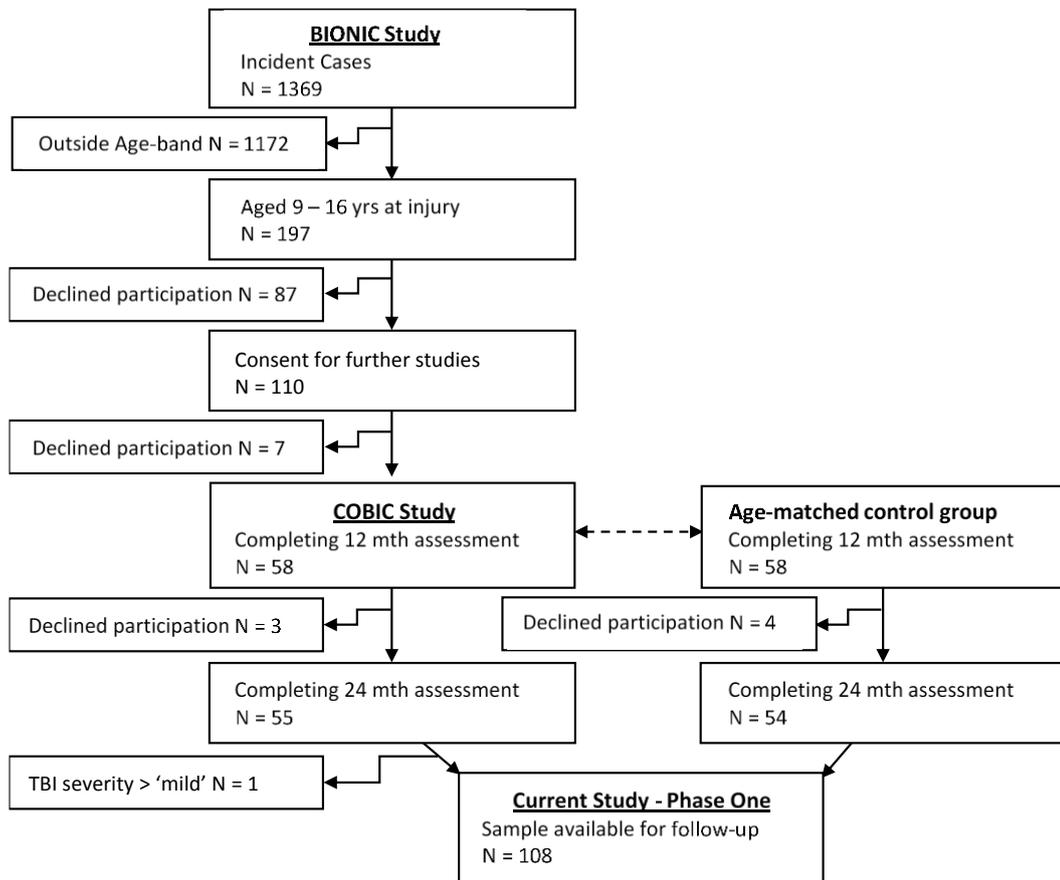


Figure 5. CONSORT diagram of participants included at baseline, 12 and 24 month time points from BIONIC and COBIC studies.

Caregiver-adolescent dyads at 12 and 24 months post-injury, and at equivalent time-points for a non-injured, age-matched comparison group were then identified. This permitted the analysis of caregiving experiences relative to the same recipient at two stages of adolescent development as well as the comparison of experiences of caregivers of adolescents with TBI with caregiving “as usual”.

Finally, to focus experiences of caregiving as a consequence of the most frequently sustained severity of traumatic brain injury, only adolescents with injuries classified as “mild” (mTBI) using the WHO and the GCS criteria (Teasdale & Jennett, 1974), and their caregivers were selected. Specifically, a GCS score of 13 to 15 and less than 24 hours of post-traumatic amnesia.

Participants

To enhance the reliability of findings, data from all dyads with prior experience of mTBI and their matched comparison dyad (a total of 108 dyads), were included in the current study. Given the comprehensiveness of the source studies, this resulted in a uniquely representative sample. Dyads were assigned to either the mTBI or comparison group on the basis of prior adolescent mTBI.

A total of 54 caregivers (50 female and 4 male) of adolescents (20 female, 34 male) with prior mTBI aged between 10.0 years and 16.11 years (inclusive) at the 12 month COBIC assessment were included in the current study. This was matched with a comparison group of 54 caregivers (51 female, 3 male) and adolescents (20 female, 34 male), as assigned by the source studies.

Adolescents in both groups were predominantly male, while caregivers were typically female. The ethnicity of both adolescent groups was comparable. Caregivers of injured adolescents were more likely to identify as Māori or not state their ethnicity. Comparison group caregivers were more likely to describe themselves as of European or ‘other’ ethnicity. Adolescents were of similar age ranges, while caregivers in the comparison group were typically older than carers of injured adolescents. (Further details of this sample are provided in the Results section, Table 1).

Measures

For all mTBI participants and comparison group dyads measures of caregiver health-related quality of life, mood, and caregiving experiences as well as adolescent injury characteristics and behaviour measures (self and caregiver report) were analysed. Background and demographic information and injury characteristics were also included in the analyses.

Background and demographic information. Information regarding caregivers' age, relationship to the injured adolescent, ethnicity, employment status, education level, marital and socio-economic status were requested from each caregiver. Consistent with current models of caregiving (Raina, et al., 2010), this enabled the identification of environmental variables associated with caregiver experiences. Similarly, data on adolescent age, ethnicity, and injury severity were also collected. In addition, information was also gathered about subsequent mTBI, previous disability and current medications as factors which may impact on caregivers' roles.

Caregiver health-related quality of life. The RAND 36-Item Health Survey from the Medical Outcomes Study – version 1, Australia/New Zealand adaption (SF-36), is a generic health-related quality of life (HRQoL) questionnaire for individuals aged from 14 years (Hays, Sherbourne, & Mazel, 1993). The SF-36 is commonly used to measure caregiver perceptions of their own health in mTBI research (Emanuelson, Andersson-Holmkvist, Bjokland, & Stalhammar, 2003) and is considered a valid and reliable measure for New Zealand populations (Scott, Sarfati, Tobias & Haslett, 1999; Scott, Sarfati, Tobias, & Haslett, 2000).

The SF-36 uses multi-item scales to assess an individual's overall subjective health status. It is comprised of two summary measures and eight subscales: physical health (physical functioning, role limitations due to physical health, bodily pain, general health perceptions) and mental health (vitality, social functioning, role limitations due to mental health, general mental health). The questionnaire also includes one item designed to estimate change in health status over the past year (McDowell, 2006).

Responses utilise a variety of 3 (e.g. "yes, limited a lot", "yes, limited a little", "no, not limited at all"), 5 (e.g. "definitely true", "mostly true", "don't know", "mostly false", "definitely false") or 6 (e.g. "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"), option answer categories, as well as dichotomous (yes/no) options. Raw scores are summed before being transformed to a 0 – 100 scale. Standardised scores are produced for the two summary measures and eight subscales, with higher scores representing positive perceptions of health.

Internal consistencies (Cronbach's alpha) range from 0.82 to 0.93 for the physical health measure and 0.78 to 0.82 for the mental health measure (Scott, et al., 1999). Similarly, two-week test-retest reliabilities for the physical health (0.72 – 0.93), mental health (0.63 – 0.80) and summary measures are adequate (Marx, Menezes, Horovitz, Jones, & Warren, 2003).

In the current study, both summary measures (physical health and mental health), were used to investigate caregiver perceptions of their physical and mental health related quality of life. Normative data for New Zealand populations were used for analysis (Scott, et al., 1999).

Caregiver mood. The Hospital Anxiety and Depression Scale (HADS) is a brief self-report questionnaire assessing symptoms of anxiety, depression and emotional distress in individuals aged 13 years and older (Zigmond, & Snaith, 1983). Originally developed as a screen to identify and discriminate between clinically significant anxiety and depression in medical settings, the HADS is extensively used in general populations (McDowell, 2006; Whelan-Goodison, Ponsford, & Shonberger, 2009).

The measure is arranged into two 7-item subscales capturing experiences of generalised anxiety (HADS-A) and anhedonia (sub-clinical depression) (HADS-D), during the past week (Roberts, Bonnici, Mackinnon, & Worcester, 2001; Flint, & Rifat, 2002). Items are scored using various 4 option scales (e.g. “definitely as much”, “not quite as much”, “only a little”, “hardly at all”). Responses are then recoded, generating scores from 0 – 21 for each subscale. Higher scores represent greater distress (Whelan-Goodison, et al., 2009) with cut-off scores of 8 on either subscales indicating mild intensity in that domain (McDowell, 2006).

Internal consistencies (Cronbach’s alpha) for the HADS–A subscale range from 0.68 to 0.93 and for the HADS-D from 0.67 to 0.90 (Mykletun, Stordal, & Dahl, 2001). The HADS has also been found to have good to very good concurrent validity with average correlations of 0.60 (HADS-D), 0.80 (HADS-A) and 0.68 – 0.73 for the Total score when compared to other commonly used measures of depression and anxiety (Bjelland, Dahl, Haug, & Neckelmann, 2002).

In the current study, HADS-A, HADS-D subscale scores were used to investigate caregiver self-reported anxiety and depressed mood as a result of caregiving.

Caregiver outcomes. The Bakas Caregiving Outcomes Scale - revised (BCOS) is a 15-item self-report scale designed to assess positive (gain) and negative (burden) changes in daily living for informal caregivers of individuals with chronic conditions (Bakas, Champion, Perkins, Farran, & Williams, 2006). Originally developed to assess caregiver experiences in stroke research, the BCOS is unique in measuring changes in caregivers' social, emotional and physical health specifically as a result of providing care (Bakas, McLennon, Carpenter, Buelow, Otte, Hanna, et al., 2012).

The uni-dimensional scale assesses changes in caregiver social functioning, physical health, and subjective well-being compared to one year ago. Comparisons of financial well-being, levels of energy, role and physical functioning and perceptions of general health are also captured (Bakas, & Champion, 1999). An additional item; "In general, how has your life changed as a result of taking care of the child / compared to one year ago?" is used to assess criterion-related validity and is not added to the final BCOS score (Bakas, Champion, Perkins, Farran, & Williams, 2006).

All items are rated on a 7-point Likert scale ("changed for the worst" to "changed for the best"). Individual responses are transformed to a 1 to 7 scale with higher scores representing improved caregiver outcomes. The total scale score, obtained by summing individual scores, ranges from 15 – 105. Values below 60 suggest worsening experiences and values above 60 indicate enhancement (Bakas, et al., 1999).

The BCOS has been found to have good psychometric properties with internal consistencies of 0.90 (Cronbach's alpha). Two-week test-retest reliabilities range from 0.41 – 0.74. (Bakas, et al., 2006). Correlations with the

general health subscale of the SF-36 questionnaire ($r = 0.32, p < .001$) and with the criterion variable assessing how the caregivers life has changed in general ($r=0.67, p < .001$) indicates the BCOS possesses adequate validity for use in caregiver populations.

In the current study the BCOS score was used as a measure of caregiving burden/gain. In addition, the supplementary criterion-validity item; “In general, how has your life changed as a result of taking care of the child / compared to one year ago?” was used as a measure of perceived change in caregiving outcomes over the past 12 months. This single item score was used on the basis that it had a high correlation with the 15-item BCOS ($r = .67$), indicating that it measured similar underlying factors. However, the wording of the item required respondents to make a general retrospective comparison on which to base a single rating of perceived overall change.

Adolescent functioning. Care recipient functioning following injury is thought to impact caregiving experiences (Jorgensen, et al., 2010; Raina, et al., 2004). To provide a measure of adolescent behaviours, emotions and the characteristics of their relationships with others, responses to two measures were collected from adolescents and caregivers.

The Strengths and Difficulties Questionnaire (SDQ) is a brief screening questionnaire assessing positive and negative emotions, behaviours and relationships (Goodman, 1997). The measure is used extensively in research, clinical and educational settings to identify problematic emotions and behaviours in children and adolescents and has been assessed as valid for use in Australasian populations (Hawes, & Dadds, 2004). The extended 25-item self-report and

parent report versions for 11 to 17 years olds were used in this study (Goodman, 1997).

The SDQ is comprised of five core subscales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, pro-social behaviour) each comprised of 5 items.

Items in both the parent and self-report versions are rated with reference to the last six months on a 3-point Likert scale (“not true”, “somewhat true”, “certainly true”). Transformed scores on the five sub-scales range from 0-10. Summing all subscales excluding the pro-social behaviour sub-scale generates a total difficulties score ranging from 0 to 40. An impact score (capturing the impact of difficulties experienced) is generated by summing SDQ items relating to overall distress and impairment, yielding scores from 0 to 10. Higher scores on the first four subscales, total difficulties and impact indicate greater problems, while higher scores on the pro-social scale indicate better social functioning. Analysis of subscale scores enables adolescent strengths and difficulties to be grouped into categories: close to average, borderline or abnormal (Goodman, Renfrew, Mullick, 2000).

Internal consistencies (Cronbach’s alpha) for the parent-report version range from 0.57 to 0.77 for the subscales and reach 0.82 for the Total score (Woemer, Fletitlich-Bilyk, Martinussen, Fletcher, Cucchiaro, Dalgarrondo, et al., 2004). The internal consistency is somewhat higher for the total difficulties score at 0.85. Test-retest reliabilities at 4-6 month intervals range from 0.57 to 0.72 (Goodman, 2001).

Completed questionnaires were scored using syntax for SPSS provided by the authors of the questionnaire (see <http://www.sdqinfo.com>). At the time this

study commenced New Zealand norms for this questionnaire were not available and Australian norms were used to determine whether scores fell in the normal, borderline or abnormal range (Mellor, 2005). Gender and age group provide cut-off scores.

Total difficulties and impact scores were used in the current study to obtain information about adolescent behaviours likely to influence caregiver experience.

The Behavioral Assessment System for Children – 2nd edition (BASC-2) is a widely used multidimensional system for assessing the adaptive and maladaptive behaviour, emotions and self-perceptions of individuals aged 2 to 21 years (Reynolds, & Kamphaus, 2004). The multi-rater measure is commonly used in educational settings and is also applied to the neuropsychological assessment of behavioural problems and emotional disturbances following paediatric mTBI (Semrud-Clikeman, 2001; Sullivan, & Riccio, 2006).

Measures from both the parent report versions appropriate to children (PRS – C) and adolescents (PRS - A), aged 2 – 11 and 12 – 21 years respectively, as well as the self-report versions suitable for children (SRP – C) and adolescents (SRP – A) in the same age ranges were used.

The self-report versions of the BASC-2 focus on assessing emotions and feelings over the past month and are comprised of 176 questions aggregating to 16 primary scales and 5 composite scales (emotional symptoms, school problems, internalising behaviours, inattention/hyperactivity, and personal adjustment). The parent-report measures focus on identifying problem behaviours and contain 159 and 150 items respectively arranged into 14 primary scales and 4 composite scales (externalising problems, internalising problems, behavioural symptoms, and

adaptive skills). Scores are age standardised and scale and composite scores are not directly comparable between test versions (Reynolds, et al., 2004).

Items are responded to using either dichotomous (yes/no), frequency-based options (i.e. always, often, sometimes and never), or 4-point Likert rating scales. Responses are rescored to yield scores from 1-100. On clinical scales, high scores suggest that the individual's behaviour is negative or undesirable, or the child was rated more negatively than warranted. On the adaptive scale, low scores indicate problematic or maladaptive behaviours (Reynolds, et al., 2004). The measure is computer-scored generating T-scores for each primary and composite scale and as well as measures of socially desirable responding.

Internal consistencies (Cronbach's alpha) for the BASC - 2 range from 0.80 – 0.90 for the composite scales and 0.60 – 0.90 for individuals scales (Reynold, 2010). Mean test-retest reliabilities range from 0.70 to 0.90 (Reynolds, et al., 2004).

In the current study, T-score values for the four composite scale scores (Externalising Problems, Internalising Problems, Behavioural Symptoms and Adaptive Skills), were used to assess caregiver perceptions of adolescent behaviours as well as overall adolescent functioning, daily living and prosocial skills. Similarly, T-score values for the five self-report composite scale scores (Emotional Symptoms, School Problems, Internalising Behaviour, Inattention/hyperactivity, and Personal Adjustment), were used to gauge adolescent perceptions of internal emotional states and external behaviours.

Procedure

At the 12-month post-injury follow-up caregivers were telephoned to confirm eligibility and interest in participation in a further study. Simultaneously,

individuals responding to recruitment advertisements for comparison group participants were screened for eligibility and additional background information was collected. Contact and basic demographic information (e.g. age of child or adolescent, gender, ethnicity, school attended) was collected from eligible participants. From this point the same assessment procedure was followed for both groups.

Eligible caregivers expressing interest in inclusion in the study were e-mailed or posted further information (Appendix A). Approximately one week later, they were contacted to confirm receipt of the information. Where there was continued interest, an initial interview was scheduled at a time convenient to the caregiver and adolescent.

The initial interview began with a review of the study information sheet before written consent was obtained (Appendix B). Where the TBI participant was younger than 16 years of age, this was first sought from the caregiver on behalf of the child or adolescent. Where the TBI participant was over 16 years of age, written consent was first sought from the adolescent, including consent to speak with the caregiver about them before seeking consent from the caregiver.

Once consent had been received, interviews were completed with adolescents and caregivers using a series of questionnaires. Each interview took approximately 2.5 hours to conduct and was completed over two sessions for convenience and to reduce fatigue. Information was primarily collected face to face, but was also collected over the phone if more convenient for the participant.

Much of the data analysed in the current study had already been collected from source study participants. However, the author of the current study was involved in the collection of data from 25 non-injured adolescents and their

caregivers in the comparison group at the 24-month follow-up. This involved contacting participants one month before the 24-month anniversary of their TBI or equivalent time-point, and determining whether they wanted to take part in the study again. Where interest was shown, the study procedures outlined above for the 12-month post-injury follow-up were reapplied.

Time between T1 and T2 assessments ranged from 0.55 years to 1.60 years ($M = 1.02$ years) for adolescents in the mTBI group and 0.96 years and 1.84 years ($M = 1.18$ years) for individuals in the comparison group.

Statistical analysis was completed using SPSS statistics version 21 (IBM Corp., Armonk, NY). To determine the most appropriate method of analysis and interpretation, variables were evaluated for normality and visually assessed to exclude bimodal distributions. Where normality was violated, equivalent non-parametric analyses were conducted. Where findings were consistent, parametric analysis was reported. The results of normality tests and any non-parametric tests are included in Appendix C.

