

**The effect of caregiver traumatic brain injury on children's  
long-term functioning.**

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## **Ethical Approval**

Approval to conduct survey research with undergraduate students was obtained from the University of Canterbury Human Ethics Committee which was granted on 31 January 2020 (ref: HEC 2019/170, see Appendix A).

## **Definitions**

### *Acquired Brain Injury:*

A term used to describe all types of brain injury which occur after birth. This includes but isn't limited to stroke, brain tumour, traumatic brain injury etc. (Teasell et al., 2019). Throughout this thesis, the term 'brain injury' and 'acquired brain injury' are used interchangeably. The term 'parental ABI' describes a caregiver who has suffered an acquired brain injury.

### *Traumatic Brain Injury:*

A type of acquired brain injury caused by sudden trauma to the head via an external physical force. This may include incidents such as assault, falls, motor accidents etc. (ACC and NZGG, 2007). The term 'parental TBI' refers to a caregiver who has experienced a traumatic brain injury.

## **Abstract**

Traumatic brain injury (TBI) is a common and debilitating event affecting millions of individuals globally. Although one-third of TBI patients are believed to have dependent children, the long-term impact of the injury on children is unknown. Due to patients experiencing persistent difficulties following injury, many children will likely face consequences to their own mental health following parental TBI. The current study investigated the long-term adaptive functioning, psychological problems and life satisfaction of adults exposed to parental TBI in childhood (age < 18), compared to same-aged norms. Additionally, this study examined whether experiencing a parent with TBI during childhood, would predict clinical levels of mental health problems, adaptive functioning and satisfaction with life in early adulthood. The sample consisted of 253 first year undergraduate students, aged between 18-33 years old who completed self-report questionnaires to collect caregiver and self TBI history and to assess adaptive functioning, psychological problems and life satisfaction. Participants who were affected by parental TBI in childhood reported significantly higher scores for internalising, externalising and total psychological problems and reduced satisfaction with life in adulthood compared to same-aged norms. There was a significantly higher proportion of respondents meeting clinical diagnostic criteria for total psychological problems, externalising problems and life satisfaction by those who reported exposure to parental TBI in childhood compared to the normative sample. There were no significant differences in scores or the proportion meeting clinical criteria for adaptive functioning or substance use for the those with caregivers who had TBI compared to the control group. Exposure to parental TBI in childhood was a risk factor for clinical levels of psychopathology with those affected more likely to report clinical scores for adaptive functioning (OR = 6.27), externalising problems (OR = 10.72), total mental health problems (OR = 6.41) and satisfaction with life (OR = 3.68), compared to same-aged norms. Children affected by parental TBI in childhood report increased psychological problems and poorer satisfaction with life compared to same-aged norms. These results provide evidence for parental TBI as a

predictor of clinical levels of psychological functioning in adulthood and a promising foundation for future research and policy to consider parental TBI as an adverse childhood experience (ACE).



## **Chapter One: Introduction**

Chapter One discusses the impact of brain injury on the effected individual, the effect of the injury on others within the family system and covers the patient's accounts of parenting following parental ABI.

### **Background**

Traumatic brain injury is a worldwide health concern currently impacting an estimated 57 million individuals globally (Langlois, Rutland-Brown & Wald, 2006). In the context of Aotearoa/New Zealand, it is estimated that 36,000 individuals suffer TBIs every year, among which Māori and Pacific people are highly overrepresented (ACC, 2017; Feigin et al., 2013; Lagolago et al., 2015). However, those with less severe injuries do not seek out medical attention meaning that the true incidence rate of TBIs is likely underestimated by epidemiological studies, which often rely on hospital admission and discharge records (Feigin et al., 2013). The range of severity of TBI is clinically defined as mild, moderate or severe, with classifications varying depending on the criteria used (Khan, Baguley & Cameron, 2003). It is estimated that 70-90% of all TBIs are mild. The most common causes of TBIs include, but aren't limited to, motor vehicle accidents, falls, assault and sport injuries (Majdan et al., 2011). While other forms of acquired brain injuries, such as stroke or a brain tumour, tend to result in more localised damage to the brain, more diffuse damage is characteristic of TBI due to the brain ricocheting within the skull on impact. As a result, many problems can arise with cognitive and processing functions following TBI, such as impaired executive functioning, regulation of mood, memory and attention (Fleminger & Ponsford, 2005).

Regardless of the severity of their injuries, patients living with TBI report a spectrum of persistent difficulties post-injury which affect the individual's ability to take part in relational, occupational and physical roles that they previously engaged in (Levack, Kayes & Fadyl, 2010). The sense of loss is profound amongst those living with TBI, with many reporting feeling disconnected

from who they used to be and the quality of life they had prior to the injury (Levack et al., 2010). Treatment often utilises an interdisciplinary approach to address issues such as resuming daily living activities, undergoing cognitive and behavioural therapies and management of pain (Khan et al., 2003). Some rehabilitation treatments focus on maximising life satisfaction following injury to enhance wellbeing whilst others suggest holistic, long-term intervention which involve collaborating with each patient, their families and their carers (Charles, Butera-Prinzi & Perlesz, 2007; Duclos et al., 2014; Khan et al., 2003). Although individuals recovering from TBI report difficulties in resuming previous responsibilities and acknowledge the social burden of TBI, little consideration is given to establishing former relational duties.

### **The Role of Family following Caregiver TBI**

Families play a key role in re-establishing the life trajectory, meeting the developmental needs and reintegrating of the family member affected by persistent injuries, such as TBI, into other social systems (Rolland, 1999). In the context of Aotearoa/New Zealand, the significance of whānau (family) is emphasised in Māori culture, with family health (taha whānau) often outlined as a *necessary* component to overall well-being (Durie, 1998). Furthermore, '*Ala Mo'ui*, a pathway of Pacific wellbeing, highlights fāmili (family) as a central part of life and a *key* component to achieving equitable health outcomes in Pacific peoples (Ministry of Health, 2014). According to Māori and Pasifika worldviews, understanding the impact of TBI on affected family members would be imperative for the overall health of the injured individual. The provision of support to families and acknowledgement of their role in the rehabilitation process is also outlined in contemporary views of health. As the injured individual's roles and responsibilities are tied to others, their impaired functioning is collectively shared with those around them, including the family unit (Rolland, 1999). Rolland's (1999) family systems-illness framework suggests that following parental illness or long-term injury, rehabilitation must consider the interactive nature of the injury, the patient and the family unit. This model recognises the potential of injury to disorient the system, though as a strength-

oriented framework, considers family relationships as a potential resource for resilience and growth, rather than a liability.

Due to the incapacitating effects of brain injury, however, families adjusting to parental TBI experience several difficulties such as high levels of dysfunction, increased marital stress, violence in the home and financial strain (Charles, Butera-Prinzi & Perlesz, 2007; Perlesz, Kinsella & Crowe, 1999). Often, relatives of the patient face ramifications to their own wellbeing as a result of the injury, such as increased persistent stress, loneliness, and clinically significant levels of anxiety and depression (Brzuzy & Speziale, 1997; Jumisko, Lexell & Söderberg, 2007; Marsh et al., 2002). Family members may feel an ethical duty towards the injured individual and oftentimes place their needs as second compared to those of person affected by TBI. Despite such findings, relatives of brain injured individuals report insufficient attention by health professionals regarding their psychological wellbeing (Jumisko, Lexell & Söderberg, 2007).

### **Parenting with Acquired Brain Injury**

Although data regarding parenting with TBI is scarce, Stilwell et al. (1997, as cited in Edwards, Daisley & Newby, 2014) report that approximately one third of patients who suffer TBI in the UK have dependent children under the age of 18. TBI is the leading cause of long-term disability globally in adults under the age of 35 and statistics from Aotearoa/New Zealand shows incidence of TBI is typically highest in infancy and between the ages of 15-34-years (ACC, 2017; Feigin et al., 2013; Langlois, Rutland-Brown & Wald, 2006). Therefore, it is likely that a large proportion of TBI patients will have family members that depend on their attention and care, which may be compromised due to changes in the individuals' skills and capabilities.

Despite research highlighting psychological, economical and physical burden for families impacted by parental brain injury, the effect of parental brain injury on children's wellbeing has

received limited research attention (Charles, Butera-Prinzi & Perlesz, 2007; Perlesz, Kinsella & Crowe, 1999). From a family systems perspective, when a parent develops a serious injury or illness such as TBI, the system is severely taxed, with the injured parent likened to an additional child, for whom family members will be expected to care for (Rolland, 1999). Loss of attention for children will be inevitable as the injured parent competes for increased care, whilst the uninjured spouse may have an increased burden as they manage added responsibilities (Rolland, 1999).

Research exploring the experiences of parents following brain injury have found the consequences of injury hinders individuals' ability to manage their role as a parent. Several parents affected by brain injury reported being treated solely as a patient, rather than a person who others may be relying upon. They note clinicians focusing on treating the physical manifestations of their condition, with little to no discussion of how the family unit, particularly children, may be adjusting to the changed dynamics. Brain injured patients recognised the reversal in roles between themselves and their children, noting reduced parental authority as well as a loss of equality as a parent compared to the uninjured parent (Edwards, Daisley & Newby, 2014). Uysal and colleagues (1998) reported parents affected by TBI had impairments limiting their ability to participate in activities with their children. The losses reported by parents from these studies suggest a potential deterioration of the parent-child relationship following parental brain injury.

Parents recognise that it may be difficult for children to understand the changes in the injured parent following TBI, particularly the 'invisible' injuries which have a major impact on their overall functioning, though they are not physically observable (Edwards, Daisley & Newby, 2014). Many caregivers note reduced mobility as a deficit limiting their capabilities as a parent as everyday activities, such as kicking a ball with a child or active involvement with children, are restricted, further impeding the development of the parent-child relationship (Edwards, Daisley & Newby, 2014; Uysal et al., 1998). Speech and language difficulties can also limit parents' ability to bond with their child

and partake in daily activities such as providing support with homework or establishing appropriate rules within the home. Additionally, parents with TBI were more likely to use relaxed forms of discipline compared to the uninjured spouses (Uysal et al., 1998). Research cites a persistent sense of loss amongst individuals with brain injury due to their inability to fulfil previous roles (Fleminger & Ponsford, 2005). Persistent difficulties following TBI may contribute to the frustration and increased familial dysfunction observed in families affected by parental brain injury, hindering the patient's ability to fulfil their role as a parent.

### **Aim of Current Investigation**

The limited pool of research addressing this topic highlights the difficulties faced by individuals with brain injury when adjusting to previous parenting responsibilities. Feelings of detachment from their children both physically and emotionally are commonly reported (Edwards, Daisley & Newby, 2014). Significant alterations in family functioning are presumed to have a lasting impact on dependent children due to major discontinuous changes and role shifts that occur following injuries with persistent complications such as traumatic brain injury (Rolland, 1999). Literature regarding rehabilitation following TBI underscores the importance of considering the impact of injury to those within the wider family system (Perlesz, Kinsella & Crowe, 1999; Marsh et al., 2002). Despite evidence that the impact of TBI extends beyond the injured individual, the impact of such injuries on children within the family has not been widely studied. Research has begun to assess the experiences of children affected by parental acquired brain injury, yet, little attention has been given to the long-term impact of parental TBI on affected children. The current study aims to explore the long-term adaptive functioning, problems and life satisfaction of adults who were affected by caregiver traumatic brain injury during childhood, compared to the general population within an Aotearoa/New Zealand context, in hope of providing insights for those working to support families after traumatic brain injury.

## **Chapter Two: Literature Review**

The current chapter summarises recent research examining children's outcomes following parental TBI. Through a systematic literature review. A short rationale and methodology for the review is provided followed by an evaluation of relevant research exploring the impact and experiences of parental brain injury on children. To conclude the chapter, considerations of how the available evidence may inform TBI rehabilitation practice and policies within Aotearoa/New Zealand are offered.

Though research has considered the experiences of families living in the context of parental brain injury, the attention is usually given to the parents, spouses or caregivers of the injured individual whilst children remain largely overlooked. However, it is well documented that the consequences of TBI are wide-ranging from neurological, cognitive, behaviour and personality changes, which will likely have a significant and potentially negative effect on dependent children (Perlesz, Kinsella & Crowe, 1999). Undoubtedly, the injured individual's relationships will be affected, including that between themselves (the parent), and their children, which the child will need to adjust to, keeping in mind their role as children in the family system. A child's role within the family can vary and is framed by the culture of the family, as well as the culture in which they live. Children rely on adult relatives for their nurturance and support (Peterson & Green, 2009). Due to the imbalance of power present between children and caregivers within the family system, children will likely be directly affected by the choices impacting their parents. In addition to this, there are other factors that could moderate the effect of parental TBI on the child including the developmental stage of the child, the construction of the family as well as the supports available for each family.

The following review aims to identify, appraise and summarise the available findings relating to parental TBI and its effect on affected children. The review provides a starting point from which to identify inconsistencies or gaps within the literature to better inform the direction of the proposed

thesis. Details of the selection and critique of the chosen studies are outlined below, followed by a review of the current findings.

### **Search Strategies and Selection of Articles**

Two preliminary searches were conducted using relevant databases (PsycINFO and Scopus) concentrating on the population of focus (*children*) and the dependent variable of interest (*parental TBI*). Each primary search involved searching the following in three fields: (a) *traumatic brain injury* or *tbi*, (b) *parent\** and (c) *child\**. Each search yielded 668 and 757 results from the PsycINFO and Scopus databases respectively. The search was refined on PsycINFO database to include articles published within the last thirty years (i.e. 1989 and onwards); include participants or results pertaining to children (< 18 years of age); and were published in an English-language peer-reviewed journal. After inclusion criteria were established, this search yielded 439 results. The following parameters were added to the Scopus database to only include items published within the last thirty years (i.e. 1989 and onwards) and articles or reviews. The search was further refined to include key words highlighting the dependent variable (*traumatic brain injury, mild traumatic brain injury, parent, parents*) and the target population (*child, adolescent, school child, infant, child behaviour, child-parent relations*) and potential outcome measures (*social behaviour, coping behaviour, child behaviour, child behaviour checklist, adaptive behaviour, child behaviour disorders*) to yield 644 results. Following inspection of titles and abstracts to assess relevance and suitability to study aims, 3 articles were selected from PsycINFO and no additional items were chosen from the Scopus database.

Secondary searches were conducted using both PsycINFO and Scopus. As databases could rarely distinguish between the parent or child as the injured/ill individual, search terms were modified to address this limitation. Searches involved searching each of the following terms in one field: (a) *parental traumatic brain injury* or *parental tbi*. Each search yielded 32 and 103 items from the

PsycINFO and Scopus databases respectively. Although dissertations were excluded, further parameters were not added as to include as many relevant items as possible due to the paucity of research on this topic. Assessment of titles and abstracts for suitability and relevance led to the selection of 2 additional articles from the first search and none from the second search.

Primary searches highlighted a limited number of studies specific to parental TBI. Therefore, inclusion criteria were adjusted to incorporate studies relating to parental ABI or parental brain injury more broadly to understand the outcomes and difficulties faced by children living in similar circumstances. In the PsycINFO database, the terms a) *brain injury* or *head injury* or *traumatic brain injury* or *acquired brain injury* or *tbi* or *abi* and b) *parent* were searched as keywords. Of 177 results, 5 additional articles were selected. A similar search on Scopus identified 1 additional study. 4 additional studies were identified from reference lists of chosen studies.

Inclusion criteria required articles to be:

- 1) Published in an English peer-reviewed journal
- 2) Published within the last 30 years (1989-2019)
- 3) Examining the impact of parental brain injury on children by exploring the:
  - a) Experiences or psychological outcomes of children who were living with a parent with ABI.
  - b) Psychological outcomes or experiences of individuals who were affected by parental brain injury as children.
- 4) The exposure to parental ABI or brain injury must have taken place in childhood i.e. under the age of 18 years old.

The term 'living with a parent with ABI' refers to children whose experiences or psychological outcomes were examined whilst they were still in childhood, rather than children who



were *physically* living in the same household as the injured parent. Living with the brain injured parent at the time of injury was not a requirement for inclusion. The retrospective outcomes or experiences of adults who were affected by parental brain injury were also included as they give insight into the potential long-term effects of experiencing parental ABI as a child. Due to the limited pool of research in this area, no further requirements were included. Articles were read in full to further establish eligibility to the inclusion criteria of the current review. Of the 16 studies, 13 met inclusion criteria. 2 studies were excluded as it could not be established if exposure to parental TBI occurred during childhood. An additional review was excluded for including studies where timing of participants' exposure to parental TBI could not be established.

Once eligibility was established, the key details of each article were recorded (see Table 1). Key details included were *study location, theoretical framework, hypothesis/research aim, methodology, analysis/results, strengths/weaknesses, implications for practice and implications for future research* were briefly outlined to aid the appraisal process. Each study was then appraised based on its research design and methodological rigor. Articles using quantitative methods were assessed based on the study design, as well as the reliability, validity and presentation of statistical findings. Governed by the appraisal guidelines by Smith (2009), the type of statistical tests used and the level of significance was to be outlined, with provision of details of appropriate measures. Qualitative research designs were appraised based data collection and analysis, as well as meaningful interpretation of findings (Smith, 2009). Overall, the main prerequisite for all papers, regardless of the methodology employed, was congruence between the stated aim and the procedures used for data collection.

## **Search Results**

The results of the literature search identified a small collection of relevant articles with disparities in research aims and methodological design utilised. In general, studies could be pooled into one of the following categories:

1. Psychological outcome measures of children exposed to parental ABI [Kieffer-Kristensen, Siersmaa & Teasdale, 2013; Kieffer-Kristensen, Teasdale & Bilenberg, 2011; Pessar et al., 1993; Redolfi et al., 2017; Sieh, Meijer & Visser-Meily, 2010; Stanescu & Romer, 2011; Uysal et al., 1998; Van de Port et al., 2007; Visser-Meily, Post, Meijer, Maas, et al., 2005; Visser-Meily, Post, Meijer, van de Port, et al., 2005].
2. Children's experiences of living with parental ABI [Butera-Prinzi & Perlesz, 2004; Coppock et al., 2018; Kieffer-Kristensen & Johansen, 2013; Rohleder, Lambie & Hale, 2017].

Both qualitative and quantitative research offer insights into the effect of parental ABI on children. However, due to methodological inconsistencies and the heterogeneity of results between and within the chosen studies, classification as above means meaningful conclusions cannot be made from the data. The lack of an overarching theoretical framework across all reviewed studies further led to difficulties in interpretation of findings. For this reason, review and appraisal of all articles, including study aims, methodological details, results and critique, is provided in Table 1 below. Subsequently, rather than categorising studies into methodologically similar groups, a discussion of the main themes present within the literature is provided, followed by an appraisal of the evidence.