Differences between TBI and comparison group demographic information were assessed using Pearson's chi-squared tests of independence, Fishers' exact and independent samples t-tests. 2 x 2 mixed/repeated measures ANOVA were used to examine the effects and interaction of group membership and time on caregiver physical health, mental health, caregiving outcomes and the reported impacts of caregiving. Pearson's product moment statistics were used to determine the strength of linear relationships between physical health, mental health, caregiving outcomes and the reported impacts of caregiving relative to adolescent age and also gender. In addition, 2 x 2 mixed/repeated measures ANOVA were used to examine the effects of group membership and time on

reports of adolescent functioning. Pearson's product moment statistics were then used to determine the strength of linear relationships between caregiver and self-reports of adolescent functioning relative to adolescent age and gender. Finally, a series of Pearson's product moment statistics were conducted to determine the strength of linear relationships between caregiving outcomes and group membership, caregiver physical health, mental health and adolescent age and functioning for both groups at Time 1 and Time 2.

Significance levels for all analysis were set at $p < 0.05$ (2-sided) unless otherwise stated. As this was not a clinical study, the magnitude of effect sizes were described in terms of *practical* significance (Kirk, 1996).

Results

Analysis included a total of 216 individuals, comprising 108 caregiver/adolescent dyads (54 dyads with previous experience of mTBI and 54 comparison dyads). Data was collected at 12 and 24 months post-injury or equivalent time points. Incomplete data as a result of loss to follow-up resulted in sample sizes for individual measures that varied from 68 - 108. Sample sizes for each measure are included with the relevant analyses.

General demographics

Adolescent characteristics. Differences in the gender, ethnicity and presence of diagnosed health problems in adolescents with and without mTBI were examined (Table 1).

Pearson's chi-square tests of independence identified no statistically significant differences in gender and the presence of health problems between the two groups. Similarly, a Fisher's exact test of independence found no statistically significant differences in the ethnicity of the groups. Finally, an independent

samples *t*-test performed to compare the distribution of ages between the two adolescent groups, did not identify any statistically significant differences.

Table 1. Comparison of gender, ethnicity, presence of diagnosed health problems and age for adolescents with and without mTBI.

Variable	mTBI		Comparison		χ^2	<i>p</i>	<i>phi</i>
	<i>n</i>	%	<i>n</i>	%			
Gender							
Male	34	63.0	34	63.0	0.00	1.00	0.00
Female	20	37.0	20	37.0			
Ethnicity							
European/Pakeha	39	72.2	42	77.8	1.73 †	0.68	0.13
Maori*	9	16.7	7	13.0			
Other	6	11.1	4	7.4			
Not stated	0	0.0	1	1.9			
TBI Severity							
Mild/low	24	22.2					
Mild/medium	8	7.4					
Mild/high	22	20.4					
Presence of diagnosed health problems	17	31.5	16	29.6	1.08	0.58	0.10
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>		<i>d</i>
Age at Time 1	13.63	2.0	13.5	2.1	-0.24	0.81	0.05
Age at Time 2	14.75	2.3	14.7	2.1	-0.15	0.88	0.00

Note: * Includes individuals identifying as Māori and part-Māori, † Fisher's Exact test statistic.

Overall, injured adolescents were more likely to be male and identify as Pākeha/European. Analysis of injury severity identified a bimodal distribution (major mode = mild/low, minor mode = mild/high), with these modes capturing 42.6% of injuries.

Caregiver characteristics. Chi-square and Fisher's exact tests of independence were conducted to compare the gender, ethnicity, relationship status, occupational group, paid working hours, and highest education level achieved by caregivers (Table 2). No statistically significant differences were found between the caregiver groups with the exception of ethnicity, relationship status and age.

Table 2. Comparison of gender, ethnicity, relationship status, occupational group, paid working hours, highest education achieved and age for caregivers of adolescents with and without mTBI.

Variable	mTBI		Comparison		χ^2 [†]	<i>p</i>	<i>phi</i>
	<i>n</i>	%	<i>n</i>	%			
Gender							
Male	4	7.4	3	5.6	0.15	0.70	0.04
Female	50	92.6	51	94.4			
Ethnicity							
European/Pakeha	32	59.3	40	74.1	13.28	0.004**	0.35
Maori ^a	7	13	2	3.7			
Other	5	9.3	11	20.4			
Not stated	10	18.5	1	1.9			
Relationship status							
Married/defacto/civil union	32	59.3	43	79.6	11.16	0.010**	0.31
Separated/divorce/widowed	8	14.8	8	14.8			
Never married/single	6	11.1	3	5.6			
Not stated	8	14.8	0	0.0			
Occupation group							
Manager	6	11.1	4	7.4	9.95	0.25	0.30
Professional	10	18.5	15	27.8			
Technician/Trades	1	1.9	2	3.7			
Community/Personal Service	8	14.8	8	14.8			
Clerical/Administrative	7	13	12	22.2			
Sales	6	11.1	0	0.0			
Labourer	3	5.6	2	3.7			
Unemployed	11	20.4	10	18.5			
Not stated	2	3.7	1	1.9			
Paid working hours							
35+ hours per week	19	35.2	20	37	4.69	0.33	0.21
20 - 34 hours per week	9	16.7	12	22.2			
1 - 19 hours per week	5	9.3	10	18.5			
No paid hours per week	18	33.3	11	20.4			
Not stated	3	5.6	1	1.9			
Highest Education							
University	12	22.2	19	35.2	6.13	0.14	0.25
Polytechnic	18	33.3	19	35.2			
High School	21	38.9	15	27.8			
Primary School	0	0.0	1	1.9			
Not stated	3	5.6	1	1.9			
Age at Time 1							
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	2.14	0.035*	0.45
Range (years)	42.60	6.16	45.44	6.60			
	(28.5 - 55.5)		(32.7 - 66.9)				

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, [†]Fisher's Exact test used for groups larger than 2x2, ^a Individuals identifying as Maori or part-Maori,

Caregivers of adolescents with mTBI were more likely to identify as Māori or choose not to state their ethnicity. These caregivers were also less likely to report being married, in a civil union or defacto relationship, and more likely to

prefer not to state their current relationship status. The effect statistics for these differences (ethnicity $\phi = 0.35$, relationship status $\phi = 0.31$) exceed Cohen's (1988) convention for medium effect sizes, suggesting moderate practical significance.

Independent samples *t*-tests were performed to identify differences in the average age of caregivers in the two groups. On average, those caring for injured adolescents were significantly younger than caregivers in the comparison group. Effect size statistics ($\phi = 0.45$) suggest that this difference was of moderate practical significance.

Adolescent functioning.

Adolescent reports and the effects of time and group membership. The impact of group membership and time since injury on adolescent self-reports of emotional, behavioural and social functioning (as measured by the BASC-2, and the SDQ), were assessed using a series of 2 (group: mTBI and comparison) by 2 (time: 12-months and 24-months post-injury equivalent) mixed measures ANOVA (Table 3). Sample size was small due to data being unavailable for each participant at both time points.

Analyses indicated that the interaction between group membership and time since injury on adolescent reports of school problems was statistically significant. Further analysis of sample means revealed that adolescents with mTBI reported increasing rates of school problems between 12 and 24 months since injury, while non-injured adolescents reported decreasing rates of school problems over the same time period. Effect size statistics ($p = .044$, $\eta^2 = 0.09$), suggest the difference was of small practical significance. No other significant interactions or main effects were evident.

Table 3. Strengths and Difficulties Questionnaire (SDQ) and Behavioral Assessment for Children (BASC-2): Analysis of variance in self-reports of emotional, behavioural and social functioning in adolescents with and without MTBI.

Variable	mTBI (n = 17)		Comparison (n = 29)		Main effects						Interactions			
	Time 1	Time 2	Time 1	Time 2	Time			Group			Time x Group			
	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2	
BASC-2														
Emotional Symptoms	46.12 (9.66)	46.29 (9.44)	46.62 (8.35)	45.66 (7.53)	0.12	0.73	0.00	0.00	0.98	0.00	0.25	0.62	0.01	
School Problems	48.06 (10.40)	50.24 (11.33)	49.03 (10.91)	46.00 (9.34)	0.12	0.74	0.00	0.31	0.58	0.01	4.29	0.044*	0.09	
Internalising Behaviours	47.59 (10.18)	48.94 (11.71)	46.62 (7.85)	45.62 (8.44)	0.02	0.88	0.00	0.70	0.41	0.02	0.98	0.33	0.02	
Inattention / Hyperactivity	53.88 (12.82)	54.41 (11.89)	52.17 (11.89)	49.10 (11.01)	1.00	0.32	0.02	1.08	0.30	0.02	2.01	0.16	0.04	
Personal Adjustment	53.82 (10.77)	53.12 (9.14)	52.31 (6.66)	52.45 (6.70)	0.05	0.82	0.00	0.27	0.61	0.01	0.11	0.74	0.00	
SDQ														
Total Difficulties	12.65 (7.09)	12.41 (7.88)	11.38 (5.71)	9.79 (5.48)	1.26	0.27	0.03	1.21	0.28	0.03	0.70	0.41	0.02	
Difficulties Impact	1.00 (2.03)	0.76 (1.60)	0.41 (1.08)	0.34 (0.89)	0.86	0.36	0.02	1.74	0.19	0.04	0.26	0.62	0.01	

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Adolescent reports relative to age. To determine the nature of the relationship between adolescent age and self-reported emotional, behavioural and social functioning (as measured by BASC-2 and SDQ responses) at Time 1 and Time 2, Pearson's product-moment correlation statistics were calculated (Table 4).

For adolescents with mTBI, statistically significant, weak, positive relationships were found between age and school problems at 12 ($r = 0.40$, $p = .016$) and 24-months post-injury ($r = 0.33$, $p = .039$). A statistically significant, moderate, positive relationship was also found between adolescent age and self-reports of inattention and hyperactivity at 12 months post-injury ($r = 0.46$, $p = .005$). For adolescents in the comparison group, a moderate, inverse relationship between age and total difficulties experienced at Time 1 ($r = -0.42$, $p = .005$). No other statistically significant relationships were identified.

Adolescent reports relative to gender. To assess the nature of the relationship between adolescent gender and self-reported emotional, behavioural and social functioning at Time 1 and Time 2, Pearson's product-moment correlation statistics were calculated for both groups (Table 5). Gender coding resulted in positive correlation coefficients indicating a relationship between variables and males.

For adolescents with mTBI, a positive relationship approaching moderate strength, between gender and self-reported school problems 24-months post-injury ($r = 0.45$, $p = .004$), with males reporting higher levels of dissatisfaction. For adolescents in the comparison group, a weak, inverse relationship between gender and emotional symptoms was found at Time 2 ($r = -0.34$, $p = .024$), with females reporting higher levels of emotional symptoms.

Table 4. Correlations between adolescent age and self-reports of emotional, behavioural and social functioning in adolescents with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
BASC-2												
Emotional Symptoms	36	0.11	0.52	40	-0.11	0.51	46	0.06	0.69	42	0.04	0.80
School Problems	36	0.40	0.016*	40	0.33	0.039*	46	-0.06	0.70	42	-0.20	0.20
Internalising Behaviours	36	0.17	0.31	40	-0.07	0.66	46	-0.04	0.81	42	-0.11	0.49
Inattention / Hyperactivity	36	0.46	0.005**	40	0.16	0.32	46	-0.02	0.91	42	-0.19	0.22
Personal Adjustment	36	-0.08	0.66	40	0.14	0.38	46	-0.07	0.64	42	-0.20	0.90
SDQ												
Total Difficulties	27	-0.11	0.60	39	0.04	0.82	40	-0.42	0.005**	43	-0.03	0.86
Difficulties Impact	27	0.15	0.47	38	0.10	0.54	40	-0.28	0.07	42	-0.16	0.30

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, BASC-2 and SF-36 test scores are age standardised.

Table 5. Correlations between adolescent gender and self-reports of emotional, behavioural and social functioning in adolescents with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
BASC-2												
Emotional Symptoms	37	-0.06	0.71	40	-0.08	0.62	46	-0.16	0.28	43	-0.34	0.024*
School Problems	37	0.26	0.12	40	0.45	0.004**	46	0.04	0.78	43	-0.15	0.32
Internalising Behaviours	37	-0.01	0.96	40	0.01	0.96	46	-0.07	0.66	43	-0.21	0.17
Inattention / Hyperactivity	37	0.02	0.90	40	0.00	0.99	46	-0.08	0.59	43	-0.29	0.06
Personal Adjustment	37	0.01	0.98	40	0.07	0.67	46	0.02	0.91	43	0.34	0.024*
SDQ												
Total Difficulties	27	0.10	0.63	39	-0.03	0.85	47	-0.07	0.65	44	-0.07	0.64
Difficulties Impact	27	-0.09	0.66	38	-0.09	0.57	47	0.17	0.24	43	0.19	0.23

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1

Also at Time 2, a weak, positive relationship between gender and personal adjustment was identified ($r = 0.34$, $p = .024$), with males reporting lower levels of personal adjustment. No other statistically significant relationships were identified.

Caregiver reports and the effects of time and group membership. To assess the impact of group membership and time since injury on caregiver perceptions of adolescent behavioural, emotional and social functioning, further 2 (group: mTBI and comparison) by 2 (time: 12-months and 24-months post-injury equivalent) mixed measures ANOVA were conducted (Table 6).

Results indicated that group membership had a significant effect on caregiver ratings of adolescent externalizing and internalizing behaviours, with caregivers of injured adolescents reporting significantly higher levels of externalising behaviours and internalising behaviours than caregivers in the comparison group. Effect size statistics (externalising behaviours $p = .003$, $\eta^2 = 0.13$, internalising behaviours $p = .041$, $\eta^2 = 0.06$), indicated these differences were of small practical significance. No significant effects of time or interactions were found for adolescent measures.

Caregiver reports relative to adolescent age. Pearson's product-moment correlation statistics were calculated to examine the nature of the relationship between adolescent age and caregiver ratings of adolescent functioning for both groups (Table 7). For adolescents with mTBI, a weak, inverse relationship was identified between adolescent age and total difficulties 24-month post-injury ($r = -0.33$, $p = .034$). For adolescents in the comparison group, a weak, inverse relationship was identified between adolescent age and caregiver reports of internalising behaviours at Time 1 ($r = -0.39$, $p = .008$) and Time 2 ($r = -0.35$, $p = .024$), with caregivers reporting reduced levels of problematic behaviours in older individuals. No other significant relationships were evident.

Table 6. Strengths and Difficulties Questionnaire (SDQ) and Behavioral Assessment for Children (BASC-2): Analysis of variance in caregiver reports of emotional, behavioural and social functioning in adolescents with and without mTBI.

Variable	mTBI (n = 28)		Comparison (n = 39)		Main effects									
	T1	T2	T1	T2	Time			Group			Interactions			
	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2	
BASC-2														
Externalising Behaviours	53.75 (10.38)	54.21 (12.58)	47.03 (5.98)	47.44 (8.10)	0.34	0.57	0.01	9.83	0.003**	0.13	0.00	0.97	0.00	
Internalising Behaviours	52.89 (10.54)	51.54 (13.97)	47.38 (11.45)	46.21 (8.97)	1.67	0.20	0.03	4.36	0.041*	0.06	0.01	0.93	0.00	
Problem Behaviours	53.54 (11.49)	52.96 (12.84)	48.49 (8.32)	49.00 (10.02)	0.00	0.97	0.00	3.32	0.07	0.05	0.38	0.54	0.01	
Adaptive Skills	48.18 (10.89)	48.00 (12.88)	51.87 (7.42)	50.85 (10.01)	0.59	0.45	0.01	1.84	0.18	0.03	0.29	0.59	0.00	
SDQ														
Total Difficulties	10.14 (7.39)	9.29 (7.66)	6.87 (5.52)	7.26 (5.69)	0.31	0.58	0.01	2.94	0.09	0.04	2.11	0.15	0.03	
Difficulties Impact	1.14 (2.03)	1.32 (2.29)	0.49 (1.10)	0.56 (1.21)	0.61	0.44	0.01	3.54	0.06	0.05	0.10	0.76	0.00	

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table 7. Correlations between adolescent age and caregiver ratings of adolescent emotional, behavioural and social functioning in adolescents with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
BASC-2												
Externalising Behaviours	39	0.07	0.68	40	-0.10	0.54	46	-0.23	0.12	42	-0.15	0.34
Internalising Behaviours	39	-0.10	0.52	40	-0.29	0.07	46	-0.39	0.008**	42	-0.35	0.024*
Problem Behaviours	39	-0.16	0.34	40	-0.17	0.28	46	-0.15	0.33	42	-0.11	0.50
Adaptive Skills	38	0.10	0.55	40	0.03	0.88	46	0.07	0.64	42	0.05	0.76
SDQ												
Total Difficulties	41	-0.24	0.13	41	-0.33	0.034*	44	-0.22	0.16	40	-0.17	0.31
Difficulties Impact	41	-0.21	0.19	41	-0.26	0.10	44	0.04	0.81	40	0.01	0.94

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, BASC-2 and SF-36 test scores are age standardised.

Caregiver reports relative to adolescent gender. Pearson's product-moment correlation statistics were then calculated to assess the relationship between adolescent gender and caregiver perceptions of adolescent functioning for both groups. (Table 8). For adolescents in the comparison group a statistically significant, positive relationship approaching moderate strength, was identified between adolescent gender and externalising behaviours at Time 1 ($r = 0.45$, $p = .002$), with caregivers reporting higher levels of externalising behaviour in adolescent males. No other statistically significant relationships were found between any of the variables of interest for either group at either time point.

Caregiver experiences

Caregiver experiences and the effects of time and group membership. The impact of group membership and time on caregiver self-reported HRQoL (related to physical and mental health), mood (symptoms of anxiety and depression), and caregiver outcomes and impacts were assessed using a series of 2 (group: mTBI and comparison) by 2 (time: 12-months and 24-months post-injury equivalent) mixed measures ANOVA (Table 9). Analyses identified a significant interaction between group membership and time since injury for caregiver outcomes.

Analysis of group means identified that, over time, caregivers of adolescents with mTBI reported improved caregiver outcomes, while caregivers of non-injured adolescents reported worsening outcomes. Effect size statistics ($p = .001$, $\eta^2 = 0.19$) indicated that the practical impact of this interaction was small. No other statistically significant effects or interactions were identified.

Table 8. Correlations between adolescent gender and caregiver ratings of adolescent emotional, behavioural and social functioning in adolescents with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
BASC-2												
Externalising Behaviours	39	0.17	0.29	40	0.19	0.24	46	0.45	0.002*	47	0.25	0.10
Internalising Behaviours	39	-0.26	0.11	40	-0.22	0.18	46	0.05	0.74	47	-0.03	0.85
Problem Behaviours	39	-0.17	0.31	40	-0.03	0.84	46	0.26	0.08	47	0.18	0.23
Adaptive Skills	38	0.04	0.82	40	-0.05	0.76	46	-0.17	0.27	47	-0.23	0.11
SDQ												
Total Difficulties	41	-0.07	0.67	41	-0.08	0.64	53	0.21	0.13	45	0.14	0.36
Difficulties Impact	41	-0.29	0.07	41	-0.08	0.63	53	0.25	0.07	45	0.21	0.16

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1

Table 9. RAND Short Form 36 Health Survey (SF-36 v2), Hospital Anxiety and Depression Scale (HADS) and Bakas Caregiving Outcomes Scale (BCOS): Analysis of variance in caregiver self-reported quality of life related to physical and mental health, symptoms of anxiety and depression and reported outcomes and impacts of caregiving for adolescents with and without mTBI.

Variable	mTBI (n = 26)		Comparison (n = 39)		Main effects								
	T1	T2	T1	T2	Time			Group			Interactions		
	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2	F	<i>p</i>	partial η^2
SF-36 v2													
Overall Physical Health	79.82 (17.89)	84.53 (18.45)	81.99 (18.65)	84.11 (14.14)	2.63	0.11	0.05	0.04	0.83	0.00	0.38	0.54	0.01
Overall Mental Health	80.32 (14.74)	82.53 (11.52)	82.46 (9.55)	79.47 (13.34)	0.03	0.87	0.00	0.01	0.91	0.00	2.32	0.13	0.04
HADS													
Anxiety	4.00 (2.93)	3.65 (3.23)	3.89 (2.18)	3.64 (2.45)	0.92	0.34	0.02	0.00	0.99	0.00	0.08	0.78	0.00
Depressive Symptoms	1.91 (1.85)	1.68 (1.59)	1.67 (2.54)	2.19 (2.87)	0.31	0.58	0.01	0.05	0.82	0.00	1.97	0.17	0.03
BCOS													
Outcomes	62.14 (6.96)	69.86 (11.71)	67.03 (11.13)	64.72 (9.04)	3.93	0.05	0.07	0.00	0.96	0.00	13.44	0.001***	0.19
Change	4.23 (0.69)	4.59 (1.10)	4.64 (1.05)	4.53 (0.81)	0.69	0.41	0.01	0.76	0.39	0.01	2.44	0.12	0.04

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Caregiver experiences relative to adolescent age. To assess the nature of the relationship between adolescent age and caregiver reports of their HRQoL, mood (anxiety and depression) and caregiving outcomes and impacts, Pearson's product-moment correlation statistics were calculated for both groups (Table 10). No statistically significant relationships were found between any of the variables of interest for either group at either time point.

Table 10. Correlations between adolescent age and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety and depression and outcomes and impacts of caregiving for adolescent with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
SF-36 v2												
QoL - Physical Health	36	0.27	0.11	41	0.28	0.08	44	0.21	0.16	47	0.19	0.20
QoL - Mental Health	37	-0.07	0.69	41	0.20	0.22	44	0.09	0.55	47	0.26	0.08
HADS												
Anxiety	38	-0.04	0.82	41	-0.13	0.48	44	-0.08	0.59	47	-0.08	0.58
Depressive Symptoms	38	-0.10	0.56	41	-0.22	0.16	44	-0.09	0.57	47	-0.19	0.21
BCOS												
Outcomes	33	0.06	0.73	42	0.09	0.57	42	0.11	0.48	47	-0.25	0.09
Change	33	0.07	0.69	42	-0.04	0.79	42	0.01	0.98	47	-0.22	0.13

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Caregiver experiences relative to adolescent gender. To assess the nature of the relationship between adolescent gender and caregiver reports of their HRQoL, mood and caregiving outcomes and impacts, Pearson's product-moment correlation statistics were calculated for both groups (Table 11). No statistically significant relationships were found between any of the variables of interest for either group at either time point.

Table 11. Correlations between adolescent gender and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety and depression and outcomes and impacts of caregiving for adolescents with and without mTBI.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
SF-36 v2												
QoL - Physical Health	36	0.02	0.90	42	0.07	0.67	49	0.20	0.18	47	-0.04	0.80
QoL - Mental Health	37	-0.04	0.81	42	-0.28	0.08	49	0.03	0.82	47	-0.16	0.28
HADS												
Anxiety	39	0.28	0.09	41	0.08	0.64	44	-0.01	0.96	48	0.13	0.37
Depressive Symptoms	39	0.11	0.50	41	0.18	0.25	44	-0.01	0.96	48	0.08	0.60
BCOS												
Outcomes	33	0.14	0.45	42	-0.07	0.64	42	-0.11	0.49	48	-0.04	0.78
Change	33	0.11	0.55	43	0.03	0.85	43	-0.07	0.64	48	0.12	0.43

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1

Caregiver experiences relative to health, mood and adolescent factors.

Given the limitations of sample size and variable type (Tabachnick, & Fidell, 2001), Pearson's product moment correlations were used to explore the relationship between caregiver outcomes (i.e. of burden or gain as measured by BCOS), group membership, adolescent age and behaviours (internalising and externalising behaviours as measured by BASC), and caregiver health (HRQoL related to physical and mental health as measured by SF36), and mood (symptoms of anxiety and depression as measured by HADS), at Time 1 and Time 2.

At Time 1, significant, inverse, weak relationships were evident between caregiver outcomes and group membership ($r = -0.35$, $p = .002$), and between caregiver outcomes and adolescent internalising behaviours ($r = -0.41$, $p < .001$). Also identified was a significant positive, weak relationship with caregiver outcomes and QoL related to mental health ($r = -0.27$, $p = .023$). No other statistically significant relationships were found at this time-point.

At Time 2, no statistically significant relationships were found between caregiver outcomes and the variables considered (Table 12).

Table 12. Correlations between caregiver outcomes (BCOS) and variables hypothesised to influence caregiver outcomes.

Variable	Time 1				Time 2			
	n	r	p	M(SD)	n	r	p	M(SD)
Group	75	-0.35	0.002**	1.50 (0.50)	90	0.04	0.72	1.50 (0.50)
Adolescent Age	75	0.10	0.39	13.57 (2.03)	89	-0.06	0.57	14.71 (2.19)
Adolescent Internalising Behaviours	72	-0.41	< .001***	49.33 (11.47)	87	-0.12	0.29	47.62 (10.70)
Adolescent Externalising Behaviours	72	-0.03	0.82	49.69 (8.72)	87	0.00	0.97	49.61 (9.80)
Caregiver HRQoL - Physical	71	0.07	0.55	83.85 (17.87)	88	0.08	0.43	84.20 (17.48)
Caregiver HRQoL - Mental	86	0.27	0.023*	80.82 (16.94)	88	0.13	0.23	80.11 (15.55)
Caregiver Mood - Anxiety	83	-0.03	0.82	3.86 (3.27)	89	-0.08	0.44	3.69 (2.83)
Caregiver Mood - Depression	83	-0.20	0.10	1.69 (2.35)	89	-0.11	0.31	2.09 (2.68)

Note * $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

Phase one aimed to identify how providing care for adolescents with mTBI was associated with caregivers' perceptions of their quality of life, mood and experiences of caregiver burden and gain 12 and 24 months post injury. Quantitative approaches were used to explore the hypothesis that (a) the experiences of caregivers of adolescents with traumatic brain injuries would be positive; with (b) similar perceptions of quality of life, mood, and caregiver outcomes to those of a caregivers of adolescents without mTBI in a matched comparison group. The relationships between caregiving outcomes and the existence of injury, increasing adolescent age (as an indicator of adolescent cognitive, behavioural and social development), gender and functioning along with caregiver quality of life and mood were also explored to determine how these variables were associated with caregiving outcomes in the current cohort. It was hypothesised that the existence of injury, adolescent age and behaviours would have the strongest relationship with caregiver outcomes.

As anticipated, at both 12 and 24 months after injury, caregivers of injured adolescents reported positive mood and quality of life in the ‘normal’ range. They also reported predominant gains from their caregiving activities. On average, caregivers of adolescents with mTBI rated their QoL related to physical health and mental health (as measured by the SF-36), consistently higher (better) than the general New Zealand population (Scott, et al., 1999). Similarly, ratings of mood (as measured by the HADS) were in the ‘normal’ range (Crawford, Henry, Crombie, & Taylor, 2001). Caregivers in the comparison group reported similarly positive HRQoL, mood and caregiver outcomes.

Unexpectedly, despite being universally positive at both time points, caregiver outcomes differed between the two groups. For caregivers caring for adolescents with mTBI, caregiver outcomes became progressively more positive as time since injury elapsed. Conversely, progressively fewer caregiving gains were reported by caregivers in the comparison group, although experiences remained in the positive range. Similarly, two years after injury, caregivers of adolescents with mTBI experienced *improving* HRQoL related to their physical health with increasing adolescent age. This relationship was not evident for caregivers in the comparison group.

Analysis of selected caregiver health and adolescent variables implicated in caregiver outcomes, identified three factors related to caregiving outcomes 12-months after mTBI. As hypothesised, significant relationships existed between adolescent internalising behaviours (social withdrawal, dependency and somatization) and caregiver outcomes, and between group membership and caregiver outcomes. However, adolescent age was not found to be significantly related to caregiver experiences. Rather, a significant relationship was found

between enhancing caregiver outcomes and enhancements in caregivers' QoL related to their mental health. Two years post-injury, no relationships existed between these or other variables considered and caregiver outcomes.

Caregiver characteristics. Few differences were found between the caregiver groups studied. However, aligned with more general analysis of caregiving in New Zealand (Infometrics, 2014), caregivers of adolescents with prior mTBI were more likely to identify as Māori, were younger on average than those in the comparison group, and were less likely to be in a formalised relationship. Also consistent with previous analysis, caregivers in both groups were predominantly female (Statistics NZ, 2015).

As previously identified (Department of Labour, 2011), the two groups of caregivers had comparable educational and occupational backgrounds, and worked a similar number of paid hours. However, given that caregivers of adolescents with mTBI were less likely to be in a formalised relationships (and therefore possibly more likely to be in single adult/income house-holds), they may have fewer financial resources available to them.

The moderate practical significance associated with these differences suggests that for caregivers of adolescents with mTBI, psychosocial and socio-economic factors may play a greater role in their caregiving experiences. Accordingly, recognising and accommodating such differences are valuable considerations for those seeking to share information and intervention strategies with this cohort. Additionally, the likelihood that caregivers of injured adolescents may have access to fewer practical and emotional supports on a daily basis than caregivers of adolescents without mTBI should be taken into account

by medical services, schools and other parties involved in the provision of, or seeking to provide, support.

Adolescent functioning. Overall, few differences in adolescent behaviours, emotions and their relationships with others were noted between the two groups. Average social, emotional and behavioural functioning, as perceived by both caregivers and adolescents, fell within the “normal range” of measures at both time points. This is consistent with previous research concluding that the impacts of mTBI are minimal while enduring adverse impacts of are uncommon (Carroll, et al., 2004).

Within this overall picture, group differences were apparent. Caregivers of injured youth reported higher rates of externalising behaviours than caregivers in the comparison group. These elevated levels are consistent with previous findings of a modest increase in such behaviours following injury (Max, et al., 2001). This is reinforced by the lack of elevated rates of such behaviours two years following injury.

Reports of higher rates of externalising behaviours in injured youth may also reflect pre-existing patterns of behaviour and parenting factors contributing to their behaviour following injury (Woods, et al., 2013). Specifically, injured youth may have exhibited modestly higher rates of disruptive or problematic behaviour prior to their mTBI. This explanation highlights the role of prior behavioural tendencies as a predisposing factor for the future incidence of mTBI (Light, et al., 1998) as well as being a factor in post-injury outcomes. Contributing to such behavioural tendencies may be a particular sensitivity to the emotional extremes of adolescence and initially poorer emotional control (Hill, et al., 2000; Kuhn, 2015). Caregiving style in response to the injury may also be a factor in

differences in adolescent behaviours in the 12 months following injury (Crosswhite, et al, 2009; Dekovic, et al, 2003).

Given the potential for these factors (i.e. parenting style, prior behavioural tendencies), to be interrelated (Woods, et al., 2013), further research into the risk-taking profile and caregiver perceptions of emotional social and behavioural functioning of individuals before and after the adolescent period is needed to substantiate this view.

Caregivers of injured youth reported also higher rates of internalising behaviours than caregivers in the comparison group. These higher rate of internalising behaviours (social withdrawal, dependency and somatization), are also consistent with previously observed impacts of mTBI (Peterson, et al., 2013; Max, et al., 2012). While pre-existing and parenting differences may also be present, given the mild nature of injuries, the increase may also reflect the increased physical and emotional dependency of adolescents recovering from the physical and psychological effects of an unexpected acute trauma.

A further difference between the two groups noted by caregivers was the different patterns in the relationship between emotional and behavioural functioning and adolescent age. Caregivers in the comparison group, observed a decrease in problematic internalising behaviours at Time 1 and at Time 2. However, caregivers of adolescents with mTBI did not perceive decreases in problematic emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems (total difficulties) until two years after injury.

The apparent “delay” in reductions in total difficulties is contrary to current expectations that mTBI has few and quickly resolving physical and cognitive impacts (Carroll, et al., 2004; Hesse, 2010). Considering the role of

experience and practice in the development of adolescent capabilities (Janacsek, et al., 2012; Zatorre, et al., 2012), this suggests that experiencing a mTBI, temporarily disrupts this developmental process. The decrease in total difficulties two years following injury reiterates previous findings that despite the possible existence of such propensities, individuals sustaining mTBI ultimately resume an appropriate developmental trajectory (Babikian & Asarnow, 2009).

If such a disruption does occur, it does not appear to apply to all aspects of functioning. Both caregiver groups perceived decreases in problematic behaviours (with age consistent with typical adolescent development. Specifically, the increasing capability for cognitive and emotional control (Nelson, et al., 2005; Steinberg, 2010) occurring as a result of neural maturation (Ladouceur, et al., 2012). It is notable that, despite the age standardised scores used, meaningful decreases were found possibly reflecting the use of non-New Zealand norms.

Caregiving experiences. Few group differences were identified in caregiver HRQoL, mood and caregiving outcomes. For both caregiver cohorts, average QoL and mood measures at all time points were in the ‘normal’ range where this was applicable. Similarly, caregiver outcome scores and perceptions of change due to caregiving in both groups indicated predominantly positive experiences.

Within this overall picture, the outcomes of caregiving differed between the two groups. Caregivers of adolescents with mTBI reported enhanced outcomes as time since injury increased, while caregivers of non-injured adolescents reported fewer gains from caregiving between Time 1 and Time 2. Additionally, two years post-injury caregivers of injured adolescents reported

higher levels of quality of life related to their physical health compared with twelve months prior as adolescents aged. No significant change in HRQoL related to physical health was reported by caregivers in the comparison group.

These group differences can be explained by a positive model of caregiving (Carbonneau, et al., 2010). Such models are underpinned by the concepts of benefit finding and traumatic growth which hold that psychological growth is experienced as a result of effectively responding to adversity and other challenges. (Bowers, et al., 2008). Improvements in physical health and overall outcomes are seen as resulting from the combination of compensatory factors inherent to the act of caregiving. These include: opportunities for feelings of self-efficacy which lead to a more positive focus (Stephens, Kinney, Franks, & Norris, 1990); better utilisation of coping strategies in order to effectively respond to adversity (Steffen, et al., 2002); as well as improvements in the relationship arising from opportunities for closeness and expressions of gratitude (Fortinsky, Kercher, & Burant, 2002). Ultimately, experiencing traumatic events can generate gratitude and a more appreciative philosophical and accepting outlook (Helgeson, 2004).

The injury of a child, uncertainty of injury outcomes, and increased expectations of care are traumatic and challenging experiences for caregivers, as well as adolescents (Aitken, et al., 2009). However, this shared adversity provides an opportunity to foster enhanced relationships in a period typified by the changing relationships arising from an increased adolescent drive for independence. Additionally, it is possible that feelings of usefulness and purpose inherent in the parenting role are transferred to the role of caregiver in the event of injury, enabling caregivers to make sense of their experiences thereby enhancing

their self-esteem, and physical and mental wellbeing. Finally, injury during adolescence, as at other times and for other caregiver-care-recipient dyads, provides caregivers with an opportunity to test their personal strength and resourcefulness generating an enhanced sense of self-efficacy. Consequently, the act of providing care following adolescent mTBI leads to enhanced perceptions of QoL.

Given the transitory nature of injury sequelae and absence of impact to caregivers' mood/psychological health this benefit appears to be focussed on their physical health. Collectively, these mechanisms contribute to improved outcomes overall, i.e. enhanced social functioning, physical health, and subjective well-being, financial well-being, levels of energy, role and physical functioning and perceptions of general health.

Also, contributing to these differences in caregiver outcomes may be inherent differences between the two groups. Specifically, given their younger average age, parents of injured adolescents may employ a different caregiving style or have greater personal resilience as a group. Further research is required to substantiate the existence of differences in caregiving and their influence on adolescent behaviours following acute injury events such as mTBI.

Despite recognised differences in the developmental trajectory (Giedd, et al., 2012) and behaviours of adolescent males and females (Ruigrok, et al., 2014), and the gender differences in the expression of mTBI impact (Bazarian, et al., 2010) for the current cohort, adolescent age and gender did not influence caregiving outcomes. This reiterates the generally minimal and transient nature of mTBI impacts but also suggests that caregiver's prior understanding and

expectations of their child enables them to anticipate and effectively accommodate such age and gender differences.

Of all the potential determinants of caregiver outcomes considered by this study, adolescent internalising behaviours were found to be most influential. Higher rates of such behaviours were most strongly associated with reductions in positive caregiver experiences, with caregivers perceiving the highest rate of internalising behaviours in adolescents with mTBI.

The identified relationship between adolescent internalising behaviours and reduced caregiver outcomes one year after injury, suggests that reducing such behaviours may lead to improved caregiver outcomes. Given the established link between caregiver coping and recovery and adaption following injury (Anderson, et al., 2005), strategies might include: providing information adolescents and caregivers to make them more aware of what internalising behaviours are and how they might be expressed. Equally, providing caregivers with more effective parenting so that they can actively manage such behaviours or avoid inadvertently contributing to them may prove beneficial.