**Table 1: Literature Review Articles**

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Findings	Critical Appraisal
Butera-Prinzi and Perlesz (2004) <i>Australia</i>	Exploring experiences of children living with father with ABI.	Phenomenological approach	N = 4 children (aged 7-12 years)  Parental ABI: 2-4 years post parental ABI.	Semi-structured interviews.  Observations.  Questionnaires (self-report and parental report with non-injured parent).	Adjustment to parental ABI was difficult for affected children, especially concerning physical and psychological changes in the injured parent.  Only study to report increased violence in the family following fathers' ABI.  Positive coping strategies were reported.	Strengths: congruence between study aim and employed methodology; data gathered through observations as well.  Limitations: small sample size; potential sampling bias (children from families who sought counselling); measures incongruent with phenomenological approach that was employed; limited use of quotes to support themes.
Coppock et al. (2018) <i>United Kingdom</i>	Gaining insight into experiences of families affected by parental ABI. This review focused exclusively on children's responses.	Guided by Constructivism principles where it is stated that people develop an understanding of the world through reflection of past experiences.	N = 10 children from 3 families (aged 8-16 years old).  Parental ABI: 18-46 months since parental stroke.	Semi-structured interviews with 3 levels of cognitive operation. 1 <sup>st</sup> level - individuals' reaction to events. 2 <sup>nd</sup> level - reflective functioning i.e. how other family members would react to events. 3 <sup>rd</sup> level - externalisation where participants were asked to consider ABI as separate to the parent.	Thematic analysis lead to identification of several themes.  Children faced great difficulty trying to understand the changes in injured parent and the initial trauma of the incident.	Strengths: congruence between study aim and methodology; externalisation helped children to speak on the negative experiences of parental ABI; some diversity in familial structure (i.e. inclusion of single parent families); great use of data to support themes.  Limitations: low participation rate may indicate sample bias; rigid exclusion criteria may have underestimated true effect of parental ABI on families.

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Findings	Critical Appraisal
<p>Kieffer-Kristensen and Johansen (2013)</p> <p><i>Denmark</i></p>	<p>Exploring experiences of children showing elevated PTSS* levels following parental ABI.</p> <p><i>*post-traumatic stress symptoms.</i></p>	Phenomenological approach	<p>N = 14 children (aged 7-14 years)</p> <p>Parental ABI: &lt; 5 years post parental ABI.</p>	Semi-structured interviews.	<p>Four main themes were highlighted: fear of losing parent, distress and estrangement from those who did not understand their circumstance, increased responsibility, and coping strategies.</p> <p>Children experienced many losses in adjustment following parental ABI, which were often neglected in attempt to protect the ill parent and to preserve the family system.</p>	<p>Strengths: congruency between study aims, method and phenomenological perspective.</p> <p>Limitations: sampling bias (only children exhibiting elevated PTSS following parental ABI); variance in lengths of interviews (younger children could not discuss feelings or experiences in detail due to developmental stage).</p>
<p>Kieffer-Kristensen, Siersma &amp; Teasdale (2013).</p> <p><i>Denmark</i></p>	To relate family and illness factors to emotional and behavioural problems in children affected by parental ABI.	Rolland's Family Systems Illness Model	<p>N = 35 families (with one child between ages 7-14 years old).</p> <p>Parental ABI: &lt; 5 years post parental ABI.</p>	Measures (child self-report; child parental report; parental self-report by both the injured and non-injured parent)	<p>Family stress variables associated to the healthy spouse were associated with increased risk of stress and behavioural and emotional problems in children.</p> <p>Children's wellbeing following parental ABI depends on family factors, especially the level of stress in the healthy parent.</p>	<p>Strengths: congruence between study aim, methodology and theoretical approach; use of standardised measures; use of multiple view-points for measures.</p> <p>Limitations: low participation rate and use of volunteer, non-referred two parent families may indicate sample bias; small sample size (increased chance of type II error).</p>

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
<p>Kieffer-Kristensen et al. (2011)</p> <p><i>Denmark</i></p>	<p>Exploring children's PTSS* and psychological wellbeing following parental ABI.</p>	<p>Not specified.</p>	<p>N = 35 families affected by parental ABI (with one child aged 7-14); Parental ABI: &lt; 5 years post parental ABI.</p> <p>Comparison group: N = 20 families affected by parental diabetes (with one child aged 7-14); &lt; 5 years post diagnosis.</p>	<p>Measures (child self-report; child parental report)</p>	<p>Children were found to be at risk of developing PTSS following parental ABI. 46% of children of a parent with ABI exhibited clinically significant elevated levels of PTSS compared to 10% of children in the control group.</p> <p>Parents of children affected by parental ABI reported greater emotional and behavioural difficulties compared to published norms, but not significantly different from comparison group.</p>	<p>Strengths: congruence between study aim and methodology; use of standardised measures; use of child self-report; inclusion of comparison group and published populations norms; only one child chosen to participate from each family (avoids inter-sibling variance).</p> <p>Limitations: small sample size, potential sampling bias (excluded non-two-parent families, volunteer sample).</p>
<p>Pessar et al. (1993).</p> <p><i>USA</i></p>	<p>Explore the effects of parental TBI on children's behaviour and psychological functioning.</p>	<p>Not specified.</p>	<p>N = 24 family units with 52 children (between 2-23 years old).</p> <p>Parental ABI: 16-84 months post parental TBI.</p>	<p>Measures (all parental report).</p>	<p>According to the uninjured parent, most (91.7%) children experienced negative behaviour change following parental TBI.</p> <p>Correlates of poor outcomes for children were the injured parent's gender, compromised parenting of both the injured and uninjured parent and depression in the uninjured parent.</p>	<p>Strengths: consistency between study aim and methodology.</p> <p>Limitations: sampling bias (small sample size; volunteer sample; only married couples included in study); data collection (children's and injured parent's perspectives gathered by uninjured spouse, use of non-standardised measures (change on measures not clearly defined)).</p>

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
Redolfi et al. (2017).  <i>Italy</i>	Investigate the emotional and behavioural impact of having a parent with a severe ABI on children.	Not specified.	N = 25 couples and their 35 children (15 only children and 10 pairs of siblings – aged between 3-14 years).  Parental ABI: 6-12 months post parental ABI.	Measures (child self-report; child parental report; parental self-report).  Observations (3 x 50 minute sessions with psychologist).	According to psychologists' observations, 62.9% of children showed significant emotional distress, which was underestimated by parental report.  Quality of the marital relationship as reported by both parents was a significant predictor of children's psychological outcomes.	Strengths: consistency between study aim and methodology; data collection (use of natural observations, collection of data from multiple view-points, use of standardised measures); high participation rate.  Limitations: sampling (only two-parent households; small sample size); data collection (observations conducted with one psychologist – having at least one more would allow overall reliability index).
Rohleder, Lambie & Hale (2017).  <i>United Kingdom</i>	To examine the difficulties, emotional coping strategies and support needs of children affected by parental ABI.	Attachment theory briefly mentioned.	N = 6 children affected by parental ABI (between the ages 9-18 years old).  N = 6 parents and N = 3 support workers were also interviewed to gain insight of children's experiences.	Semi-structured interviews.	Thematic analysis revealed four overarching themes: encountered difficulties, emotions experienced, coping strategies and support needs.  Children reported using several adaptive and maladaptive coping strategies, though consistently conveyed the need for sharing experiences with those who 'truly' understood their situation.	Strengths: congruency between study aim and methodology; sampling (included "data collection (triangulated view of children, parents and support workers; siblings interviewed separately).  Limitations: sampling (lack of control group caused difficulty in disentangling 'normal' family stresses from those specific to children living within the context of parental ABI); data collection (no objective measures used to measure coping strategies, only reported experiences).

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
Sieh et al. (2010) *  <i>Netherlands</i>	To explore risk factors for stress in children 3 years after parental stroke.	Not stated.	N = 44 children affected by parental stroke (between 7-18 years old).  Parental ABI: 3 years since parental stroke.	Measures (child self-report; adult self-report).	Long-term stress in children after parental stroke was associated with the gender of the child (girls report more stress than boys), the depressive symptoms and marital dissatisfaction of patients' spouses.  Greatest correlation to childrens' stress was observed for depressive symptoms of ABI parent, not patient gender or functioning.	Strengths: consistency between study aim and methodology; data collection (use of standardised measures with reports of reliability and validity, children's perspective considered); use of longitudinal method (establishment of trends in data, cross referencing of data from multiple time points).  Limitations: sampling (small sample size; lack of control group meant no comparative data for measures; potential sample bias as children of parents who had more than one stroke, or were separated, were excluded); data collection (marital dissatisfaction only measured for spouse).