The association between enhanced caregiver outcomes and improvements in HRQoL are also consistent with a positive view of caregiving. Specifically, the quality of the daily relationship, role meaning and feelings of accomplishment arising from effectively coping with an injury event (Carbonneau, et al., 2010). While further research are needed to explore this relationship, supporting caregivers' psychological well-being may enhance their ability to effectively cope. This might include reinforcing the importance of self-care and providing opportunities to interact with others in similar situations, reinforcing the value of their role, and provide opportunities to reinforce their sense of self-efficacy.

The lack of an identified relationship between any of these factors (adolescent internalising behaviours, group membership, caregivers HRQoL) and caregiver outcomes two years following injury (or any significant relationship between other potential determinants of caregiver outcomes), reiterates the transient and minimal impact of mTBI (Cassidy, et al., 2004; Hessen, et al., 2007). It suggests that two years after injury adolescent cognitive, social, emotional capabilities and behaviours have resumed an expected developmental trajectory and that caregivers perceive that their role has returned to “parenting as usual”. Alternatively, it may suggest that two years following injury adolescents and their carers have successfully implemented any necessary accommodations and adjustments and any changes in parenting have become normalised within the family. The impact of maturing adolescent social, emotional, psychological and behavioural capabilities should also be considered. Again, this possible explanation would benefit from further statistical analysis permitted by a larger study sample.

The sample size of the current study did not permit more sophisticated analysis (i.e. hierarchical multiple regression) of the relationship between caregiving outcomes and adolescent and caregiver factors (Tabachnick, & Fidell, 1996). Consequently, an investigation of the role of adolescent internalising behaviours in caregiver experiences would appear to be a promising target for future studies.

Measures. The measures used to gather information about caregivers’ quality of life (SF36), caregiving experiences (BCOS), and adolescent functioning (SDQ) were determined by the source studies and were relevant to the purposes of those studies. However, the application of some of these measures to the

examination of the experiences of parents providing care following sub-acute injury is limited in some respects.

As a well-established measure of caregiving outcomes, particularly for those providing care to older family members post-stroke, the BCOS is not ideally suited to capturing the experiences of parent caregivers. Particularly, sub-acute injuries with few impacts which are expected to quickly resolve. Alternative measures of family caregiving such as the Pediatric Inventory for Parents (PIP) (Streisand, Braniecki, Tercyak, & Kazak, 2001), may be worthy of consideration. While more limited in scope than the BCOS and without New Zealand norms, the PIP provides an index of parental distress associated with sub-acute childhood disease and illness (Lewin, Storch, Silverstein, Baumeister, Starwser, & Geffken, 2005). Given that parents currently (and are increasingly likely to), provide care to their children in the event of sub-acute injuries, this more specific approach may enhance future similar studies.

The SF36 is also a well-established measure, and has been extensively used in the general population to measure QoL. Of further benefit is the existence of New Zealand based norms. However, the authors of the SF36 stress the importance of ensuring that up to date norms are used to interpret scores (Hays, et al., 1993). Similarly, differences in the response of ethnic minority populations have been noted (Scott, et al., 1999). Given the changing demographics of the population in the fifteen-plus years since New Zealand norms were first established, results should be interpreted with these potential limitations in mind.

The current study used American-based norms for the SDQ, limiting the conclusions of analysis. However, New Zealand norms have now been produced for the SDQ (Kersten, Vandal, McPherson, Elder, Naybar, & Dudley, 2015). Using

these recently available norms would help to enhance the relevance of findings for New Zealand populations.

Finally, the measures used in the current study were part of a battery of questionnaires and testing activities completed by participants. While this typically took place over two sessions and measures were consistent across all participants, individual differences in personality and mental health have been found to generate variation in subjective fatigue and subsequent performance (Ackerman, & Kanfer, 2009). Consequently, the differential impacts of fatigue may have influenced participant responses. Such effects may interact with general perceptions of burden or gain and should be taken into account when interpreting findings.

Overall the current study found that regardless of the presence of injury, the experience of those caring for adolescents was typically positive. However, subtle differences in the experiences of the two groups were identified. Firstly carers of injured youth are demographically distinct from parents or similarly aged children in general. The adolescents they care for may possess pre-existing differences, distinguishing their needs from others adolescent groups as well as increasing the risk of injury. Further study of the significance and mechanisms of these differences may provide further opportunities to support carers and enhance the outcomes of injured adolescents.

Parents of adolescents unexpectedly thrust into a caregiving role by acute injury, attract additional benefits over and above those gained from parenting “as usual”. Consequently, the experience of caregivers caring for their adolescent children following mTBI appears to be more closely aligned with positive models of caregiving, under pinned by the concepts of benefit finding and traumatic

growth (Carbonneau, et al., 2010; Bowers, et al., 2008). However, the potentially negative influence of increased adolescent dependency, social withdrawal and somatization on caregiver experiences during the first year following injury appear to be better explained by a burden model of caregiving. Reconciling these inconsistency into a comprehensive, balanced view would be a valuable step in more fully understanding the experience of carers and of caregiving.

The finding of phase one suggest not only that the anecdotally negative view of the adolescent period may not be justified, but that caring as a result of injury is more accurately viewed as an opportunity for strengthening carers social, emotional and physical health. Phase two of the current study aimed to explore the experiences caregivers of adolescents with mTBI in order to achieve better understanding the factors contributing to caregiver outcomes as they are expressed in carers' day-to day lives.

“It's made me more aware of how a simple thing, a simple head injury could happen. You don't actually realize that it can just be a part of your family tomorrow. You really have no idea...the fact that things can happen so quickly, and you're thrown into that role so quickly.”

(Female, 50 years, caring for female, 15 years).

Chapter Four – Phase Two

Phase two built on phase one by qualitatively examining the experiences of caregivers caring for adolescents with prior mTBI. It focussed on exploring the question “what are the experiences of caregivers caring for adolescents following mild traumatic brain injury?” This question sought to understand caregivers’ lived experiences and the realities of their daily lives as carers. It also aimed to identify commonalities and differences within the individual experiences of mTBI carers, and to tease out the nature of their expectations and perceptions of adolescent behaviours. Finally, phase two intended to further assess how the experiences of those caring for adolescents following mTBI aligned with current models of caregiving burden and gain.

Analytic Approach

Consistent with a pragmatic research paradigm, qualitative analysis was selected to expand on quantitative findings obtained in phase one. Given the focus in phase two of accurately capturing the lived experiences of caregivers, a qualitative descriptive methodology and thematic analysis approach were selected as ideally suited to addressing the research questions concerning individuals’ experiences, views and perceptions (Joffe, 2011).

A qualitative descriptive methodology seeks to derive a “comprehensive summarisation, in everyday terms, of specific events experienced by individuals or groups of individuals” (Lambert, & Lambert, 2012, p. 255). The methodology is typically used to explore understudied events and frequently uses interviews and methods of content analysis to capture and interpret information (Thorne, 2008). By being atheoretical and minimally interpretive, a qualitative descriptive

methodology helps to ensure descriptive validity and is considered optimally suited to generating unbiased descriptions of common events (Sandelowski, 2000; Sandelowski, 2010).

Consistent with this methodological approach, thematic analysis (TA) is a widely used, theoretically flexible approach used to identifying, analysing and reporting patterns (themes) within qualitative data in psychological research (Alhojailan, 2012). An additional advantage, given the researchers' inexperience in conducting qualitative research, was the methodology's relative accessibility (Braun, & Clarke, 2014).

A TA approach requires users to make a series of decisions about how the technique will be applied (Braun, & Clarke, 2006). In the current study a semantic, deductive (theory-driven) approach was chosen as the best way to directly respond to the research question using the whole data set within the scope permitted by this thesis.

Information for thematic analysis was gathered using semi-structured interviews. Semi-structured interviews are a commonly used qualitative research methodology designed to collect detailed information from a specific population. They have been found to generate reliable and comparable qualitative material for analysis (DiCicco-Bloom, & Crabtree, 2006). The relaxed, conversational style of the semi-structured interview is ideally suited to eliciting a greater breadth and depth of information about individuals' perceptions of complex and nuanced issues in their own terms (Warren, & Karner, 2005).

Qualitative approaches are frequently criticised for their lack of rigour (Mays, & Pope, 1995; Rolfe, 2006). To achieve rigour in phase two, the research design was consciously and systematically considered from the outset. To ensure

the reliability and replicability of research results, all interviews were recorded and summaries were reviewed with participants, data collection methods were described in detail, and the product of each stage of the analysis process was electronically recorded. Finally, the results of data analysis and the communication of subsequent conclusions were reviewed with colleagues to ensure accuracy and comprehensibility. Throughout phase two, emphasis was placed on ensuring a valid, justifiable and objective interpretation of the information gathered to produce a credible and appreciable account of caregivers' experiences.

Method

As suggested by Braun and Clarke (2006), a six-phase approach was used to identify, analyse and report themes within the data. This involved: familiarisation with the data, the generation of initial topic categories, the sorting of categories into themes, the review and refinement of themes, the definition of themes, and a final analysis.

Familiarity with the data was initially achieved through the process of review, playback and rechecking necessary to generate accurate verbatim transcripts for each interview. Transcript data was then read and re-read in order to become immersed in and intimately familiar with each caregiver's stated experiences. Individual transcripts were then reviewed in detail to identify patterns in the frequency of word or concept use. At this point, initial ideas about data content and consistencies with current models of caregiving were noted on the transcript (or whatever the process) ensuring each line of text was explored.

From this initial appraisal, code labels were generated. These were intended to succinctly highlight features of the data that appeared to respond to

the research question. Using this list of codes as a starting point, the initial topic categories were allocated to transcript passages. All transcripts were first coded individually, then crosschecked to ensure consistent application, adding codes or recoding as necessary. Coding and analysis was directed by existing models and concepts (deductive) and reflected the explicit content of the data (semantic). NVivo qualitative data analysis software (QSR International, 2012) was used to store transcripts as well as assign and organise initial topic categories.

The codes were then examined and collated to identify broader patterns of meaning. Next, codes were grouped into related themes using a visual mind map generated using XMind 6 version 3.5.1 for Mac (XMind Limited, 2014), a mind-mapping and brainstorming software programme. At this point, the interrelationships between the emerging themes were considered to determine the best way to organise themes in relation to each other and to identify potential subthemes. Codes that did not appear fit within the emerging thematic structure were set aside for subsequent analysis.

Following this, identified themes were reviewed against each transcript to ensure that they accurately reflected the data collected. This resulted in some identified themes being refined and a new theme being created to better accommodate aspects of the data that weren't accurately captured. The use of XMind facilitated this time consuming process. XMind was also used to populate a thematic map with data extracts supporting each category and associated theme. The resulting visual representation supported the ready refinement and reorganisation of data until the most descriptive and succinct fit was achieved.

Using the thematic map and supporting data extracts, information within each theme was independently assessed for coherence. The thematic structure as

a whole was also independently assessed. Previously discarded coded extracts were reconsidered and re-incorporated as appropriate. The essential quality of each theme was then described in detail and names for each theme were created which sought to capture the essence of this description.

While discussed here sequentially, the process followed to achieve the final thematic structure was highly iterative.

Participant Recruitment.

After reviewing BIONIC4you study participant records, 21 carers of adolescents aged 13.0 – 15.11 years between 1 October 2014 and 28 February 2015 (inclusive) who had a TBI four years ago were identified. While narrower than the age range used in phase one of the current study, this range provided a manageable number of participants who were all likely to have reached adolescence and be experiencing similar schooling structures. Of the initial 21 participants identified, one was no longer resident in the Hamilton/Waikato region, one did not consent to contact regarding additional studies and one had sustained a TBI of a severity greater than mild (Figure 6).

Two weeks after the BIONIC4you assessments, these 18 potential participants were posted an information sheet and invitation to participate in the current study (Appendix D). One week after posting, caregivers were telephoned, reintroduced to the study and asked whether they were interested in taking part. Where interest was shown, an appointment made to conduct an interview at a mutually convenient time and location.

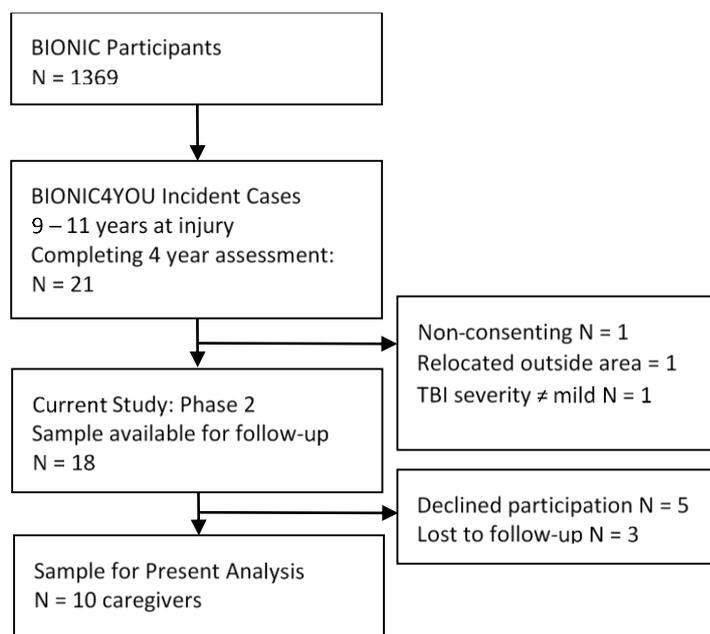


Figure 6: Summary of initial sample of eligible BIONIC4you participants included in the current study.

Consequently, participants in the current study represent a subsample of all eligible participants within a specified time-frame. Initially a means of ensuring completion of the current study within specified parameters, the practical need for using a time-frame for sampling was balanced by the aim of including a wide range of experiences to ensure relevance (Sandelowski, 2007). As a result, the time-frame for inclusion was periodically reviewed and progressively extended until no new concepts were apparent in participant accounts. The inclusion of all consenting participants within this time-frame helped to ensure the representativeness of participants and the validity of findings.

Of the 18 potential participants approached, ten (53%) consented to be interviewed for the current study, five (28%) did not wish to participate and three (17%) were lost to follow-up. A description of the 18 caregivers approached is provided in Table 13.

Table 13. Characteristics of initial sample of eligible participants approached to participate in the current study and characteristics of caregivers interviewed.

Variable	Caregivers				Adolescents				
	No consent		Consented		No consent		Consented		
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Gender									
Male	1	12.5	1	10.0	3	37.5	7	70.0	
Female	7	87.5	9	90.0	5	62.5	3	30.0	
Ethnicity									
European/Pakeha	5	62.5	7	70.0	5	62.5	8	80.0	
Maori*	2	25.0	2	20.0	2	25.0	1	10.0	
Other	1	12.5	1	10.0	1	12.5	1	10.0	
TBI Severity									
Mild/low	-	-	-	-	4	50.0	4	40.0	
Mild/medium	-	-	-	-	1	12.5	3	30.0	
Mild/high	-	-	-	-	3	37.5	3	30.0	
Relationship status									
Married/defacto/civil union	3	37.5	5	50.0	-	-	-	-	
Separated/divorce/widowed	1	12.5	2	20.0	-	-	-	-	
Never married/single	2	25.0	2	20.0	-	-	-	-	
Not stated	2	25.0	1	10.0	-	-	-	-	
Occupation group									
Manager	1	12.5	0	0.0	-	-	-	-	
Professional	2	25.0	1	10.0	-	-	-	-	
Technician/Trades	0	0.0	0	0.0	-	-	-	-	
Community/Personal Services	0	0.0	2	20.0	-	-	-	-	
Clerical/Administrative	1	12.5	1	10.0	-	-	-	-	
Sales	0	0.0	0	0.0	-	-	-	-	
Labourer	0	0.0	0	0.0	-	-	-	-	
Unemployed	1	12.5	5	50.0	-	-	-	-	
Not stated	3	37.5	1	10.0	-	-	-	-	
Paid working hours									
35+ hours per week	3	37.5	0	0.0	-	-	-	-	
20 - 34 hours per week	0	0.0	1	10.0	-	-	-	-	
1 - 19 hours per week	0	0.0	3	30.0	-	-	-	-	
No paid hours per week	1	12.5	5	50.0	-	-	-	-	
Not stated	4	50	1	10.0	-	-	-	-	
Highest Education									
University	0	0.0	2	20.0	-	-	-	-	
Polytechnic	1	12.5	2	20.0	-	-	-	-	
High School	1	12.5	5	50.0	-	-	-	-	
Primary School	0	0.0	0	0.0	-	-	-	-	
Not stated	6	75.0	1	10.0	-	-	-	-	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age at Injury		39.9	3.3	41.1	5.8	10.70	0.97	9.85	0.69
Range (years)		(35.7 - 46.6)		(32.9 - 50.9)		(9.5 - 12.1)		(9.1 - 11.0)	

Note. * Includes individuals identifying as Māori and part-Māori

Potential participant caregivers were predominantly female ($n = 16$), European/Pākeha ($n = 12$), and typically reported being in formalised

relationships (n = 8). The adolescents within this sample were predominantly male (n = 10), of European/Pākeha ethnicity (n = 13), and most commonly had injuries classified as mild/low (n = 8). Common reasons for not participating in the current study were that caregivers felt they had contributed enough from their experiences, that they were no longer impacted by the injury and wished to focus on their current lives.

Caregivers consenting to participation were more likely to report that they were not in paid employment (n = 5), and had achieved a university education (n = 2). However, many caregivers did not provide demographic information, allowing only tentative comparisons to be made. The adolescents they cared for were likely to be younger than those in the sample as a whole.

Data Collection

Information about caregiver experiences were gathered using semi-structured interviews. These were conducted primarily as individual interviews but also including others involved in the daily provision of care to the adolescent (i.e. a spouse or partner of the caregiver) if this was the identified caregiver's preference.

A semi-structured interview format sought to gather a detailed description of caregivers' experiences with the flexibility to add various clarifying questions or pursue topical trajectories as these arose. This enabled the identification and exploration of aspects of experiences not previously considered.

The interview guide developed for the current study was comprised of open-ended questions derived from the current understanding of caregivers' experiences (Appendix E). Interview questions emphasised potentially positive experiences, but also provided untargeted opportunities to comment on

experiences. Questions explored the presence and meaning caregivers' ascribed to opportunities for personal satisfaction, skill acquisition, benefits to the caregiver's relationship with the adolescent and any other social benefits they may have experienced. This included questions referencing concepts included in Carbonneau, et al., (2010) positive aspects of caregiving framework i.e. daily enrichment experiences, feelings of accomplishment, and quality of the daily relationship. Caregiver perceptions of their role (role meaning) were also explored.

Factors associated with caregiver burden (Raina, et al., 2004) were examined through interview questions targeting caregiver perceptions of the contribution of brain injury (i.e. adolescent characteristics, behaviour, caregiving demands and coping factors) to caregiving expectations. Finally, an opportunity was provided for caregivers to add any additional experiences they wished to share.

Prior to interviews being conducted, the study information sheet (Appendix D) was reviewed with caregivers. All caregivers were advised of the provisions for and limits of confidentiality and that the interview would be recorded for accuracy, and of their right to withdraw their information from the study within two weeks of the interview. Written consent was then obtained with signed copies of the study information sheet and consent form retained by both the participant and the researcher (Appendix F).

During the first interview, it became apparent that two additional topic areas naturally followed from the discussion of caregiver experiences: the extent to which caregivers perceived their experiences as due to adolescence or the consequences of the adolescents' head injury; and the extent to which they

perceived their role as parenting versus caregiving. These topic areas were incorporated into all subsequent interviews.

All interviews were audio-recorded for subsequent transcription to ensure accuracy and support the development of rapport during discussions. Recordings were transcribed verbatim and anonymised. A realist perspective, taking participant statements at face value, was adopted.

Interviews lasted approximately 30 – 60 minutes and were conducted face-to-face. With two exceptions, requested by the caregiver for their convenience, all interviews were completed in the caregivers' home. Transcripts were created manually directly into NVivo version 10 for Windows (QSR International, 2012), before being rechecked against the original audio recordings for accuracy prior to analysis.

Approximately one week after each interview, caregivers were telephoned by the researcher to review a summary of the transcript for accuracy. This also provided an opportunity to clarify any aspects of the interview that were unclear at transcription. Any additions were recorded and the date of inclusion was noted to inform subsequent analysis. Once all information had been gathered, caregivers were reminded of their ability to withdraw their information from the study within the next two weeks and thanked again for participating in the study.

Results

Analysis of the 10 interview transcripts capturing the experiences of 11 caregivers resulted in 27 topic categories. Categories were then refined and explored for connectedness and grouped into five themes: initiation to the caregiving role; injury impacts and attributions; accommodation and adjustment

in caregiving following injury; caregiving is a valued experience; and caregiving is just part of the job (Figure 7).

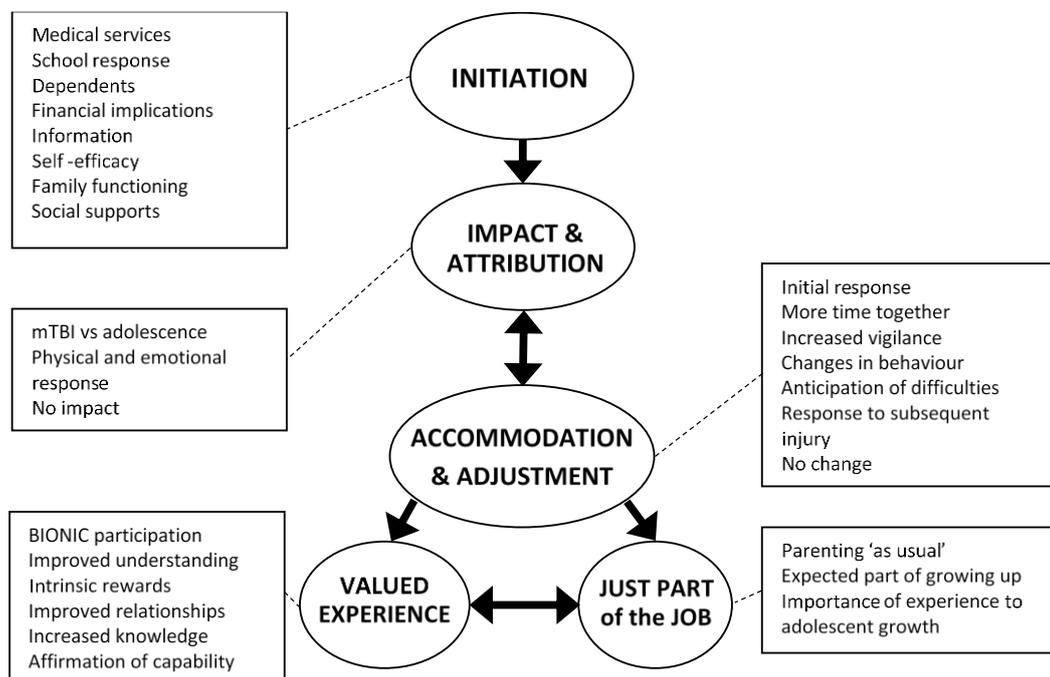


Figure 7: Themes of caregiver experiences and associated topic categories.

A temporal interrelationship between themes was apparent, with caregivers describing their experiences in the form of a sequential narrative starting with their initiation to the role of caregiver, followed by their experiences of its impacts, and any changes needed to accommodate these impacts, before concluding with reflections on their experiences and the meaning they ascribed to the caregiving role.

To enhance readability while providing appropriate context, the interpretation of themes were “semi-quantified” (Anderson, 2010, p. 5). Quotes were chosen as poignant or most representative of the theme being conveyed, or because they communicated an emergent or divergent view. To ensure the anonymity of participants, quotes are contextualised by including an indication of

the caregivers' age and gender, and the age and gender of the adolescent they were caring for are provided.

Theme 1. Initiation to the caregiving role. This theme captured the environmental and internal factors caregivers experienced on being unexpectedly thrust into the role of caregivers by adolescent injury. Caregivers described a continuum of supportive to frustrating responses from schools and medical services immediately following the adolescents' injury. Many caregivers spoke of access to information or a lack of it as a key factor shaping their experience. The ability to draw on their own sources of knowledge (past experiences, family and friends) to support their initiation to the role appeared to be particularly valued. Initial experiences described by caregivers as either exasperating or enabling, were attributed to their subsequently being respectively distracted from or aided in focusing on their roles as caregivers. In all cases, this initial response made a lasting impression on caregivers, who were typically able to recall them in detail four years later.

Around two-thirds of the injuries in this sample occurred at school. Only a few caregivers described feeling particularly supported and empowered by the school's response following their child's injury. Responses meeting caregivers' expectations of the care of their child and communication with carers were viewed as expected and described as contributing to a positive relationship and enhanced confidence in the school and its staff as a whole.

“The thing I value the most was the response of the school. You know the school followed their procedures...they treated him, they gave him time, then they rang me and they informed me what they surmised should

happen next, which is roughly what you'd get from our [national] health line so I thought they did quite well.”

(Female, 40 years, caring for male, 13 years)

However for many caregivers, a perceived lack of communication left them feeling excluded and disempowered. The majority of this group were disgruntled at the level of care provided, and indicated that they felt let down by school staff. Typically, for caregivers with less positive experiences, hindsight and the passage of time generated a more balanced perspective to explain the school's frustrating response. However, in a few cases this experience led to considerable stress and anger, with significant levels of frustration and disappointment evident four years after the injury.

“I had to be an investigator to find out what was wrong. That was actually quite hard on me. You want to go in to school and say ‘what the hell is wrong with my child?’ ‘How could you not see [that] he was not right?’”

(Female, 40 years, caring for male, 14 years)

Most caregivers stated that they were able to quickly access medical services, describing staff as empathetic and competent. These experiences left caregivers with a positive view of formal support providers and reportedly contributed to a sense of calm and competence, enabling caregivers to focus on the needs of adolescents.

“Throughout the whole thing the medical side of things has been fantastic. We've been well supported. They were always really cautious and did the right things, so that helps you feel a bit better.”

(Male, 44 years, caring for male, 15 years)

However, a few caregivers recalled access to medical services as a particular barrier and source of frustration. Caregivers' of adolescents with recurring injuries alongside their TBI were most likely to report feeling isolated and unsupported by medical services. In these cases the immediate needs of adolescents were still attended to, but carers were more likely to report feelings of being overwhelmed by their care.

“I tried to get her into my doctors, oh my God they’re so hopeless...let’s not go there... so I took her to the A&E.”

(Female, 50 years, caring for female, 15 years)

“I went down with a child with a head injury and the local A&E’s closed - at 8 o’clock in the evening! So, I took him up to the hospital, you know, you’ve got to wait but at least it’s still going to be seen.”

(Female, 40 years, caring for male, 13 years)

For many caregivers, the provision of accurate and relevant information contributed strongly to their sense of competence and ability to act confidently. Similarly, timely information enhanced caregiver’s self-perceived composure and sense of control. Ideally, this information was provided in written form to enable caregivers to take the information away and access it at their own pace.

“Having written information to take away was particularly valuable as I didn’t take in much information at the time. Being able to take it away allowed me to process what had happened and respond more quickly.”

(Female, 45 years, caring for male, 14 years)

A few caregivers had access to medical expertise within their families and referred to this as being a significant factor in the calm and sense of control with which they responded to the injury event and it’s immediate after effects. A third

of caregivers had prior experience of TBI personally or professionally, and expressed a strong sense of self-efficacy.

“Because it wasn’t the first [injury I’ve seen] and it was my field of expertise, I wasn’t overly concerned. Definitely calm, and it does help in the situation, ‘cause it keeps the child calm too.”

(Female, 50 years, caring for female, 15 years)

Although a carers few commented on the difference in the increased anxiety they felt when their own child was in need of care they associated with their professional role. Overall, caregivers described their prior knowledge and experience as a key factor in their sense of personal strength and resilience in response to the injury and informing the action they ultimately took.

“I’ve seen adults with head injuries but never a child. Being my own, I’m like ‘wow’. I think I could have handled it if it had been somebody else’s child. Being my own I was...’oh, my gosh, how am I going to do this?’”

(Female, 54 years, caring for female, 14 years)

In single income households (which comprised a third of those participating in the study), the financial implications of injuries were a significant consideration before action was taken. This led to caregivers either not seeking medical help immediately or seeking but being prepared to wait for care i.e. through hospital accident and emergency departments. Having to compromise the care their child received was a source of some distress for these caregivers. As a result, they typically had very negative views about the level of support available to them from primary health providers.

“Ok, you're going to take him to the A&E, the biggest thing is it's going to be cost. You know as a single parent on a single income... I actually rang the A&E to see how much it was going to cost before I took him down.”

(Female, 40 years, caring for male, 13 years)

However, generally caregivers did not report any long-term financial disadvantage. Because of the timing of the injury, not all caregivers decided to take time off work. In other instances they were the primary caregiver for the family and arrangements were already in place to accommodate the care of sick children within the family.

“It didn't bother me [taking three weeks off work], because it was family and that's what you do”

(Female, 54 years, caring for female, 14 years)

Where providing care did require caregivers to take time off work, employers were described as understanding, allowing caregivers to work flexibly if needed. In general, any reduction in income was temporary and viewed as having minimal impact on the household.

“I didn't get paid for the time I take off, so financially it has an impact...but, I can pick up my job when I go back so that was OK.”

(Female, 44 years, caring for male, 13 years)

Prior family functioning contributed to most caregivers' sense of self-efficacy in response to the injury. Most caregivers commented on the collective effort required to respond to the needs of adolescents, particularly initially. For many caregivers the needs of other dependents competed for their attention. This occurred both at the time of injury and for a few was a longer-term source of discord.

“We can look back and say as a family unit we probably worked quite well. We were quite coordinated in our efforts to make sure everybody was looked after”

(Female, 44 years, caring for male, 13 years)

Social support from friends and their wider family was also cited as an enabler allowing caregivers to focus on the needs of injured adolescents. However, a few caregivers preferred not to involve others instead relying on their own resources or members of their immediate family for support.

“I guess I don't share much with people because I don't think other people have gone through what I've gone through or experiences what I've experienced. So I don't think they'd understand. It's not that I don't welcome their views, but I don't think that they get me”

(Female, 40 years, caring for male, 14 years)

While frustrations of some form were been prominent in many caregivers' recollections of their experience immediately following the injury, the initial response of most caregivers was to either ignore these or adopt a problem-solving stance.

“Yeah, I was frustrated, but I was more concerned about my son. You know, I was annoyed but I just got on with it”

(Male, 44 years, caring for male, 15 years)

Perhaps unsurprisingly, schools and medical services feature strongly in caregiver recollections of the injury event. For some carers the availability of advice and assistance and open communication received was enabling and supportive. However, many caregivers described feeling isolated and disempowered by the response of medical providers and schools. This suggests

that such service providers play an important role in enabling caregivers to effectively respond to mTBI. Caregivers' access to information and support through their family and social networks also appears to be an important factor for service providers to identify immediately following injury.

Theme 2: Injury impacts and attributions. A second theme characterising how recognised changes in adolescent behaviours were interpreted by caregivers is captured under the title “injury impacts and attributions”. This theme reflects any impacts of the mTBI that were perceived and whether and to what any changes were attributed by caregivers. This ranged from caregivers perceiving little impact to those who discerned a qualitative difference years later. Caregivers also varied in the degree to which they attributed noted changes in behaviours to the impacts of the injury or as expected manifestations of adolescent development.

While a few caregivers maintained that the injury had had no discernible effects on the adolescent, this was the exception. Most caregivers reported transient neurological effects (e.g. tiredness, the adolescent being quieter than usual, uncharacteristic irritability) in the weeks following injury. While the time period of such perceived effects was marginally longer for some, all caregivers characterised these effects as minor and short-lived.

“Probably the only thing I could significantly say was that she was just a lot more tireder (sic). No significant changes. She just got rattled a bit more with [her siblings] for a couple of weeks.”

(Female, 37 years, caring for female, 13 years)

While such effects were clearly viewed as the result of the mTBI, the source of longer-term changes in expected adolescent behaviours were less clear-

cut. Many caregivers reported that that they were able to differentiate whether the unexpected or unwanted behaviours were the result of adolescence or the head injury. With caregivers tolerance and expectations of adolescent behaviours reflecting these attributions.

“If he’s tired then I put it down to the head injury. If it’s defiance, then I say teenager. I know when it’s his head injury because ‘the look’ doesn’t work.”

(Female, 40 years, caring for male, 14 years)

Comparisons between the adolescents’ behaviour prior to their injury and the behaviour of any older siblings at a similar age were frequently used to illustrate these perceptions. However, for some caregivers a distinction was difficult to discern. Consequently, they regularly questioned whether changes in behaviour were attributable to the impacts of the TBI or the onset of puberty. There appeared to be more tolerance of and allowance made for behaviours associated with injury effects.

“He goes, ‘I don’t know what came over me, I’m so sorry’ and I’m like, ‘Well, you are a teenager and different things are happening’. But there are just a little bit, not often, you just think ‘oh, poor kid’, is that from his head injury, you know, you just wonder.”

(Female, 40 years, caring for male, 14 years)

Perhaps unsurprisingly, caregivers with professional knowledge of TBI or those caring for adolescents with multiple TBI were most likely to express on-going concern for potential impacts of the TBI.

“I think because I [work in the medical field] I was a little more cautious about what happened to her. Even now, some days I look at how she is

behaving and I wonder whether I am seeing the consequences of her injury. It's likely to be nothing but, my knowledge of how bad it might have been colours how I see things."

(Female, 50 years, caring for female, 15 years)

Typically, caregivers saw few impacts of mTBI beyond the first few weeks following injury. Adolescence were generally more likely to be viewed as the cause of any subsequent out of character behaviours and tolerated as such. It was notable that those with more information about the possible impacts of TBI were more likely to express concern about long-term injury impacts, even in the absence of specific behaviours. Given the importance of a consistent parenting approach to adolescent development, this suggests that any comments or information about the characteristics of possible medium to long term impacts of mTBI, be carefully considered and balanced to avoid undue concern or unwarranted caregiver responses.

Theme 3. Accommodation and adjustment in caregiving following injury. This theme represented any changes made by caregivers in order to care for and support the needs of adolescents post TBI. This included environmental or relational changes made to initially or long-term to accommodate the needs of the adolescent. In some cases adjustments had been consciously implemented. In others caregivers responded more instinctually to the needs of adolescents, only subsequently recognising changes that had occurred.

In the majority of cases caregivers stated that they had not made any enduring changes to the way they cared for adolescents. However, all carers referred to avoiding taxing adolescents' reduced resources immediately following the injury by temporarily restricting activities or minimising sensory antagonists

(i.e. light, noise). This response was typically based on advice from formal care providers or where this input was minimal, their own understanding of the best way to meet the needs of their child based on prior experiences.

“We didn't parent him any differently...well, we treated him quietly, quietly for the first couple of weeks, I guess and then within a month everything was back to normal.”

(Female, 45 years, caring for male, 14 years)

Where changes were acknowledged, they generally involved caregivers seeking to increase their contact with adolescents by temporarily rearranging work schedules or graduating the adolescents' return to school. For a few caregivers this took the form of a more permanent changes designed to increase one-on-one time with the adolescent. This increased time with the adolescent was typically highly valued and a pattern that, on reflection caregivers' acknowledged had continued long-term.

“Four years later I still see the importance of those special times together. I'd never noticed that before. Until then you're just flat out, you are so busy all the time.”

(Female, 50 years, caring for female, 15 years)

The desire for increased contact also took the form of a greater vigilance or protectiveness following the injury. A few caregivers took a practical approach and described becoming particularly conscious of the benefits of seeking medical advice quickly. However, typically caregivers reported establishing more explicit boundaries with adolescents in the form of higher expectations of communication and transparency. They also found themselves taking a more active role in know where there adolescent was and with whom.

“I’m very protective now than before. I used to let her go out with her friends and that, but now... I always like her to let us know where she's going.”

(Female, 54 years, caring for female, 14 years)

In two cases on-going difficulties, characterised as lasting twelve months or more were noted. Within this group some caregivers described accommodating changes in the adolescents’ behaviour. In all cases these changes were conceptualised as the result of injury. For a few, this involved enabling the adolescents’ avoidance behaviours in the case where they had developed anxieties following their injury.

“He really don't like staying away from home. He'll say 'mama I'll go [to stay at a friend’s house] but will you come and pick me up when I call?’ and I will, no matter what the time is.”

(Female, 42 years, caring for male, aged 14 years)

While others managed the adolescents challenging behaviours by actively intervening in their relationships with others:

“It was difficult because of his communication with others as well. His interactions with his peers and so forth, it was always the little things that popped up. You have to be the peacemaker.”

(Male, 44 years, caring for male, 15 years)

The most obvious accommodations and adjustments recalled by caregivers occurred in response to the transient effects of mTBI during the first few days and week following injury. Longer – term changes were less commonly made but can be characterised as caregivers seeking to increase the level of influence and oversight they had with adolescents. Given the characteristic adolescent drive for

independence, caregivers would need to be sensitive to changes in adolescent desire for increased contact immediately following injury to ensure conflict was avoided as adolescents recovered.