*\*Papers refer to different time points within a single longitudinal study.*

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
Stanescu and Romer (2011)  <i>Germany</i>	Investigate the interrelation between family functioning and children's psychological health in families with a parent with TBI.	McMasters Model of Family Functioning.	N = 46 families affected by parental TBI (with at least one child aged 11-17).	Measures (child self-report; child parental report; parental self-report)	<p>Family dysfunction was found to be positively associated with psychological symptoms of adolescents.</p> <p>Different coping styles, such as affective responsiveness, affective involvements, role acceptance and communication, were positively linked to children's problems.</p>	<p>Strengths: consistency between study aim and methodology;</p> <p>Limitations: sampling (small sample size; excluded single/divorced/ concubine parents); data collection (children's perspectives not considered to report family coping strategies).</p>
Uysal et al. (1998)  <i>USA</i>	To examine: 1) The parenting skills of individuals with traumatic brain injury (TBI) and their uninjured spouses 2) The effects of parental TBI on children. 3) The effects of parental TBI on the depression of all family members.	Not specified.	<p>N = 16 families affected by parental TBI (with at least one child, aged 7-18 years old).</p> <p>Parental ABI: Mean time since TBI, M = 9.3 years.</p> <p>Comparison group: N = 16 families not affected by parental TBI (with at least one child, aged 7-18 years old).</p>	Measures (child and parental report)	<p>No statistically significant difference in the frequency of behavioural problems between children of parent with TBI and the comparison group.</p> <p>Children affected by parental TBI experienced more depressive symptomology than control group.</p>	<p>Strengths: consistency between study aim and methodology; inclusion of comparison group; data collection (child perspective considered for parenting behaviours; use of many measures); results (lot of evidence used to support findings).</p> <p>Limitations: sampling (small sample size; only included two-parent families); data collection (limited information of how collection of data occurred and ethical concerns for children).</p>



Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
<p>Van de Port et al. (2007) *</p> <p><i>Netherlands</i></p>	<p>To examine long-term effect 3 years after parental stroke on children (including caregiving, behavioural problems and child stress).</p>	<p>Purposely not specified – as study was exploratory.</p>	<p>N = 44 children affected by parental stroke (between 10-21 years old).</p> <p>Parental ABI: 3 years since parental stroke.</p>	<p>Measures (child self-report; child parental report).</p>	<p>Stress was significantly associated with gender of the child. It was also linked to depression and life satisfaction of the injured parent as well as the patient not being able to partake in daily activities.</p> <p>Many children (66%) assisted ill parents with care, with most feeling more mature (81%), more needed (56%) and like they had more responsibilities (72%). Many (43%) children noted feeling more positive following parents' ABI.</p> <p>Externalising symptoms were more commonly reported in younger children.</p>	<p>Strengths: consistency between study aim and methodology; use of longitudinal method (establishment of trends in data); examined children's positive experiences.</p> <p>Limitations: sampling (small sample size; lack of information regarding participants lost from previous study, see Visser-Meily et al., 2005; lack of control group meant no comparative data for measures; potential sample bias as children of parents who had more than one stroke, or were separated, were excluded); data collection (use of one non-standardised measure for perceived positive changes, measure did not clarify between no change and negative change).</p>

*\*Papers refer to different time points within a single longitudinal study.*

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
Visser-Meily, Post, Meijer, Maas, et al. (2005) *  <i>Netherlands</i>	To investigate: 1) Support given to children of patients with stroke by rehabilitation teams. 2) Characteristics that predict children's adjustment 2 months following parental stroke.	Purposely not specified – as study was exploratory.	N = 82 children at the start of patient rehabilitation. N = 77 children at 2 months following discharge post-stroke (between 4-18 years old).  Parental ABI: 2 months after discharge following parental stroke.	Measures (child self-report; child parental report; parental self-report)	Half of all children received support from rehabilitation team (defined as at least one consultation with a rehabilitation staff member or attending full-day of therapy).  Receipt of support was linked to the severity of disability of the parent with stroke, not the health status of the child at the start of the stroke victim's stay at inpatient rehabilitation.  Children's adjustment 2 months following stroke patient's discharge was related to marital strain of parents and not to patients' characteristics or to support from rehabilitation team.	Strengths: consistency between study aim and methodology; data collection (use of standardised measures, children's perspective considered); longitudinal method (establishment of trends in data); reporting of ethical process.  Limitations: sampling (small sample size; potential sample bias as only children who lived in two-parent household and whose parent has been selected for inpatient rehabilitation and was moderately disabled, was selected); data collection (definition of support from rehabilitation team was crude); outcomes relating to the parent with ABI focused on impairment level without consideration of other factors such as depression or perception of marital status).

*\*Papers refer to different time points within a single longitudinal study*

Chosen Paper	Study Aims	Theoretical Framework	Participant Details	Data Collection	Analysis/Results	Critical Appraisal
Visser-Meily et al. (2005) *  <i>Netherlands</i>	To explore: 1) Course of children's functioning (i.e. health status, depression, behaviour problems) during the first year after stroke? 2) Which factors measured at inpatient rehabilitation, can predict children's functioning at 1 year after stroke?	Purposely not specified – as study was exploratory.	N = 82 children at the start of patient rehabilitation. N = 71 at 1 year post-stroke (between 4-18 years old).  Parental ABI: 1 years since parental stroke.	Measures (child self-report; child parental report; parental self-report)	At 1 year after stroke, fewer children (29% vs. 54%) exhibited one or more clinical problems, compared to at the start of the patient's rehabilitation.  Children's functioning at 1 year after stroke was best predicted by children's functioning at the start of patient rehabilitation.  Level of depression of the uninjured parent and their perception of the marital relationship were also significant predictors of child functioning at 1 year after parental stroke.	Strengths: consistency between study aim and methodology; data collection (use of standardised measures, information regarding patients lost from start of study clearly outlined; longitudinal method (establishment of trends in data); reporting of ethical process.  Limitations: sampling (small sample size; potential sample bias as only children who lived in two-parent household and whose parent has been selected for inpatient rehabilitation and was moderately disabled, was selected); outcomes relating to the parent with ABI focused on impairment level without consideration of other factors such as depression or perception of marital status).

*\*Papers refer to different time points within a single longitudinal study*

## **The Effect of Caregiver Acquired Brain Injury on Children.**

Throughout the literature, seven main areas of childhood outcomes following parental brain injury (BI) were identified. Across the selected articles, these included i) *initial trauma*, ii) *living with the injured parent's physical/psychological changes*, iii) *loss of attention and care*, iv) *relationship with the uninjured parent*, v) *overall psychological functioning*, vi) *changes in Day-to-Day Life*, vii) *coping strategies and support*. The following sections outline key findings within each topic.

### *Initial Trauma*

Specific experiences of children in the acute phase of trauma is largely ignored in the quantitative literature. However, it is believed that children affected by parental brain injury are likely to display increased levels of short-term stress following parental ABI due to the event-specific traumas and sudden onset associated with brain injury (Rolland, 1999). Results by Kieffer-Kristensen and colleagues (2011) revealed that compared to 10% of children with diabetic parents, 46% of children affected by parental ABI had clinically significant elevated PTSS. Many children admit to reminiscing about the specific events involving witnessing, learning about the injury and seeing the ill parent (Kieffer-Kristensen & Johansen, 2013). One child stated '*I feel I'm okay, even though I think a lot about what happened that day*' (Kieffer-Kristensen & Johansen, 2013, pg. 1564). Others recalled more vivid experiences and fear of parental death; '*it was so upsetting. I thought she would die, and I would never see her again*' (Kieffer-Kristensen & Johansen, 2013, pg. 1565). Fears of the healthy parent, siblings or even the child themselves becoming ill were also common. Though many acknowledged that parental brain injury was not something '*you could ever prepare anyone for*' (Coppock et al., 2018, p. 479), some felt guilty for not reacting differently at the time of injury. One boy recalls his sadness as '*(he) heard a bump from the bathroom and found (his father) with froth coming out of his mouth and all white in his eyes. I was sure he was dying and collapsed totally crying*' (Kieffer-Kristensen & Johansen, 2013, pg. 1565).

### *Living with the Injured Parent's Physical/Psychological Changes*

A common theme identified within the work by Coppock et al. (2018) was *parentification*, where children were expected to take on a seemingly parental role towards the injured parent. A 16-year old boy notes *'well now it's like looking after four children now instead of like three'* and compares his father to a peer rather than a parental figure, stating *'he's still a Dad like he cares for me and all that, but most of him now, he's like a friend now'* (Coppock et al., 2018, pg. 480). Comparatively, an adolescent girl noted *'you have to be patient with them and you can't like, stress them out a lot'* (Coppock et al., 2018, pg. 480).

The most common experience noted by ABI affected children could be termed as *ambiguous loss*, where although the parent exists physically, they are no longer the same person (Rohleder et al., 2017). One child noted *'I really do like my mum as she is, but it is just that I sometimes really miss my old mum'*. For a 14-year-old girl, the feeling of loss was clearer, stating *'For me, it is like he died, and I got a stepfather instead. This is a tough thought to have. It would have been 100% easier if he had died; then everybody would understand that he was gone'* (Kieffer-Kristensen & Johansen, 2013, pg. 1566). Though some noted positive changes such as the ABI parent being more physically present, less stressed or less strict, this was substantially outweighed by seemingly negative changes in parental personality (Kieffer-Kristensen & Johansen, 2013; Rohleder et al., 2017).

In work by Rohleder and colleagues (2017), almost all (N = 5/6) children noted increases in parental anger with one child noting changes in his father's expression of anger: *'he got more irate, more things wound him, well the same things wound him up but he just made a bigger deal out of it...'* (Rohleder et al., 2017, pg. 201). In some instance children reported this leading to increased parental discord: *'he never seemed in a good mood. And, a lot, lots of times they were arguing and it's such a small house it's quite hard not to hear, and that was quite upsetting, yeah, I think that was probably one of the worst bits'* (Rohleder et al., 2017, pg. 201). This was further validated by reports

from a social worker who noticed ‘*certainly, one particular father that I spoke to, his daughter, I think she was about 2 years old and found it really difficult to comprehend kind of why daddy lost his temper so quickly*’ (Rohleder et al., 2017, pg. 202). One aspect which is often overlooked is the impact that difficulties in communication and memory following parental brain injury have on children, which is often likened to a sense of ambiguous loss of the parent. One son described interactions with his father as ‘*a constant game of charades*’. A daughter spoke of her mother not understanding sarcasm or humour: ‘*family jokes – she didn’t find them funny anymore. Or simple things like sarcasm – doesn’t understand it, or just not being herself really... to see someone in your mum’s body but not the person she was before. And you can’t, you can’t understand why it’s not the same person*’ (Rohleder et al., 2017, pg. 202). This is further corroborated by findings of Redolfi et al. (2017) who found that 77.3% of emotionally distressed children in the sample had ABI parents affected by memory disorders, compared to 27.7% of emotionally distressed children whose injured parent was not affected by this cognitive disorder.

Though not discussed in other studies, children in Butera-Prinzi and Perlesz’s study (2004) reported increases in verbal and physical abuse in the home. Interestingly, children did not disclose such incidents during their interviews, but only in subsequent therapy sessions which emphasises the importance of being cautious and attentive to the possibility of family violence in the home following parental ABI.

### *Loss of Attention and Care*

Though the topic of *ambiguous loss* was the most noted sense of loss felt by young people affected by parental brain injury, findings indicate that these children experience numerous losses, though many are suppressed to protect the injured parent (Kristensen & Johansen, 2013). One daughter spoke of feeling neglected due to her mother’s cognitive state following her injury, stating ‘I feel that she can look after me most of the time, but like the other day – I know that I’m 12 and I

can get my own dinner and do that, I'm not the best, ... cos now she's sort of forgotten I needed to eat. She forgot I needed dinner' (Rohleder et al., 2017, pg. 202). Another child spoke of loss of attention and care from the non-injured parent who was preoccupied with the injured parent's care: 'I guess at the time I felt like I had just lost one parent, I have kind of ... [also] lost my mum, but she was kind of not there because she was with him at the hospital for just like maybe 3 months or so while it was really serious' (Rohleder et al., 2017, pg. 202). One mother spoke of her realisation of the effect this loss of attention had on her child: 'I spent a lot of time at the hospital and one of the things that my daughter has since said, which at the time I didn't even realize at all was that she said, "you stopped reading to me at bedtime" [...] I realized that that really had and still has had an impact on her... I wasn't around very much and it was at a time when they probably needed me around more' (Rohleder et al., 2017, pg. 202).

### *Children's Relationship with the Healthy Spouse*

Several studies showed a positive link between the mental health issues of the uninjured parent and increased stress or behavioural problems in affected children (Pessar et al., 1993; Sieh et al., 2010; Visser-Meily et al., 2005). Kieffer-Kristensen et al., (2013) revealed that high parental distress in the healthy spouse was associated with significantly higher post-traumatic stress symptoms in children compared to low parental distress [ $OR = 1.09$ , 95%CI = 1.02-1.17]. Additionally, high stress in parent-child interactions with the healthy spouse was associated with increased problematic behaviour in the preceding 6 months compared to minimal stress during parent-child interactions [ $OR = 1.28$ , 95%CI = 1.06-1.55,  $p = 0.01$ ]. Similarly, Visser-Meily et al., (2005) found that depressive [ $OR = 0.59$ , 95%CI = 0.07-1.11], internalising [ $OR = 2.22$ , 95%CI = 0.93-3.51] and externalising behavioural symptoms [ $OR = 1.28$ , 95%CI = 0.16-2.41] and poor health status [ $OR = -2.31$ , 95%CI = -0.98-(-3.46)] of children 1 year following parental stroke was associated to depressive symptoms of the healthy spouse at time of admission to inpatient rehabilitation.

A study by Redolfi et al., (2017) revealed that whilst healthy parents observed 22.9% of children as emotionally distressed, psychologist observations revealed 62.9% of total children showed significant emotional distress. Additionally, the quality of the marital relationship according to the healthy parent, was negatively associated with emotional distress in children, as observed by the psychologist. School-aged children perceived healthy parents to be stricter, more burdened, stressed and appeared to not engage with previously enjoyed activities (Kieffer-Kristensen and Johansen, 2013). According to Redolfi et al. (2017), healthy spouses who did not feel the burden of caring for the injured parent, more frequently observed conditions of emotional distress in their children [87.5%] compared to healthy parents who perceived a greater burden in caring [12.5%]. Similar findings were obtained by Pessar et al. (1993) where reduced parental performance of the uninjured parent was associated with a significant increase in acting out behaviours [ $r = 0.46$ ] and emotional problems [ $r = 0.64$ ] in their children. To contrast, however, longitudinal results by van de Port (2007) noted that stress in young people 3-years post parental stroke, was not associated with the variables related to the healthy spouse.

### *Overall Psychological Functioning*

Greater than 90% of families affected by parental brain injury, report negative changes in dependent children's behaviour since injury (Pessar et al., 1993). In a 3 year-longitudinal exploratory study, van de Port and colleagues (2005) found that 10.8% of individuals in this group experienced clinically significant levels of stress. 25% of young people under the age of 16 experienced behavioural problems in the clinical/sub-clinical range, whereas this number was much lesser for youth aged 17 and over (6.7%). Similar to findings by Sieh et al. (2010), girls showed significantly higher stress levels compared to males following parental ABI (van de Port et al., 2005). Research by Redolfi and colleagues (2017) also highlight differences in child functioning following parental brain injury as a function of age and gender. According to observations, psychologists found that behavioural disorders were more common in males [66.7%] than females [23.5%], whereas somatic



complaints were more frequently found in younger children than older children [60% vs 16%]]. In contrast, Uysal and colleagues (1998) found no significant behavioural differences between children of parents with TBI and children with no TBI parent.

### *Changes in Day-to-Day Life*

Van de Port et al. (2007) found that when interviewed, 100% of children in their sample reported performing at least one house-hold activity (i.e. cooking, cleaning their room or buying groceries etc.). Children also reported assisting the injured parent with various tasks (66%) such as whilst eating (39%), pushing their wheelchair (34%) or helping the injured parent dress (16%). Increases in responsibility were not limited to household tasks, as one child stated ‘...*I comfort my younger sister and then my older sister comforts me*’, denoting a sense of increased emotional responsibility (Kieffer-Kristensen & Johansen, 2013). Many children noted having to take over responsibility for the tasks the injured parent could no longer conduct, and having less leisure time as a result. However, several positive changes in children were also noted following parental brain injury. Children reported feeling more needed (56%) and mature (81%), whilst parents reported children spending more time with them (24%) and were more positive post-injury (43%) (van de Port et al., 2007). Children also reported experiencing closer relationships with family members and increased empathy towards others with disabilities (Kieffer-Kristensen & Johansen, 2013).

### *Coping Strategies*

Kristensen and Johansen (2013) identified several coping strategies employed by young people to manage various stresses. Whilst some found *distracting* themselves with friends or leisure activities as an effective coping mechanism, others found it easier to *accept and adjust* to events. One child stated, ‘I have to remind myself that it is more difficult for my parents than it is for me because it doesn’t help me that I feel sorry for myself all the time!’ (Kieffer-Kristensen & Johansen, 2013, pg. 1566). Some noted *helping others* using their own experiences, but others reported feeling more

mature than their peers: 'I find it so annoying when my girlfriends complain about how fed up they are with their mothers - I think they are lucky just to have a normal mother' (Kieffer-Kristensen & Johansen, 2013, pg. 1566).

Three common emotional coping strategies were also identified by Rohleder et al. (2017) being *avoidance*, *suppression* and *talking to others*. Gender differences should be noted as whilst all girls chose to talk to their girlfriends about problems, less than 15% of males chose to do the same (Kieffer-Kristensen & Johansen, 2013). This was further corroborated by one girl who stated seeing a psychologist as the 'best thing she ever did' whereas one boy refused this offer as they were afraid of being stigmatised (Kieffer-Kristensen & Johansen, 2013).

Stanescu & Romer (2011) studied the interrelation between family functioning, family coping strategies and adolescent mental health following parental TBI, and found that higher youth self-reported psychological symptoms positively correlated with increased family dysfunction [ $r = 0.30$ ]. Additionally, when reframing was used as a coping strategy, significantly negative associations were found to family problem solving [ $r = -0.33$ ] and increased interest in family member's activities [ $r = -0.35$ ].

### *Support*

Immediately post injury, children noted the availability of several support systems. Though this helped maintain routine and lessened the burden for the uninjured spouse, to whom most of the support was offered to, much of this diminished once the injured parent was brought home (Kieffer-Kristensen & Johansen, 2013). Most children identified the healthy parent as their main source of support, though some acknowledged approaching grandparents or siblings for support.