Theme 4: Caregiving as a valued experience. This theme described the four factors identified by most caregivers as beneficial outcomes of their experiences. While one or two caregivers found it difficult to identify any value in their experience, in order of greatest endorsement, these factors were: improved relationships with others; increased knowledge of injury; participation in the BIONIC study; and affirmation of their capability as carer.

The majority of caregivers volunteered that following the injury event relationships improved between themselves and the adolescent. This was experienced as; improved communication (i.e. higher rates of communication, less problematic communication), and/or increased emotional closeness. Some caregivers perceived that relationships between the adolescent and their siblings had likewise improved. In other instances, caregivers made particular note of increased cohesiveness of the connections between all family members.

“It [the injury] made us stronger as a family. We are a very close family and we are quite a united little family and I think those sort of experiences make us more grateful, more accepting of when things aren't good.”

(Female, 40 years, caring for male, 14 years)

Many caregivers described the most valued aspect of their experience in terms of the practical knowledge they gained. The majority perceived that the experience had contributed to their preparedness to respond to similar events in the future. This appeared to translate into increased confidence in practical knowledge and enhanced self-efficacy as reflected in the next comment.

“It’s obviously added to our life experiences...if [we] go through something similar again, it will be, 'oh well, we’ve been here before', so we sort of know a little bit of what to deal with.”

(Female, 44 years, caring for male, 13 years)

A few caregivers had stated that they felt poorly equipped to deal with the practical needs of their child following injury. In these instances, their experiences had inspired them to revalue and seek practical first aid skills and resources, to increase their preparedness for injuries in general.

“First aid knowledge and resources are now high on our priority list.”

(Female, 45 years, caring for male, 14 years)

Many caregivers related that participation in the BIONIC study was beneficial for them. Participation was valued in that the repeated assessments and reflection of their experiences enabled them to gain a sense of perspective and of change over time. For some caregivers, the most valued aspect of participation was the ability for their experiences to be used to contribute to the knowledge available to others going through similar circumstances. Similarly,

“When we started with the study you think about all the other stuff that happens. When you look at that egg [on the injured adolescent’s head], you think ‘whoa, if it looks like that on the outside, what happened on the inside?’ You get all these thoughts and you don’t see anything wrong and you’re like ‘Thank God’”

(Female, 42 years, caring for male, 14 years).

For one caregiver, involvement in the study had been particularly important in facilitating an increase in their understanding of their own head injuries and poor cognitive health. Specifically, they valued the opportunity

participation had given them to access information relevant to them as well as giving them an opportunity to ask questions which they had felt unable to do in previous contact with formal health providers.

Finally, several caregivers (30%) conceptualised their experiences as a situation that they had had no option but to respond to. In doing so they had been surprised by their own capability in the face of a 'crisis'. This observation had led them to reevaluate their own coping resources and practical skills. Consequently, these caregivers described the injury event and subsequent requirement for care as confidence enhancing.

"This whole experience has been very....satisfying, very validating in a strange way. It's really helped me to recognise that I am resilient. That I have the strength to cope. I needed that, it's helped me feel less overwhelmed by everything and more in control."

(Female, 40 years, caring for male, 14 years)

Similarly, one caregiver noted that her previously shy and timid child had become more confident and adventurous following their injury. This was attributed to the adolescent's successful navigation through a feared injury event. The caregiver stated that the resulting enhanced self-efficacy had made providing day to day care less onerous.

"For him, I think it gave him a bit more confidence....The next time he got hit he wasn't as overly concerned or reactive because of his previous experience."

(Female, 40 years, caring for male, 13 years)

The aspects of their experiences which caregivers valued vary from the practical to the intrinsic. Intrinsic benefits to self-esteem and sense of self-efficacy

appeared to increase for those caregivers' who perceived greater injury impacts and those who were managing situations with minimal support from others. In all cases, the benefits were seen to have lasting impacts on caregivers' view of the ability to effectively respond to future injury events rather than limited to the mTBI.

Theme 5: Caregiving is just part of the job. The final theme derived from in the analysis of caregiver interviews represents the perceptions caregivers appeared to have of their role after time. Reflecting on the injury event and any impacts, caregivers described the meaning they assigned to their role and carer experiences and their view of the injury and any lessons that they took from the event. These views fell into three broad categories: the belief that their caregiving activities represented parenting as usual; injury as an expected part of growing up; and relatedly, the importance of experience in growth.

Without exception and across all ages of child or adolescent, caregivers were emphatic in their view that there was not a distinction between their role as caregivers following injury and their role as parents. Specifically, interviewees saw the care they provided to their adolescent child following injury as an expected part of parenting. Caregivers typically described their role as being comprised of many facets which they may be called on to perform as the needs of their child required either through accident, injury or normative development. For caregiver's, any additional duties required of them following an injury were simply a facet of their role as parents.

“I don't think there's any special about what I did. You have to be everything for your kids. You have to be every profession in one - a teacher, a policeman, a nurse. You have to be everything for your kids.”

(Female, 40 years, caring for male, 13 years)

Most caregivers expressed the view that their child's mTBI and other such injuries were a natural part of growing up. Some referred to the formative effect of injuries they had sustained in their childhood and expressed a belief that while responding to the injury had been stressful for them, they hoped their child would gain similar benefit. Equally, some caregivers viewed

“[The] injury was a while ago, but [she] took it in her stride. It was just parenting as usual, one of those things that happens to kids.”

(Female, 37 years, caring for female, 13 years)

When queried further, caregivers stated that they recognised that attempting to protect their child from injury was both unachievable and unhelpful in the long-term. With many acknowledging that the injury as having a greater impact on them and the way they now parent than their child.

“We think that we've been over-protective at stages and we still are to a degree, but we also know that he's growing up as well and that he needs to do things himself.”

(Female, 44 years, caring for male, 15 years)

At the same time, most caregivers recognised that opportunities to stretch and test themselves played an essential role in adolescents developing into young adults.

“It's just another one of those realizations that you can't wrap them up in cotton wool. They have got to be out there enjoying life and these things happen.”

(Female, 42 years, caring for male, 14 years)

For those caring for adolescents following mTBI, there did not appear to be a meaningful distinction between parenting and caregiving. Rather, the possibility of injuries of some form during childhood and adolescence was anticipated and normalised by caregivers. Consequently, providing care was viewed as an expected and essential aspect of parenting.

Discussion

Phase two investigated the lived experiences of caregivers caring for adolescents' with prior mTBI as recalled four years post-injury. Using a qualitative approach, this phase sought to expand on the quantitative findings of phase one by exploring individual experiences in detail, with the intent of identifying commonalities or themes in the nature of those experiences.

Caregiver Experiences

As anticipated (Aitken, et al., 2009), the injury event was described as very disruptive for all caregivers, representing a considerable source of stress. Uniquely for this caregiver – care-recipient dyad, the initial response of schools and/or medical services was perceived as most influential in mitigating this initial reaction. The majority of injuries occurred at school, emphasising the significance of schools' response alongside that of medical services. Typically, caregivers' reported experience with these organisations was frustrating and disempowering. The prominence of such negative impressions in caregivers recollections four years post-injury highlights the potential role that both schools and medical providers can play in supporting parents' adaption to the additional requirements of a caregiving role.

Caregivers described the initial response of schools in one of two ways. The majority of caregivers believed that the injury had been inadequately attended to and communication poor. This resulted in frustration and some anger at the time of injury and a subsequent weakening of their relationship with the school. It also had the effect of distracting caregivers' focus and appeared to exacerbate the emotional turbulence generated by the injury event. Alternatively, caregivers felt that the adolescents' injuries had been appropriately responded to and communication had been prompt and complete. As a result caregivers described feeling empowered, and perceived that their rapport with their child's teacher and school had been strengthened. Either outcome was perceived as having enduring impacts beyond the duration of any injury impacts, reinforcing the importance of schools providing a considered, coherent and coordinated response to injury events.

Particularly emphasised in caregivers' accounts was the importance of allowing caregivers to make the decision about what if any care should be provided to their child. This approach was described as having the benefits of empowering caregivers to meet the needs of their child, while maintaining or fostering a positive relationship between the school and carers.

The initial response of medical services, utilised in some form by all caregivers, also shaped the initial experiences of caregivers. Most caregivers reported being able to quickly access formal medical care and were positive about the ensuing interactions. The ease of access, supportive care and provision of relevant information was experienced as psychologically calming, allowing caregivers to focus on their needs of their child and facilitating their transition to the caregiving role. In contrast, those caregivers reporting feeling unheard by

medical services described relying more heavily on available social supports and being less likely to engage with such services in the future. For caregivers in the latter group, reported stress levels were greater and more prolonged. The contrasting impacts of these varying experiences underline the important role primary health providers' play in orienting carers to their role and equipping them to provide sub-acute care in the community. In addition, by providing timely, reassuring and relevant information, caregiver coping resources are likely to be increased, reducing their reliance on the stretched capacities of formal health providers.

It is interesting to note that for caregivers of adolescents with mTBI, a negative view of formal providers appeared to be a direct reflection of how supported they felt, rather than of the severity of impairment or the presence of problematic behaviours as predicted by burden models of caregiving (Fournier, et al., 2009). Instead, consistent with models of caregiver gain, caregivers' sense of self-efficacy appeared to promote a positive outlook (Steffen, et al., 2002), reducing the likelihood that caregivers felt overwhelmed by their responsibilities (Farran, et al., 2004).

Single parent households, a third of all households included in the current study, generally experienced greater difficulties with prompt access to medical care due to restricted financial resources. This suggests that for this group of caregivers, the unexpected costs of accessing medical services represented a significant barrier to caregiving. Given the established relationship between lower socioeconomic status and increased injury frequency (WHO, 2009), this finding highlights the importance of considering the potential for short-term

financial burden (alongside the more recognised longer-term financial burdens), as a consequence of informal caregiving for parents on restricted incomes.

Regardless of the family composition and contrary to generally expected consequences of informal caregiving in other caregiver groups (Bitman, et al., 2007; Worrall, 2005) caregivers included in the current analysis did not report financial burden as a result of providing care. This is likely to be the result of two factors. First, due to the brevity of injury effects and the flexibility of employers, caregiver work patterns were minimally interrupted. Second, because the care recipient was the caregiver's child, caregivers conceptualised any financial impact as an expected and unavoidable consequence of providing care to their child. This indicates that financial burden may not be an equally significant factor for all caregiver groups.

Consistent with previous findings (Anderson, et al., 2011; Carroll, et al., 2004), the majority of caregivers reported that there were no discernible long-term consequences of the adolescents' mTBI. Likewise, the transient neurological effects managed by caregivers were consistent with those previously described (Catroppa, et al., 2006; Landon, et al., 2012). However, distinguishing the longer-term sequelae of injury from expected adolescent behaviours proved challenging for most caregivers who, four years later, expressed differing levels of certainty in and methods for determining the origin of undesirable behaviours. This was particularly relevant for the third of caregivers with previous experience of TBI who expressed the concern for the potential for longer-term impacts. This intersection between the possible impacts of mTBI and expected adolescent development presents a unique challenge for parent caregivers seeking to identify an emotionally responsive yet consistent response to care recipient behaviours.

As identified in previous studies, reported levels of care gradually reduced as the young person recovered (Sullivan-Bolyai, et al., 2004). Initially, all caregivers made changes to the adolescent's environment and as noted by Kerr, et al., (2012), increased their level of oversight, becoming more vigilant and protective. In addition, some caregivers subsequently identified that they had increased their availability to the adolescent. This instinct to emotional responsiveness and availability is consistent with current understanding of the optimal environment for supporting healthy adolescent development (Steinberg, 2001), and recovery following injury (Ylvisaker, 1998). The interaction of these factors is likely to have contributed to the minimal rates of problematic behaviour reported by caregivers (Taylor, et al., 2001).

Reflecting on their experiences, all caregivers identified benefits from their experiences (i.e. improved relationships with the adolescent, practical knowledge, opportunity to contribute, demonstration of self-efficacy). Consistent with positive views of caregiving, the quality of this relationship and caregivers' sense of filial duty towards their child appears to have resulted in feelings of increased closeness. This occurred despite any additional expectations placed on the caregiver as a result of the adolescent's injury. Likewise, the needs of the adolescent following injury appear to have also created opportunities for other family members to be close to the adolescent (Cohen, et al., 2002) as well as being a common goal for family members to unite around.

Alignment with Models of Caregiving

Despite initial frustrations, all of the caregivers' described and valued a number of positive outcomes of their experiences as predicted by a positive model of caregiving (Carbonneau, et al., 2010). Practical skills were valued for their

contribution to increased confidence and self-efficacy. Carers also valued the opportunity their experiences provided to share their knowledge with others through participation in the BIONIC, COBIC and BIONIC4you studies. A positive model of caregiving predicts that the value placed on practical skills and personal qualities gained in the act of caring (Grant, et al., 1993), as well as increased emotional closeness, feelings of accomplishment and social recognition contributing to positive caregiving outcomes (Carbonneau, et al., 2010).

Additionally, caregivers' value of the insights gained from their response to the tangible and psychological demands of an injury event and its consequences were perceived by caregivers as evidence of their personal resilience and capability. This outcome is consistent with traumatic growth (Helgeson, et al., 2006) and benefit-finding theory (e.g. Tennen, et al., 2002), which informs the Carbonneau, et al., (2010) model and suggests that like other caregiver groups, caregivers of adolescents with mTBI Specifically, for the caregivers included in the current study, the experience of caregiving provided a difficult situation which they were required to cope with and manage to the best of their abilities. In meeting the demands of this challenging situation, they utilised skills and personal qualities previously unrecognised (Grant, et al., 1993).

Perhaps the greatest departure from the experiences of other caregiver groups was that caregivers in the current study did not distinguish between their roles as parents and informal caregivers. Instead, they saw their role as a parent as multi-faceted, and including any caregiving necessary following the brain injury of their child. This suggests that for parent caregivers, the meaning and value of a caregiving role are closely aligned with the expectations they have of their role as parents. Consequently, drawing on the positive and valued meaning attached to

their role as parents, caregivers ascribe a similarly positive meaning to daily caregiving activities. This combination of factors leads caregivers to minimise any burdensome aspects of a caregiving role. By more readily identifying the positive aspects of caregiving, their experiences are more likely to be satisfying and enriching (Sassine, 2005).

Collectively, the experiences of parents caring for the adolescent children post mTBI can be characterised as featuring rapidly decreasing ripples of impact. With caregivers transitioning at varying rates from the initial emotional and practical disruption of the injury event, negotiating school and medical services, managing transient and short-term impacts to a final recognition of benefit and normalcy.

The common threads running through these experiences highlight a number of areas of particular relevance to caregivers of adolescents with prior mTBI. Firstly, the importance of considered, coherent, and coordination from schools following injury events. This would appear to be a key factor enabling caregivers to readily take on the role of caregiver and to maintaining a positive school-home relationship. Secondly, the value of feeling heard by medical services and the provision of timely, reassuring and relevant information regarding their child's injury. Thirdly, recognition that while long-term financial burden may not be a significant factor for this cohort, for single parent households there may be financial barriers to access, resulting in reticence to seek medical help when needed. Lastly, caregivers may benefit from practical information about the likely behavioural, social and emotional sequelae of mTBI, alongside what is known of adolescent development. Such information is likely to be a

valuable tool for enabling parent caregivers to more readily distinguish injury effects from expected adolescent behaviours.

The themes ‘caregiving is a valued experience’ and ‘caregiving is just part of the job’ identified in caregiver experiences appear to align more comprehensively with a positive framework of caregiving primarily developed to the care of older persons (Carbonneau, et al., 2010). The positive outcomes of caregiving identified by previous research into the positive outcomes of other family caregiver groups are analogous to those experienced by caregivers in the current study (i.e. increased emotional closeness, the development of practical skills, opportunities to share knowledge, and recognition of their own capability and resilience). However, the meaning caregivers in the current study attributed to their caregiving role (i.e. caregiving is just part of the job) suggests a subtle difference in emphasis between the domains and determining factors included in such a positive model of caregiving. By combining the findings of both phases of the current study, it is hoped that a more complete and accurate picture of how a positive model of caregiving might be applied.

Chapter Five – Study Summary

Having considered the implications of qualitative and quantitative findings independently, findings were integrated to explore how each phase informed interpretation of the other.

Synthesis of Findings

The aim of this study was to develop a multifaceted understanding of the experiences of caregivers of adolescents with mTBI. Phase one sought to identify how providing care for adolescents with prior mTBI was associated with caregivers' perceptions of their quality of life, mood, and experiences of caregiving burden and gain. Phase two explored the question 'what are the experiences of caregivers caring for adolescents following mild traumatic brain injury?'

Reflecting the sub-acute nature of mTBI and expectation of minimal or transitory impacts, few differences were found between the caregiver and adolescent groups studied. Adolescent functioning was typical for both groups, with few variances. Twelve months following injury, injured adolescents experienced modest disruptions to expected emotional, social and behavioural capabilities. However, by two years following injury a more typical developmental trajectory has been resumed, with any group differences likely to result from pre-existing characteristics, rather than persisting injury outcomes.

Four years post-injury, caregivers report no discerning injury impacts for adolescents, but do describe a legacy of improved relationships and emotional closeness as a result of their increased emotional vigilance and greater involvement following injury.

While few physical, psychological or social impacts were identified the act of caregiving following injury benefited caregivers. The qualitative analysis echoed the findings of phase one and identified that while unfavourable external factors may initially colour caregivers' experiences, this initial adversity ultimately fosters caregivers' sense of self-efficacy and competence.

The situation of parent carers caring for adolescents following mTBI differs from other care relationships. The act of caring attracts the benefits identified in other caregiver groups including opportunities to enhance self-efficacy, generate daily enrichment experiences and improve valued relationships. However, the minimal and transient nature of injury impacts places few if any ongoing obligations on carers that are not already viewed as an integral part of their existing role as parents. Additionally, the perspective enables caregivers to harness existing social and emotional resources to accommodate any injury impacts. Consequently, for parent caregivers of injured adolescents the meaning ascribed to their role makes a particularly important contribution to their experiences.

Combining the findings of both phases also identifies several key conclusions. Firstly, the important role schools can play in enabling caregivers to readily take on the role of caregiver. By ensuring they provide a considered, coherent, and coordinated response to injury events, schools also support a positive school-home relationship. Such a relationship is likely to ease the child's transition back to school following injury and foster a collaborative, open approach to managing any subsequent school difficulties.