Rohleder et al. (2017) identified two specific support needs for children affected by parental ABI. Several children noted *wanting more information or advice* about living with someone with brain injury to ease fears about the unknown future and provide reassurance about any potential worsening of the situation. The most commonly expressed need was the *desire to talk to others* who had experienced similar situations to themselves. One child noted *'yeah someone to talk, even via... a Facebook group, or one of those kind of things where you don't necessarily need to meet the person. But I wouldn't want someone to comfort me, and put an arm around me and tell me it's alright... I want someone to relate to, and exchange stories with, that sort of thing'* (Rohleder et al. (2017), pg. 205). This underscores the need to not only speak to any other person, but to have someone who could show genuine understanding and empathy through shared experience. Similarly, a support worker was an advocate for peer support rather than simply providing reassurance: *'What we think would be really beneficial in this situation is to have someone to meet or talk to or see in a video, other children saying this is what I experienced, you know; my dad was like this, my dad didn't understand...it might just make them feel more normal like they're not the only person in the world who's parent, you know, has clearly got difficulties'* (Rohleder et al., 2017, pg. 205). Similar views were raised from multiple viewpoints signifies the saliency of these concerns for the families in such circumstances.

## **Appraising the Current Evidence**

Due to the epistemological similarities within qualitative and quantitative research independently, the selected studies will be summarised based on its methodology.

### *Quantitative studies – Strengths and Limitations*

The quantitative studies above offer considerations of the effects of caregiver acquired brain injury on children's psychological health. Although a wide range of outcomes were reported, it is

difficult to draw meaningful conclusions from the data due to the lack of an overarching theory or consistent measures. As most studies failed to mention a theoretical foundation for the research, it was difficult to establish if the outcome measures were examining the outcomes most salient to each study. Most studies sought children's perspectives by use of self-report measures. However, in many studies the uninjured parent was used as a proxy reporter for measures pertaining to the child and in some cases, the parent with ABI (Pessar et al., 1993; van de Port et al., 2007; Visser-Meily et al., 2005). The use of non-standardised measures was a limitation evident in some studies (Pessar et al., 1993; van de Port et al., 2007). Use of non-standardised measures limits comparisons between articles using similar measures as change is not clearly defined, reducing the validity and reliability of the obtained findings.

Several study design limitations, especially pertaining to sampling, impede the generalisability of findings. Almost all studies reported small sample size and restrictive inclusion criteria, creating a potentially inaccurate representation of families affected by parental ABI. Several studies excluded non-nuclear family structures, and studies examining the longitudinal effect of parental stroke on children also excluded parents who had recurrent injuries (van de Port et al., 2007; Visser-Meily et al., 2005). Though strict inclusion criteria increases the rigor of the experimental design, generalisability of findings are reduced as the sample population no longer accurately represents the families living with parental ABI. Relationship satisfaction following spousal ABI is much poorer compared to spouses affected by other chronic illnesses, with separation and divorce rates as high as 40-55%, 6-7 years post-injury (Burridge et al., 2007; Oddy et al., (1985) & Tate et al., (1997), as cited in Burridge et al., 2007). Exclusion of parents who are separated or divorced may reduce the representativeness of the sample population, whilst simultaneously excluding the children who may be experiencing the greatest adversities, therefore, underestimating the realities of children affected by parental ABI.

Due to the cross-sectional design of nearly all the selected studies, causal inferences cannot be drawn from the reported data. The lack of comparison groups in most studies makes it difficult to disentangle children's outcomes due to parental ABI, as opposed to 'normal' familial stresses. Furthermore, unaccounted variance within findings may be explained by pre-injury variables, however, obtaining pre-injury data with illnesses such as ABI which involve sudden-onset, is challenging. Some studies demonstrated effective use of comparison groups, such as in Kieffer-Kristensen (2011) where families living with parental diabetes were used, allowing for comparison of outcome measures between populations. However, though a control group with a chronic illness mimics some factors present in ABI such as loss of parental attention, parental diabetes lacks many of the significant factors which accompany ABI such as amnesia or changed personality of the injured parent, which often has a profound impact on affected children.

Overall, there is limited quantitative research examining the effect of parental ABI on children, with 4 of the 8 publications pertaining to different time points of the same study, using the same group of participants (Sieh et al., 2010; van de Port et al., 2007; Visser-Meily et al., 2005; Visser-Meily et al., 2005). All studies were conducted in relatively homogenous Western cultures, making generalisability to families living with ABI in developing nations more challenging. Additionally, application of available evidence as best practice in New Zealand requires consideration of the various cultural and political distinctions that exist in Aotearoa.

### *Qualitative studies – Strengths and Limitations*

Most of the qualitative studies exhibited strict application of procedures with provision of clear hypotheses and epistemological stances. The chosen papers gave insight into the experiences of children affected by parental ABI. Inclusion and exclusion criteria were not as rigorous as seen in quantitative research, with some including single-parent families as well as families who had since separated (Coppock et al., 2018; Rohleder, Lambie & Hale, 2017). This may increase generalisability

of findings by including a greater variety of families affected by parental ABI. However, similar to the quantitative literature, the studies were conducted using largely homogeneous Westerns samples from United Kingdom, Australia and Denmark.

Purposive sampling was used by two of the qualitative studies. Butera-Prinzi and Perlesz (2004) recruited families who sought family therapeutic sessions whereas Kieffer-Kristensen and Johansen (2013) chose children who showed elevated levels of post-traumatic stress disorder. Though it is essential to capture the experiences of those who may be experiencing adverse outcomes, it is equally important to shed light to children who report positive experiences following parental ABI. Research tends to resort to problem-centred perspectives when assessing children's health which can increase stigma to the groups of children related to the research (Maton et al., 2004). According to Maton et al. (2004), shifting towards a strengths-based concept requires researchers to draw attention or inquire about the positive experiences children have, as well as the understandings and strengths they may offer. All qualitative studies reported on positive experiences of living with a parent with ABI. In one paper specifically, authors not only considered children's recalled experiences but also actively inquired about the coping strategies they used and the support services that helped them following parental ABI (Rohleder, Lambie & Hale, 2017).

### **Current Best-Practice in TBI Rehabilitation in Aotearoa**

Considering recent research, children require greater recognition as a part of the family system when affected by parental TBI, as well as throughout rehabilitation practices, policies and research (Maton et al., 2004). In Aotearoa/New Zealand, current best-practice for TBI rehabilitation requires clinical professionals to consider the patient's potential to perform significant life roles. This includes the ability to live independently, returning to employment or leisurely activities as well as maintaining familial relationships (ACC, New Zealand Guidelines Group, 2007). Though policies highlight the potential consequences of parental TBI to families and children, the document offers

limited information regarding the type of issues families may face or the type of supports they may need to perform their roles within the family unit. Evidently, the current scope of literature indicates that children affected by parental ABI are at risk of developing negative health outcomes of their own. As demonstrated by both qualitative and quantitative evidence, children experience a wide range of psychological and emotional adversities when adjusting to parental TBI. Furthermore, qualitative work highlight the potential for improved support services following parental TBI, encouraging resilience and coping within affected families. Many studies emphasise the importance of actively involving children in rehabilitation contexts and discussions regarding the injured parent to support their knowledge and coping following parental injury. Overall, the current literature involves a small number of studies, originating from Western populations (none of which originate from New Zealand), with even fewer studies considering the impact of traumatic brain injury on children rather than ABI more broadly. To address these limitations, further research is needed to support the establishment of evidence-based policies following parental TBI and to effectively support affected families and children.

## **Hypotheses**

The proposed thesis aimed to explore the long-term outcomes of adults who were affected by caregiver TBI as children. It will aim to incorporate strength-based approaches upon carrying out the research by ensuring both positive and negative outcomes are actively inquired about. Based on research presented, it was hypothesised that:

1. Adults who were affected by parental TBI in childhood (age <18) will show increased problems, reduced adaptive functioning and decreased satisfaction with life long-term, compared to same-aged norms.
2. Adults who were affected by parental TBI in childhood (age <18) will show a higher proportion of clinical scores for problems, adaptive functioning and satisfaction with life, compared to same-aged norms.

To investigate the relationship between caregiver TBI in childhood and long-term outcomes, it was hypothesised that:

3. The occurrence of caregiver TBI in childhood (age <18) will predict clinical levels of problems, adaptive functioning and satisfaction with life in early adulthood (age 18 to 33).



## Chapter Three: Methodology

A within-subjects design was utilised as data was collected via an online survey, completed by all participants. Participants answered both quantitative and qualitative questions relating to their adaptive functioning, problems, life satisfaction and caregiver/personal TBI history to examine potential associations between adult long-term psychological outcomes and exposure to caregiver TBI in childhood.

### Participants

The sample consisted of 253 first year undergraduate students, recruited from the Department of Psychology at the University of Canterbury, New Zealand. Recruitment was disrupted due to COVID-19 and the study was not able to recruit the number of participants needed to obtain power (see sample size calculation below). Students participated in this study as partial fulfilment of their course requirements and were awarded with the relevant number of credits for their participation and were grouped based on exposure to parental TBI in childhood, which was identified via self-report. Mean age and ethnic breakdown of each group are shown in **Table 2 (see Results, Chapter Four)**. Participation rate of the study was 95.84%. Two participants were not between the ages of 18 and 35, and therefore did not meet inclusion criteria. Additionally, 10 subjects chose to withdraw from the study after partial completion, however, reasons for withdrawal are not known.

*Sample size calculation:*

$$n = \frac{2 (Z_{\alpha} + Z_{(1-\beta)})^2 \times \sigma^2}{\Delta^2}$$

$Z_{\alpha}$  = constant according to acceptable level of significance / alpha-level and unidirectional or bidirectional effect. Constant was set at 5%  $\alpha$ -error and bidirectional effect = 1.96.

$Z_{(1-\beta)}$  = constant set according to power of the study. Power was set at 80% = 0.8146

$\sigma$  = standard deviation is assumed to be normal = 1

$\Delta$  = estimated effect size (*Cohen's d*) set at a “small” level of effect = 0.2

$$n = \frac{2 (1.96 + 0.814)^2 \times 1^2}{0.2^2} = 392.40 = 393$$

## Measures

### *Demographic Information* (Appendix B; Section I)

At the start of the survey, participants were required to answer demographic questions based on those from the Adult Self Report (ASR) Questionnaire by Achenbach and Rescorla (2003). This portion of the questionnaire included subjects’:

- i) Age, to determine if participants met inclusion criteria as the ASR survey was designed to assess adults between the ages of 18 and 59.
- ii) Gender identity, where participants identified their psychological sense of self, regardless of their assigned sex at birth.
- iii) Ethnicity, which was determined by selecting ones ethnic origin.

### *Parental and Personal Traumatic Brain Injury History* (Appendix B; Section II)

Participants answered questions pertaining to individual and caregivers’ TBI history based on the Ohio State University TBI Identification Method Short Form by Brogner and Corrigan (2007). This portion of the survey inquired about subjects’:

- i) Caregiver TBI status
- ii) Cause of caregiver TBI (if relevant)
- iii) Age and cohabitant status of participant in relation to caregiver with TBI (if relevant)
- iv) Participants’ own TBI status
- v) Cause of own TBI and age of participant during TBI incident (if relevant)

### *Assessing Problems and Adaptive Functioning (Appendix B; Section III)*

The Adult Self Report (ASR: Achenbach & Rescorla, 2003) was used as the primary measure of participant outcomes. The ASR is one of the most widely used tests to measure behavioural, emotional, social and thought problems, substance use, personal strengths and adaptive functioning in adults aged 18-59 (Rescorla et al., 2016). It contains 120 items assessing respondents' problems which were rated on a three point Likert type scale (0 = *not true*; 1 = *somewhat or sometimes true*; 2 = *very or often true*) based on the preceding 6 months. Subsets of the 120 items were used to score six DSM-oriented problems (depressive, anxiety, somatic, avoidant personality, attention deficit hyperactivity and antisocial personality) which have been deemed as being very consistent with the diagnostic categories of the DSM-5 (APA, 2013). However, amendments were made to 3 questions [30, 110 and 113] of the ASR to better encompass different genders and sexual orientations (as seen in Appendix B, Section III, pg. 82). In addition to the 120 problem items, the questionnaire contains five adaptive functioning scales which measures individuals' friends, partners, family, job, education and personal strengths which were rated using various Likert-type scales and included other specific questions (e.g. whether or not the respondent had a partner or job in the preceding 6 months). Amendments were also made to the family subsection of the adaptive functioning section where questions pertaining to 'father' and 'mother' were replaced based on the caregiver options chosen by respondents (refer to Appendix B, Section III, pg. 76-77). This did not alter scoring as the 'Family' subsection used mean scores to assess psychopathology rather than summated scores. As the ASR examines several aspects of adult functioning, it is an efficient way to measure multiple mental health issues simultaneously.

Scoring for the ASR is based on normed scores for each gender at ages 18-35 and 36-59 for adaptive functioning, internalizing problems, externalising problems, total problems, critical items and substance use (Achenbach & Rescorla, 2003). Higher scores in the internalising problems, externalising problems, total problems and substance use subscales is indicative of greater problems

or psychopathology. On the adaptive functioning subscale, however, higher scores suggest greater adaptive functioning or less psychopathology (Achenbach & Rescorla, 2003). Both clinical and borderline clinical ranges are specified to compare respondents scores to each relevant group norm and to assess severity of problems (Achenbach & Rescorla, 2003).

The ASR is a reliable and valid measure for assessing overall psychological functioning in adults (Achenbach & Rescorla, 2003). Test-retest correlations indicate very high reliability with most correlations being significant [ $r$  (range)= 0.71-0.99,  $p < 0.01$ ]. Split-half reliability coefficients indicate good internal consistency within most scales with mean alpha coefficients on the ASR of 0.83, 0.78 and 0.74 for the Empirically based Problem scales, the DSM-oriented scales and for the Critical Items, respectively (Achenbach & Rescorla, 2003). Discriminant analyses revealing 87% of participants were correctly classified as either referred or non-referred samples, indicative of content validity of problem items of the ASR (Achenbach & Rescorla, 2003). Significant associations were found between every scale of the SCL-90-R, a 90-item questionnaire measuring psychological problems in nine areas, and the ASR problems scale. Most correlations met Cohen's criteria for a large effect size [ $r \geq 0.50$ ] signifying strong associations between scores on the two instruments and measurement of a similar psychological constructs (Achenbach & Rescorla, 2003). Overall, research suggests adequate reliability and validity of the ASR as a self-report measure assessing adults' adaptive functioning and problems.

#### *Life Satisfaction (Appendix A; Section IV)*

The Satisfaction with Life Scale (SWLS: Diener et al., 1985) was used to measure participants cognitive judgements of satisfaction with their own life. The 5-item scale has been widely used as a measure of life satisfaction as it assesses individuals' evaluative judgements of his or her own life, using the individual's own criteria (Pavot & Diener, 1993).

Each item is rated using a 7-point Likert-type scale (1 = *strongly disagree*; 7 = *strongly agree*) with the possible score ranging from 5-35, where 20 represents a neutral score. Pavot and Diener (1993) report scores between 5-9 indicate extreme dissatisfaction with life whereas scores between 31-35 indicate extreme life satisfaction. As a clinical cut off score for the SWLS is not outlined, the a score of  $\leq 14$  is used in the current study, which represents dissatisfaction to extreme dissatisfaction with life.

Despite its brevity, the SWLS demonstrates good psychometric properties. Coefficient alpha for the SWLS ranged from 0.79-0.89, indicating high internal consistency (Pavot & Diener, 1993). Test-retest correlations indicate moderate temporal stability with correlations ranging between 0.54 and 0.84 with intervals ranging from a one week to a 4 year span (Pavot et al., 1991, Steger et al., 2006, Magnus et al., 1993, as cited in Pavot & Diener, 2008). Diener et al. (1985) demonstrated that the SWLS shows convergent validity with single-item measures like Cantril's ladder, a measure of current subjective well-being [ $r = 0.62, 0.66$ ], suggesting that both the SWLS and the single-item measure are assessing a single construct. Furthermore, the SWLS negatively correlated with the Beck Depression Inventory, a clinical measure of depression [ $r = -0.72, p = 0.001$ ] and several categories of the SCL-90-R [anxiety,  $r = -0.54$ ; depression  $r = -0.55$ ; overall psychological distress  $r = -0.55$ ], demonstrating discriminant validity of the measure (Blais et al., 1989, Arrindell et al., 1991 as cited in Pavot & Diener, 1993). Empirical findings prove the SWLS to be both reliable and valid in measuring the life satisfaction component of subjective wellbeing.

### **Procedure for Collection of Data**

A brief description of the aims of the current study was provided as an option to first year undergraduate students from the Department of Psychology for research participation in partial fulfilment of course criteria. If this study was selected, participants were provided with an online information sheet (Appendix C) prior to the provision of consent (Appendix D) and voluntary

participation in the study. Participants completed the self-report questionnaires assessing adaptive functioning, problems and life satisfaction, preceded by the collection of demographic information and TBI status of caregivers and oneself. Anonymity was maintained as no identifying data was collected but participants could withdraw from participation by closing the browser, if they wished to do so. Participation took approximately 30 minutes in total and subjects were awarded with 2 academic credits for participation.

## Chapter Four: Results

### Statistical Analyses

Prior to analyses, data were reviewed and recoded to detect and correct errors, to improve its quality and accuracy, and to make it suitable for further analyses. Many questionnaire variables were found to be non-normally distributed, therefore comparisons were carried out using non-parametric statistical procedures. Comparisons between the Parental Brain Injury and Normative Sample groups were made using Mann-Whitney test and alpha for significance was set to 0.05 (two-tailed). Effect sizes for statistically significant comparisons of means have been expressed with Cohen's *d*. Chi-square tests were used to compare the proportion of each group meeting clinical diagnostic scores in each subscale. Analysis of the relationship between chosen variables and clinical scores for the SWLS and subscales of the ASR were conducted using logistic regression analyses. All analyses were performed using SPSS v. 23.