Secondly, medical services can play a key role in supporting caregivers to respond calmly and confidently to injury events. Simply ensuring that the

concerns of caregivers are heard is a key factor in reducing caregivers' sense of anxiety immediately following their child's injury. Similarly, providing timely reassurance and relevant information regarding their child's injury (reinforced in written form), increases caregivers sense of self-efficacy and confidence. As well as providing relevant medical information about the likely behavioural, social and emotional sequelae of mTBI. It is important to caregivers that this information underlines that mTBI outcomes are generally positive. Practically, this could involve reassuring caregivers that while initially behaviours may subtly regress, adolescents will ultimately resume a typical trajectory of development. For medical providers, such an approach has the benefits of enhancing caregivers' sense of capability and reducing their reliance on the stretched resources of formal health providers. Given the benefits to caregiving outcomes and caregivers' physical HRQoL, this approach is also consistent with the broader health goals of medical services.

A further consideration for medical providers is the potential for limited financial resources influence the choices of caregivers in single-parent households. Given this knowledge, it may be possible for service providers to implement more flexible arrangements for this potentially vulnerable group to ensure caregivers can benefit from the timely medical care and reassurance.

Finally, given that caregiving following adolescent injury is seen as an intrinsic part of the parenting role, the benefits of caregiving for adolescent children should be communicated more widely to help dismiss negative views of caregiving and trepidation of adolescence. In particular, shifting the focus to caregiving for adolescents as an opportunity; for enhancing emotional closeness at a challenging time in human development; for developing transferrable practical

skills; to share wisdom and experience with others; and to develop personally through the recognition of capability and resilience.

Strengths and Limitations of the Current Studies

A significant strength of the current study was the opportunity to access a population based study, enhancing the generalisability of results. However, conclusions are limited by the inability to incorporate the contributions of participants choosing not to participate in the source studies or in Phase Two of the current study. The use of a rigorous mixed-method analytical approach combining the benefits of quantitative and qualitative approaches contributed to the reliability of findings. However, this approach was somewhat limited by the practical necessity of collecting quantitative and qualitative data at two different time points, introducing the possibility of inaccuracies in caregiver memories of their experiences.

Similarly, as a measure originally designed for the assessment of caregivers caring for older family members post-stroke, the applicability of the BCOS to assessment of caregiving outcomes for carers of adolescents with non-chronic conditions is open to challenge. However, by focussing on the experiences of an understudied group of caregivers, the current study offers specific insights into the experiences of those caring for adolescents following mTBI.

Conclusions

To the best of the researcher's knowledge, the current study represents the first investigation of the experiences of parent caregivers, caring for their adolescent children following an abrupt injury event such as mTBI. Despite the

broad variety of caregiving relationships, academic literature has painted a predominantly negative picture of parent caregiving, focussing on caring in the face of chronic paediatric illness or disability. To date, consideration of the potential benefits of caregiving have primarily focused on the experiences of family members caring for their elderly relatives. The findings of the current study extend the applicability of a positive model of caregiving to another caregiver-care recipient relationship.

Mild traumatic brain injury (mTBI) is one of the most frequently occurring injuries during adolescence. Given the current expectation and increasing likelihood of parents providing sub-acute care to their children. The unique characteristics and needs of parent caregivers providing such care should be considered by those involved in support them to do so. Schools and medical services play a particularly influential role in the case of adolescent injuries, highlighting the importance of timely, appropriate and balanced information to enable caregivers to focus on the care for their children and to foster a sense of self-efficacy and confidence.

For parents thrust into the role of caregiving following mTBI or other sub-acute injuries, the opportunities for personal growth and strengthening relationships injuries such as mTBI provide, particularly at an anecdotally challenging time in human development, should be reinforced and celebrated.

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Appendices

Appendix A. Information sheet sent to all COBIC study participants (phase one).



Why should I take part?

To help improve our understanding of how a head injury has affected your child and family.

The effects of head injury differ, so we need everyone who has a head injury to take part to make sure we hear everyone's story.

By taking part you will help us plan future health care and improve the treatment and services available for people with head injury.

What is COBIC?

The Consequences of Brain Injury in Childhood (COBIC) study is a follow-up from the BIONIC study.

The purpose of this study is to find out what sort of effects young people might experience in the years that follow a head injury.

The aims of the COBIC study are to find out more about how your child is functioning in the following areas:

- Thoughts and feelings
- Behaviour at school and home
- Academic performance
- Quality of life

How is COBIC different from BIONIC?

COBIC is focused on young people aged between 5 and 16 years at the time of their injury, whereas BIONIC focused on people of all ages, and followed them up for 1 year only.



COBIC is a follow-up to the BIONIC study into traumatic brain injury.

The COBIC study is interested in the long-term impacts of head injuries on children's functioning at home and school.

Principal Investigator:
Dr Nicola Starkey
School of Psychology
University of Waikato
Tel: 07 838 4466 extn 6472
Email: COBIC@waikato.ac.nz



COBIC researchers want to know how your child is at home, but we are also interested in what life at school is like for your child - how is their learning and play?

COBIC is concerned with what life is like for young people and their families in the long-term after a head injury, even if that head injury was only mild or you didn't notice major effects.

We appreciate that families today are very busy! So we have tried to make the COBIC assessment shorter than the original BIONIC assessments that you and your child participated in.

What do I have to do?

You and your child will be asked to take part in an assessment / interview now and in twelve months time.



Has your child taken part in the BIONIC study after a head injury?



Were they aged between 5 and 16 years when they were injured?

If so, we would like to know more about their experiences at home and school.

Phone: 07 838 4466 ext 6472
Email: COBIC@waikato.ac.nz



NATIONAL INSTITUTE FOR
STROKE AND APPLIED NEUROSCIENCES
AN INSTITUTE OF AUL UNIVERSITY

What happens next?

If you've received this brochure, it's because your child has been part of the BIONIC study and you have agreed to be contacted about future studies.

A COBIC researcher will telephone you within the next fortnight to invite you to participate.

If you would like more information before then, please feel free to ring us to find out more. We will tell you more about the study and you can choose if you want to take part.

Phone: 07 838 4466 ext 6472
Or 07 8384466 ext 8082
Email: COBIC@waikato.ac.nz

The study is supported by a Lottery Health Research Grant and the Health Research Council of New Zealand. It has received ethical approval from the Northern Y Regional Ethics Committee, Ministry of Health.



Why should I take part?

To find out about the long term effects of brain injury we **also need to interview children and young people who have not had an injury.**

This will help improve our understanding of the long term effects of head injury in children and young people.

By taking part you will help us develop better health care and improve the treatment and services available for people with head injury.



The COBIC study is interested in the long-term impacts of head injuries on children and young peoples' functioning at home and school.

We now need children and teenagers who have not had a head injury to take part in our study.

Principal Investigator:
Dr Nicola Starkey
School of Psychology
University of Waikato
Tel: 07 838 4466 extn 8082
Email: COBIC@waikato.ac.nz



In one year over 300 children and young people from Hamilton and Waikato had a brain injury



To find out more about the effects of brain injury, we **would like children and teenagers who have not had a head injury to take part in our study.**

Phone: 07 838 4466 ext 8082
Email: COBIC@waikato.ac.nz



What is COBIC?

The Consequences of Brain Injury in Childhood (COBIC) study is a follow-up from an earlier study (BIONIC).

The BIONIC study examined how many people had a brain injury every year and followed their recovery over the first year.

The purpose of the COBIC study is to find out what sort of effects young people might experience in the years that follow a head injury.

The aims of the COBIC study are to find out more about children and teenagers functioning in the following areas:

- Thoughts and feelings
- Behaviour at school and home
- Academic performance
- Quality of life



To find out about the effects of brain injury we need to talk to non-injured children and young people as well.

COBIC researchers want to know how children and young people are at home, and we are also interested in what their life at school is like:

- How is their learning and play?
- Are they well organised?
- What types of things do they find hard or easy?

We appreciate that families today are very busy! We can be flexible when we carry out interviews and will fit in with when is best for you.

What do I have to do?

You and your child will be asked to take part in an assessment / interview now and in twelve months time.

What happens next?

If you want to take part or are interested in finding out more about the study, please ring or email us.

We will tell you more about the study and you can choose if you want to take part.

If you know of anyone else who might be interested in the study, please pass this brochure onto them.

Phone: 07 8384466 ext 8082

Email: COBIC@waikato.ac.nz

The study is supported by a Lottery Health Research Grant and the Health Research Council of New Zealand. It has received ethical approval from the Northern Y Regional Ethics Committee, Ministry of Health.

Appendix B. Information and consent form completed by all COBIC study participants (phase one).



The Consequences of Brain Injury In Childhood (COBIC) Parent (Proxy) Information Sheet

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 children and teenagers who have had a head injury and to find out information that will make treatment better. For us to find out how head injury affects children and teenagers, we need to talk to those who have had a head injury and to those who haven't.

An invitation

The aim of this study is to examine the long term effects of head injury in children and adolescents. You are being invited to take in this research study because you represent a child who:

1) had a head injury (brain injury) between March 2010 and February 2011,

OR

2) you are volunteering your child to become part of the non-injured comparison group.

This study is coordinated by the School of Psychology, University of Waikato, Hamilton, in collaboration with the National Institute for Stroke and Applied Neurosciences, AUT University, Auckland.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you choose not to take part, any care or treatment that your child is currently receiving will not be affected. If you do agree to take part, you/ your child are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your or your child's future health care. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part.

What are the aims of this study?

The main aim of the study is to find out about the long-term effects of head injury during childhood or adolescence (under 16 years of age). We will be looking at how children and adolescents recover, 1, 2 and 3 years after their injury, and compare them to children and teenagers of a similar age who have not had a head injury.

The study aims to find out what the effects of the head injury (if any) are on:

- Social behaviour
- Memory and other cognitive functioning
- Mood and feelings
- Quality of life
- The families of people with head injury

We hope this study will be of long-term benefit to New Zealanders in identifying the effects of head injury, and we hope it will eventually lead to improved care and help for children with head injury.

Who can take part in this study?

We need two groups of children / adolescents to take part in this study - those who have had a head injury and those who haven't. You and your child can take part in this study if:

- a) You took part in the BIONIC (Brain Injury Outcomes New Zealand in the Community) study and your child was under 16 years of age when they had a head injury. This means your child had a head injury between 1st March 2010 and 28th February 2011.

OR

- b) Your child is between 1- 16 years of age, has not had a head injury and would be willing to be part of the comparison group.

We are asking for your consent (as their parent/proxy) for your child to take part. We will talk to your child directly and we would also like to ask you some questions about your child's behavior and wellbeing as well finding out about your general health. We will explain the study to your child so that they can ask any questions they might have and we will obtain their assent to take part.

In addition, we would like to ask your child's school teacher to take part so that we can find out if a head injury affects a child's behavior at school. We will ask you if you would like to nominate a teacher to answer some questions.

How many people will be in the study?

We estimate about 690 children will be involved in this study.

What happens if I do decide to take part?

If you decide you/ your child would like to take part, your participation would be for two years only. In total there will be three assessments - at the start of the study, and then in 1 year and 2 years time. Each assessment will take place over 2 sessions of approximately 90 minutes each. This is about 1.5 days of your time over 2 years.

The researcher will ring you and ask you some questions over the phone. They will then arrange a time to meet with you and your child face-to-face to complete the assessment. This meeting can be at your home, at the University or other suitable place. Each assessment will include answering some questions about any illnesses or injuries your child may have had. In addition, you will be asked questions about your child's behavior and mood, as well as questions relating to your health and wellbeing.

Most children find these tasks enjoyable. Feedback about the assessments is not routinely given. All researchers who will be asking these questions and working with your child will have been specially trained for this project. These assessments can be conducted over more than 2 sessions if you would prefer.

What will my child have to do?

We would also like to carry out some activities with your child which can be done at home. These activities will help us to monitor your child's progress and enable us to see if head injuries affect children's memory, their ability to pay attention or the way they think. We have found previously that children find these activities enjoyable and the activities will be suitable for the age of your child. The activities will last for a total of 3 hours (depending upon the age of your child) and we will do these over several sessions. You are welcome to stay with your child during these activities.

What is the time-span for the study?

The study is expected to start on 1 March 2011 and will continue until 31 October 2014.

How will the study affect me?

Taking part in this study will take some of your time and require you to answer a series of questions and for your child to complete some activities. There are no known risks caused by this study. Your (or your child's) usual medical care will not be affected in any way by participating in the study, or withdrawing from the study at any stage. Your (and your child's) participation in this study will be stopped should any harmful effects appear or if the doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you (or your child) with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, if your child has had a head injury, you will be given an opportunity to discuss this with a researcher. The results obtained from your participation may help others with this condition in the future.

Compensation

An age appropriate gift or voucher (\$20) will be provided to your child after completion of each of the interviews (3 gifts or \$60 in total).

Confidentiality

The study files and all other information that you provide will remain strictly confidential, unless there is an immediate risk of serious harm to yourselves or others. No material that could personally identify you (or your child) will be used in any reports on this study. Upon completion of the study your records will be stored for at least 10 year after your child's 16th birthday in a secure place at the University of Waikato. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust,

Telephone: **0800 555 050**, email: advocacy@hdc.org.nz.

Or Te Puna Oranga (Waikato DHB Maori Health Unit), Hockin Building, Level 1, Pembroke wSt, P.O.Box 934, Hamilton. Ph: (07) 834 3644. Fax: (07) 834 3619.

Finally

This study has received Ethical Approval from the Northern Region Y Ethics Committee Ref NTY/11/02/2016). If you would like some more information about the study please feel free to contact the researchers:

Dr Nicola Starkey, Senior Lecturer, Department of Psychology, University of Waikato, Hamilton, on 07 8384466 ext 6472 or email; nstarkey@waikato.ac.nz

Study Investigators

The principal investigator for this study is: **Dr Nicola Starkey (contact detail above)**
Please keep this brochure for your information. Thank you for reading about this study



**The Consequences of Brain Injury In Childhood (COBIC)
Parent (Proxy) Consent Form**

The form and the accompanying information sheet outline what the study involves and requests your consent to be part of the study.

- 1) I have read and I understand the information sheet (Version 3 dated 31/5/2011) for parent (proxy) participants taking part in the Consequences of Brain Injury in Childhood (COBIC) Study
- 2) I have had the opportunity to discuss this study with the research team and I am satisfied with the answers I have been given.
- 3) I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- 4) I understand that taking part in this study is voluntary (my choice), and that I (or my child) may withdraw from the study at any time, and this will in no way affect my (or my child's) continuing health care in any way.
- 5) I understand the compensation provisions for this study.
- 6) I have had time to consider whether to take part in the study.
- 7) I know who to contact if I have any questions about the study.
- 8) I understand that my participation in this study is confidential and that no material that could identify me (or my child) will be used in any reports on this study.
- 9) I understand the limits of confidentiality
- 10) I agree to an approved auditor appointed by either the ethics committee, or the regulatory authority or their approved representative, and approved by the Northern Region Y Ethics Committee reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.
- 11) I give my approval for information regarding a head injury of the child I am representing to be obtained from his/her medical records.
- 12) I understand that the GP of the child I represent may be informed about their involvement in this study.

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No
---	----------

I am a representative of _____ (the participant),
 being a person who is lawfully acting on the participant's behalf or in his or her interests.
 My relationship to the participant is _____. I agree to
 health information about the participant being disclosed for the purposes of this
 research. I also agree to participate in this research.

Signature
 (or representative)..... Signature of witness.....

Date: Name of witness.....

Project explained by..... Project role

Signature..... Date

*Note: A copy of the consent form to be retained by participant and a copy to be placed
 in the case record file.*

Appendix C. Tests of normality for statistical analyses completed in phase one.

Tests of normality for adolescent variables.

		mTBI						Comparison							
		M	SD	W	df	p	Skew	Kurtosis	M	SD	W	df	p	Skew	Kurtosis
Adolescent Age (at T1)		13.63	2.01	0.92	47	0.004**	-0.44	-1.05	13.53	2.08	0.93	48	0.006**	-0.19	-1.33
BASC-2															
Time 1	Emotional Symptoms	46.51	9.50	0.92	37	0.001**	0.96	0.64	46.78	8.85	0.89	46	0.000***	1.38	2.06
	School Problems	49.73	11.17	0.90	37	0.002**	1.31	2.11	48.24	9.87	0.94	46	0.025*	0.83	0.44
	Internalising Behaviours	47.32	9.62	0.94	37	0.061	0.76	0.41	47.07	9.09	0.93	46	0.012*	0.87	0.36
	Inattention / Hyperactivity	51.89	11.43	0.96	37	0.170	0.48	-0.62	51.98	11.85	0.97	46	0.243	0.21	-0.89
	Personal Adjustment	52.57	10.26	0.95	37	0.097	-0.79	0.49	51.39	8.45	0.88	46	0.000***	-1.34	1.93
Time 2	Emotional Symptoms	46.35	8.67	0.96	40	0.160	0.73	0.40	46.00	7.72	0.95	43	0.038*	0.53	-0.54
	School Problems	51.10	11.10	0.96	40	0.190	0.64	0.18	46.93	8.70	0.95	43	0.039*	0.33	-1.04
	Internalising Behaviours	47.70	10.57	0.93	40	0.016*	0.74	-0.16	45.93	8.34	0.94	43	0.018*	0.35	-1.00
	Inattention / Hyperactivity	53.10	11.18	0.98	40	0.775	0.05	-0.55	49.37	10.19	0.98	43	0.693	0.13	-0.67
	Personal Adjustment	52.90	8.88	0.98	40	0.519	-0.25	-0.36	52.44	6.97	0.99	43	0.838	-0.35	-0.17
SDQ															
Time 1	Total Difficulties	12.00	6.87	0.95	27	0.219	0.31	-0.95	10.96	6.52	0.95	47	0.044*	0.65	-0.16
	Difficulties Impact	0.89	1.76	0.59	27	0.000***	2.23	4.85	0.43	0.99	0.50	47	0.000***	2.92	9.66
Time 2	Total Difficulties	11.69	7.22	0.97	39	0.287	0.48	-0.01	11.69	7.22	0.94	44	0.017*	0.26	-1.20
	Difficulties Impact	0.63	1.26	0.58	38	0.000***	2.12	3.92	0.35	0.84	0.47	43	0.000***	2.26	3.84

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Tests of normality for caregiver variables.

		mTBI							Comparison						
		M	SD	W	df	p	Skew	Kurtosis	M	SD	W	df	p	Skew	Kurtosis
Caregiver Age (at T1)		42.61	6.16	0.60	47	0.595	0.17	-0.40	45.44	6.60	0.95	46	0.031*	0.81	1.67
SF-36 v2															
Time 1	QoL - Physical Health	81.46	18.76	0.82	36	0.000***	-1.63	2.73	85.60	17.17	0.74	49	0.000***	-1.94	3.44
	QoL - Mental Health	75.93	22.80	0.71	37	0.000***	-2.14	4.13	84.51	9.27	0.89	49	0.000***	-1.23	1.53
Time 2	QoL - Physical Health	82.05	21.31	0.73	42	0.000***	-1.89	2.91	86.11	13.11	0.80	47	0.000***	-2.05	5.06
	QoL - Mental Health	78.68	17.92	0.72	42	0.000***	-2.33	5.80	81.38	13.14	0.89	47	0.000***	-0.82	-0.54
HADS															
Time 1	Anxiety	4.15	4.127	0.80	39	0.000***	1.85	3.67	3.59	2.27	0.94	44	0.029*	0.05	-0.97
	Depressive Symptoms	1.92	2.344	0.731	39	0.000***	2.51	8.39	1.48	2.37	0.63	44	0.000***	2.29	4.66
Time 2	Anxiety	3.83	3.185	0.896	41	0.001**	1.14	1.04	3.56	2.51	0.94	48	0.022*	0.31	-0.87
	Depressive Symptoms	2.27	2.757	0.777	41	0.000***	1.87	3.89	1.94	2.64	0.75	48	0.000***	1.78	3.41
BCOS															
Time 1	Outcomes	60.42	8.04	0.791	33	0.000***	-0.96	7.07	68.69	13.12	0.81	42	0.000***	1.37	0.92
	Change	4.03	0.81	0.623	33	0.000***	-0.81	7.10	4.63	1.09	0.76	43	0.000***	1.04	-0.01
Time 2	Outcomes	66.14	12.19	0.829	42	0.000***	0.78	1.47	65.33	9.13	0.76	48	0.000***	2.41	7.82
	Change	4.30	0.86	0.602	43	0.000***	1.95	3.68	4.48	0.77	0.66	48	0.000***	1.52	1.54
BASC-2															
Time 1	Externalising Behaviours	52.82	10.20	0.93	39	0.016*	0.77	-0.12	47.04	6.20	0.97	46	0.216	0.37	-0.12
	Internalising Behaviours	52.49	11.38	0.93	39	0.023*	1.01	1.47	46.65	10.98	0.86	46	0.000***	1.71	3.81
	Problem Behaviours	52.59	11.19	0.92	39	0.008**	0.96	0.46	48.00	8.26	0.94	46	0.015*	0.76	-0.04
	Adaptive Skills	48.11	11.06	0.98	38	0.828	-0.23	-0.19	52.33	8.23	0.96	46	0.098	-0.46	-0.26
Time 2	Externalising Behaviours	52.40	11.21	0.92	40	0.009**	1.11	1.52	47.23	7.78	0.94	47	0.013*	0.97	1.49
	Internalising Behaviours	49.88	12.49	0.89	40	0.001**	1.27	1.48	45.70	8.57	0.94	47	0.023*	0.92	0.88
	Problem Behaviours	51.20	11.26	0.92	40	0.009**	0.96	0.75	48.26	9.74	0.92	47	0.004**	0.89	0.09
	Adaptive Skills	48.93	11.45	0.97	40	0.268	0.04	-0.91	51.87	9.81	0.95	47	0.027*	-0.65	-0.27
SDQ															
Time 1	Total Difficulties	10.20	8.02	0.92	41	0.008**	0.58	-0.80	6.51	5.19	0.88	53	0.000***	0.92	-0.28
	Difficulties Impact	1.39	2.25	0.68	41	0.000***	1.71	2.00	0.42	0.99	0.49	53	0.000***	2.54	5.88
Time 2	Total Difficulties	8.63	7.12	0.88	41	0.001**	1.26	1.26	6.84	5.53	0.90	45	0.001**	0.63	-0.81
	Difficulties Impact	1.17	2.28	0.58	41	0.000***	2.10	3.43	0.49	1.14	0.49	45	0.000***	2.39	4.61

Note: * p < .05, ** p < .01, *** p < .001

Nonparametric correlations between adolescent age and adolescent-reports of adolescent emotional, behavioural, and social functioning.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
BASC-2												
Emotional Symptoms	36	0.16	0.36	40	-0.01	0.95	46	-0.07	0.64	42	-0.13	0.43
School Problems	36	0.33	0.046*	40	0.30	0.057†	46	-0.08	0.60	42	-0.29	0.06
Internalising Behaviours	36	0.24	0.16	40	0.00	0.98	46	-0.11	0.47	42	-0.21	0.19
Inattention / Hyperactivity	36	0.47	0.004**	40	0.14	0.38	46	-0.05	0.76	42	-0.25	0.12
Personal Adjustment	36	-0.09	0.59	40	0.06	0.72	46	-0.06	0.67	42	0.04	0.79
SDQ												
Total Difficulties	27	0.01	0.97	38	0.12	0.48	42	-0.39	0.011*	43	-0.07	0.69
Difficulties Impact	27	0.19	0.33	38	0.10	0.55	42	-0.25	0.11	42	-0.23	0.15

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, BASC-2 and SF-36 test scores are age standardised, † = limits of significance

Nonparametric correlations between adolescent gender and adolescent-reports of adolescent emotional, behavioural, and social functioning.

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
BASC-2												
Emotional Symptoms	37	0.03	0.85	40	-0.07	0.69	46	-0.07	0.66	43	-0.36	0.017**
School Problems	37	0.23	0.17	40	0.45	0.004**	46	0.16	0.30	43	-0.14	0.37
Internalising Behaviours	37	0.06	0.74	40	-0.02	0.89	46	-0.05	0.76	43	-0.20	0.19
Inattention / Hyperactivity	37	0.06	0.75	40	0.02	0.91	46	-0.06	0.68	43	-0.29	0.06
Personal Adjustment	37	-0.11	0.51	40	0.10	0.56	46	-0.04	0.80	43	0.35	0.021*
SDQ												
Total Difficulties	27	0.12	0.57	39	-0.36	0.83	47	-0.10	0.52	44	-0.09	0.58
Difficulties Impact	27	-0.13	0.52	38	-0.06	0.75	47	0.16	0.28	43	0.23	0.14

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1

Nonparametric correlations between adolescent age and caregiver ratings of adolescent emotional, behavioural, and social functioning

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
BASC-2												
Externalising Behaviours	39	0.05	0.78	40	-0.08	0.64	46	-0.17	0.26	46	-0.21	0.16
Internalising Behaviours	39	-0.17	0.31	40	-0.22	0.18	46	-0.32	0.030*	46	-0.35	0.016*
Problem Behaviours	39	-0.14	0.40	40	-0.08	0.62	46	-0.08	0.60	46	-0.16	0.29
Adaptive Skills	38	0.16	0.35	40	0.01	0.95	46	0.04	0.77	46	0.08	0.59
SDQ												
Total Difficulties	41	-0.26	0.10	41	-0.25	0.11	48	-0.15	0.30	44	-0.16	0.30
Difficulties Impact	41	-0.22	0.18	41	-0.26	0.10	48	-0.22	0.14	44	-0.09	0.56

Note : * $p < .05$, ** $p < .01$, *** $p < .001$, BASC-2 and SF-36 test scores are age standardised.

Nonparametric correlations between adolescent gender and caregiver ratings of adolescent emotional, behavioural, and social functioning

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
BASC-2												
Externalising Behaviours	39	0.15	0.36	40	0.20	0.22	46	0.45	0.002**	47	0.22	0.13
Internalising Behaviours	39	-0.24	0.15	40	-0.22	0.17	46	0.04	0.82	47	-0.10	0.49
Problem Behaviours	39	-0.12	0.42	40	0.03	0.87	46	0.27	0.07	47	0.45	0.31
Adaptive Skills	38	0.01	0.94	40	-0.04	0.81	46	-0.16	0.29	47	-0.18	0.22
SDQ												
Total Difficulties	41	-0.07	0.67	41	-0.09	0.57	53	0.26	0.06	45	0.20	0.20
Difficulties Impact	41	-0.19	0.23	41	-0.12	0.47	53	0.20	0.15	45	0.30	0.05†

Note : * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1, † = limits of significance

Nonparametric correlations between adolescent age and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety and depression, and outcomes and change as a result of caregiving for caregivers of adolescents with and without mTBI

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
SF-36 v2												
QoL - Physical Health	36	0.25	0.14	41	0.21	0.193	44	0.32	0.08	47	0.17	0.24
QoL - Mental Health	37	0.05	0.76	41	0.09	0.57	44	0.16	0.31	47	0.29	0.05
HADS												
Anxiety	38	0.12	0.46	41	-0.07	0.68	44	-0.13	0.40	47	-0.07	0.63
Depressive Symptoms	38	0.11	0.53	41	-0.12	0.47	44	-0.26	0.09	47	-0.28	0.06
BCOS												
Outcomes	33	0.09	0.62	42	0.02	0.92	42	0.20	0.21	47	-0.16	0.27
Change	33	0.13	0.49	42	-0.05	0.76	42	-0.03	0.87	47	-0.23	0.01

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Nonparametric correlations between adolescent gender and caregiver self-reports of quality of life related to physical and mental health, symptoms of anxiety and depression, and outcomes and change as a result of caregiving for caregivers of adolescents with and without mTBI

	mTBI						Comparison					
	T1			T2			T1			T2		
	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>	<i>n</i>	<i>rs</i>	<i>p</i>
SF-36 v2												
QoL - Physical Health	36	0.06	0.74	42	0.00	0.98	49	0.24	0.10	47	-0.04	0.80
QoL - Mental Health	37	0.16	0.34	42	-0.25	0.11	49	-0.03	0.84	47	-0.13	0.37
HADS												
Anxiety	39	0.24	0.14	41	-0.01	0.94	44	0.00	0.98	48	0.12	0.43
Depressive Symptoms	39	0.02	0.92	41	0.17	0.28	44	0.08	0.60	48	-0.08	0.58
BCOS												
Outcomes	33	0.05	0.77	42	0.03	0.85	42	-0.07	0.66	48	0.19	0.19
Change	33	0.06	0.76	43	0.10	0.54	43	-0.02	0.90	48	0.19	0.21

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, Female = 0, Male = 1

Nonparametric correlations between caregiving outcomes and variables implicated by caregiving models

Variable	Time 1				Time 2			
	<i>n</i>	<i>rs</i>	<i>p</i>	M(SD)	<i>n</i>	<i>rs</i>	<i>p</i>	M(SD)
Group	75	-0.31	0.006**	1.50 (0.50)	90	0.04	0.73	1.50 (0.50)
Adolescent Age	75	0.18	0.12	13.57 (2.03)	89	-0.08	0.48	14.71 (2.19)
Adolescent Internalising Behaviours	72	-0.35	0.002**	49.33 (11.47)	87	-0.13	0.24	47.62 (10.70)
Adolescent Externalising Behaviours	72	-0.13	0.28	49.69 (8.72)	87	0.10	0.35	49.61 (9.80)
Caregiver HRQoL - Physical	71	0.18	0.14	83.85 (17.87)	88	0.09	0.43	84.20 (17.48)
Caregiver HRQoL - Mental	71	0.15	0.021*	80.82 (16.94)	88	0.02	0.89	80.11 (15.55)
Caregiver Mood - Anxiety	69	0.00	0.98	3.86 (3.27)	89	0.03	0.77	3.69 (2.83)
Caregiver Mood - Depression	69	-0.17	0.17	1.69 (2.35)	89	0.00	0.97	2.09 (2.68)

Note * $p < .05$, ** $p < .01$, *** $p < .001$

Appendix D: Study invitation letter and information sheet sent to all potential participants of phase two.

School of Psychology
The University of Waikato
Private Bag 3105
Hamilton, New Zealand

Phone 64-7-856 2889
Facsimile 64-7-858 5132



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

17 October 2014

Parent/Caregiver of [first name] [last name]

[address]

[address]

[post code]

Experiences of Caregivers of Adolescents with TBI

Dear Parent/Caregiver,

Thank you for agreeing to be contacted regarding future research studies being conducted at the University of Waikato. The purpose of this letter is to introduce a proposed research study into the experiences of caregivers and to invite you to participate.

As part of the requirements for a Masters in Social Sciences this study aims to explore the experiences of caregivers. A significant amount of research has been conducted into the burden experienced by carers, however little information is currently known about the positive experiences caregivers. Even less is known about the experiences of parents who care for their adolescent children following a traumatic brain injury.

Your participation is entirely voluntary (your choice). If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. To help you make your decision please read the enclosed study information sheet.

I will contact you by phone in approximately one week to discuss any questions you may have and confirm whether you are interested in participating in this study. I look forward to speaking with you then.

Yours sincerely,
Kathryn Giles

Enclosure: Study Information Sheet

Experiences of Caregivers of Adolescents with TBI

STUDY INFORMATION SHEET



Who am I?

I am a Masters student at the University of Waikato. As part of the requirements for a Masters in Social Sciences with the School of Psychology I'm interested in studying the experiences of family members who provide care to others as a result of injury or disability.

An invitation

The aim of this research is to explore the experiences of parents who care for their adolescent children following a traumatic brain injury (TBI). A significant amount of research has been conducted into the burden experienced by many carers, however little information is currently known about the positive experiences of caregiving, particularly within families.

You are being invited to take part in this research study because you and your family took part in the BIONIC4YOU (Brain Injury Outcomes New Zealand in the Community 4 year outcomes) study and you have consented to being contacted regarding future research.

Your participation is entirely your choice. You do not have to take part in this study. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part.

What are the aims of this study?

The main aim of the study is to find out about the experiences of caregivers of adolescents aged 13 – 15 years who have previously had a TBI. This will involve conducting an in-depth interview with each caregiver to build up a picture of their experiences of caregiving in these circumstances.

The interview will ask questions about:

- The impact of changes you in your child/family you attribute to their TBI,
- How you perceive others to view your role,
- What aspects (if any) of your role as a caregiver you find most rewarding,
- What impact you feel your role as a caregiver has had on you as a person.

There will also be opportunities for you to reflect on any other aspect of your experiences which you feel may be relevant.

Once all the interviews with caregivers have been completed, the information will be analysed to identify themes and patterns as well as similarities and differences between each caregivers' experience. This information will then be used to comment on and the ways these experiences may contribute to outcomes for adolescents.

I hope this study will help to increase understanding of positive experiences of caregiving for parents who care for their children following TBI.

What happens if I do decide to take part?

I will make contact you within a week of this letter to clarify whether you wish to participate in this study. If you are willing to participate, I'll arrange a suitable time to meet with you and complete the interview. This meeting can be at your home, at the University or other suitable location.

It is expected that this interview will take 1 - 2 hours, although this can be completed over two or more sessions if this is more convenient for you.

Once the interview has been completed, I'll contact you again a week later to see if there is anything further you would like to add. If you would like to add anything further, this can be covered in person, over the phone or by e-mail, whichever is most convenient for you.

How will the study affect me?

Taking part in this study will take some of your time and require you to answer a series of open-ended questions about your experiences. There are no known risks caused by this study.

While, there is no guarantee that you will benefit directly from being involved in this study, the results obtained from your participation may help other caregivers and families in the same situation in the future.

Once the study has been completed, you will be offered a summary of the findings so that you can see how your experiences might compare to caregiving experiences as a whole as captured by the study.

Compensation

A \$20 food/fuel voucher will be provided to you for participation in the study.

Confidentiality

All information that you provide will remain strictly confidential, unless there is an immediate risk of serious harm to yourself or others. No material that could personally identify you will be used in this study. All computer records will be password protected. Upon completion of the study all transcripts of information you have provided will be destroyed. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust, Telephone **0800 555 050**, or email: advocacy@hdc.org.nz

Or Te Puna Oranga (Waikato DHB Māori Health Unit), Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton. Ph: (07) 834 3644. Fax: (07) 834 3619.

Finally

This study has received Ethical Approval from the University of Waikato, School of Psychology Ethics Committee. Committee Chair, Dr. John Perrone on 07 8384466 ext 8292 jpnz@waikato.ac.nz

If you would like some more information about the study please feel free to contact the Principal Investigator:

Kathryn Giles, Clinical Psychology student, School of Psychology, University of Waikato, Hamilton 021 0826 1355 or e-mail kjg2@students.waikato.ac.nz

Dr. Nicola Starkey, Senior Lecturer, School of Psychology, University of Waikato, Hamilton, on 07 8384466 ext 6472 or email: nstarkey@waikato.ac.nz

***Please keep this leaflet for your information.
Thank you for reading about this study.***

Appendix E. Semi-structured interview guide used in phase two.

Interview Schedule

Date of Interview _____

Participant Ref: _____

Study Information Sheet Reviewed:

Consent form Reviewed:

Written Consent obtained:

1. Introductory conversation about their family, the injured child, the nature of their child's TBI and how their child is currently.
2. For you, what are the most significant changes in your child in the past year?
3. What do these changes mean for you personally?
4. How do you feel about your role as caregiver?
5. How do you think others' view your role?
6. Has your role as a caregiver changed you?
7. What is the most valuable thing you have gained from your experiences?
8. What aspects do you find the most rewarding?
9. How has this experience changed your relationship with your child?
10. How has this experience changed your relationship with others?
11. What do you see as the biggest impact (of this experience) on your life?
12. Is there anything else you would like to add about your experiences and how they have impacted you as a person?

THANK YOU – next steps

Appendix F. Consent form completed by all participants of phase two.

Experiences of Caregivers of Adolescents with TBI CONSENT FORM



- 1 I have read/had explained to me, and understand, the Information Sheet for participants taking part in the Experiences of Caregivers of Adolescents with TBI study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- 2 I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview, that I may choose not to answer any questions or stop the interview at any time.
- 3 I understand that this interview will be audio recorded.
4. I understand that I can withdraw my information from the study within 2 weeks of the interview taking place
- 5 I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.
- 6 I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- 7 I understand the limits of confidentiality.
- 8 I understand the compensation provisions for this study.
- 9 I have had time to consider whether to take part.
- 10 I know whom to contact if I have any questions about the study.

Declaration by the participant:

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Psychology Research and Ethics Committee (Associate Professor John Perrone, Tel: 07 838 4466 ext 8292, email: jpnz@waikato.ac.nz)

Participant's name (Please print): _____

Signature: _____

Date: _____

Declaration by researcher:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name (Please print): _____

Signature: _____

Date: _____

This study has been approved by the University of Waikato, School of Psychology Ethics Committee.