**Table 2:** Participant characteristics.

	Brain Injury (n = 17), n (%)	Normative Sample (n = 236), n (%)
Mean age	19.59 ( $\pm$ 1.77)	19.64 ( $\pm$ 2.53)
Male	3 (17.6)	65 (27.5)
Female	14 (82.4)	171 (72.5)
<i>Ethnicity</i>		
Māori	2 (11.1)	23 (8.7)
Pasifika	1 (5.6)	9 (3.4)
European or NZ European	13 (72.2)	197 (74.6)
Asian	1 (5.6)	26 (9.9)
Middle Eastern/Latin American/African	0 (0.0)	1 (0.4)
Other Ethnicity	1 (5.6)	8 (3.0)
<i>Caregiver TBI History</i>		
Male caregiver	10 (58.8)	-
Female caregiver	3 (17.6)	-
>1 caregiver	4 (23.5)	-
<i>Personal TBI History</i>		

Male	1 (5.8)	5 (2.12)
Female	2 (11.8)	5 (2.12)
Total	3 (17.6)	10 (4.24)

*\*Subjects were able to select more than one ethnic group, resulting in a response count greater than the number of participants in the study.*

## Results

The Parental TBI group scored significantly higher on the Internalising, Externalising and Total Problems subscales of the ASR than the Normative Sample, indicating increased problems in those affected by parental TBI (Mann-Whitney,  $p < 0.05$ ; see Table 3). For all statistically significant mean comparisons of ASR scores, effect sizes were large with little overlap between the two groups (Cohen's  $d \geq 0.9$ ). There were no significant differences on the Substance Use and Adaptive Functioning subscales of the ASR (Mann-Whitney,  $p > 0.05$ ; see Table 3). The Parental TBI group presented with significantly lower scores in the SWLS compared to the Normative sample, with moderate effect size, indicating greater satisfaction with life by those who were not affected by parental TBI (Mann-Whitney,  $p < 0.05$ , Cohen's  $d = 0.51$ ; see Table 3).

**Table 3:** Mean Scores for Adult Self Report (ASR) and Satisfaction with Life Scale (SWLS).

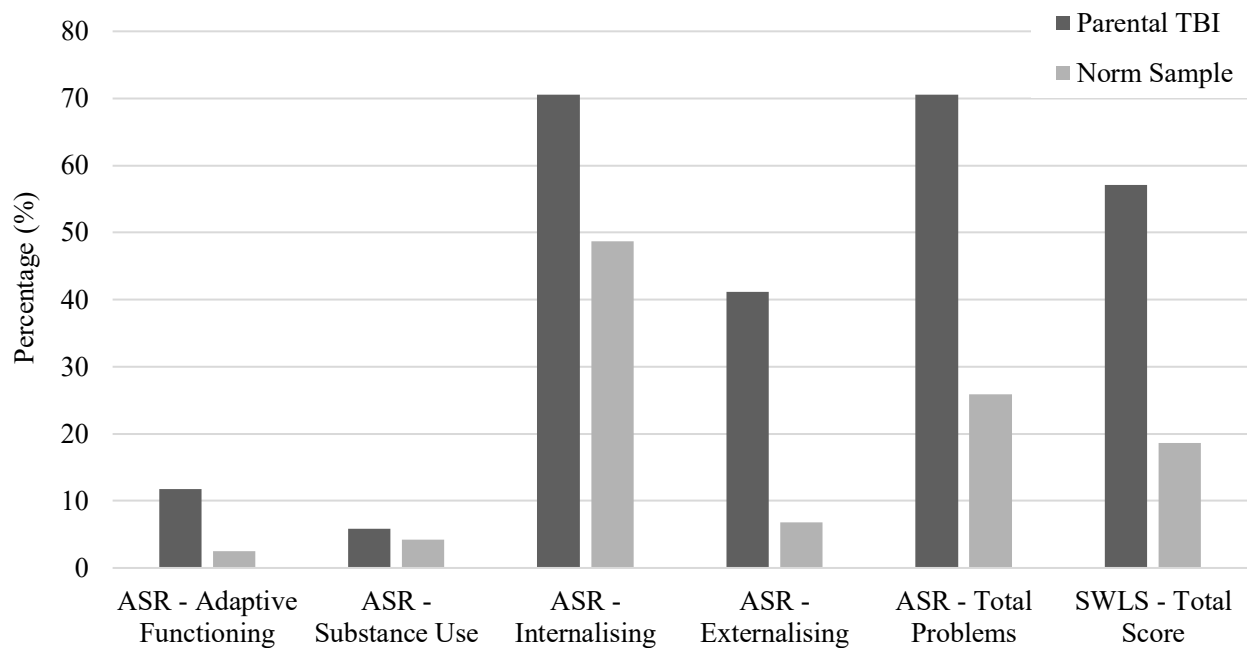
	Parental TBI (n = 17)		Normative Sample (n = 236)		<i>p</i>	Effect size
	Mean	SD	Mean	SD		
<i>ASR-Raw Scores</i>						
Adaptive Functioning	45.28	6.78	47.75	4.96	0.13	
Substance Use	16.94	28.51	17.96	35.57	0.97	
Internalising	38.35	16.50	24.94	13.07	< 0.05	0.90
Externalising	21.82	13.02	10.58	7.01	< 0.05	1.07
Total Problems	101.24	40.68	63.66	28.60	< 0.05	1.07
<i>SWLS</i>						
Total Score	17.94	7.62	21.69	7.04	< 0.05	0.51



Comparison of the Parental Traumatic Brain Injury group with same-aged norms showed that a significantly higher proportion of the Parental TBI group met clinical diagnostic criterion for the Externalising and Total Problems subscales of the ASR as well as the SWLS score ( $p < 0.05$ ). As shown in Table 4 and Figure 1, 70.59% of respondents affected by parental TBI obtained clinical scores in the Total Problems subscale of the ASR, compared to 25.85% of the Normative group (Chi-square,  $p < 0.05$ ; see Table 4). Additionally, 57.15% of participants in the Parental TBI group reported clinical scores in the Satisfaction with Life Scale compared to 18.64% of those who were not affected by parental TBI (Chi-square,  $p < 0.05$ ; see Table 4). The greatest difference between groups was seen in the Externalising subscale of the ASR, where 41.18% of those affected by parental TBI reported scores in the clinical range compared to 6.78% of same-aged norms (Chi-square,  $p < 0.05$ ; see Table 4). There was no difference in the proportion of clinical scores obtained between both groups in the Adaptive Functioning, Substance Use and Internalising subscales of the ASR ( $p > 0.05$ ).

**Table 4:** *Percentage in each group meeting clinical diagnostic criteria.*

	Parental TBI (n = 17)	Normative Sample (n = 236)	$\chi^2$ , df	<i>p</i>
	Percentage	Percentage		
<i>ASR-Raw Scores</i>				
Adaptive Functioning	11.76	2.54	3.58, 1	0.06
Substance Use	5.88	4.24	0.00, 1	0.95
Internalising	70.59	48.73	3.03, 1	0.82
Externalising	41.18	6.78	22.70, 1	< 0.05
Total Score	70.59	25.85	15.05, 1	< 0.05
<i>SWLS</i>				
Total Score	57.14	18.64	7.84, 1	< 0.05



**Figure 1:** *Percentage meeting clinical diagnostic criteria in each group.*

Participant variables were compared between the Parental TBI and Normative Sample group to assess potential confounding variables. The proportion of adults who had experienced a TBI of their own was significantly different between both groups ( $\chi^2 (1) = 5.850 ; p < 0.05$ ), however, no other significant differences were found. To account for the potentially confounding effect of self-TBI, group mean comparisons were performed removing individuals who had experienced a TBI of their own, from the Parental TBI group. The analysis did not alter the original statistical significance of each group mean comparison, following removal of respondents with TBI from the Parental TBI group (see Table 3 and 4). However, it resulted in a decrease in effect sizes for significant group mean comparisons of the ASR subscales and an increase in the effect size of SWLS scores between both groups (see Table 3 and 4).

**Table 4:** *Adult Self Report (ASR) and Satisfaction with Life Scale (SWLS) mean scores with Self-TBI removed from Parental TBI group.*

Parental TBI (n = 14)		Normative Sample (n = 236)		p	Effect size
Mean	SD	Mean	SD		

ASR-Raw Scores						
Adaptive Functioning	45.41	7.20	47.75	4.96	0.25	
Substance Use	17.93	30.81	17.96	35.57	0.95	
Internalising	37.92	17.03	24.94	13.07	< 0.05	0.86
Externalising	22.00	13.71	10.58	7.01	< 0.05	1.05
Total Problems	101.43	42.16	63.66	28.60	< 0.05	1.05
SWLS						
Total Score	17.14	7.59	21.69	7.04	<0.05	0.62

Logistic regression analyses were performed to assess the impact of a number of factors on the probability that respondents would report scores in the clinical range for the ASR and SWLS. Each model contained three independent variables (gender, reported caregiver TBI and reported self-TBI). The Externalising and Total Problems models were statistically significant, indicating that the models were able to distinguish between respondents who reported and did not report clinical scores in the ASR subscales (Model coefficient,  $p < 0.05$ ; see Table 5). However, models for adaptive functioning, substance use and internalising problems were not significant.

**Table 5:** *Model coefficients for logistic regression models.*

Regression Model	Chi-square ( $\chi^2$ )	df	$p$
ASR – Adaptive Functioning	5.80	3	0.12
ASR – Substance Use	1.57	3	0.67
ASR - Internalising	5.56	3	0.14
ASR - Externalising	14.96	3	< 0.05
ASR – Total Problems	14.57	3	< 0.05
SWLS Score	6.79	3	0.08

As shown in Table 6, only one of the independent variables, parental TBI, made a statistically significant contribution to the models. The gender of participants or having a TBI of their own did not significantly predict clinical scores in the ASR or SWLS. Having a caregiver who suffered a TBI was a significant predictor of clinical scores in the Adaptive Functioning, Externalising and Total

Problems subscales of the ASR as well as the SWLS. The Externalising subscale of the ASR, indicated that respondents who reported caregiver TBI were over ten times (10.72) more likely to report Externalising scores in the clinical range, compared to the Normative sample. Respondents were approximately six times (6.27) more likely to report clinical scores in the Adaptive Functioning and Total Problems subscales of the ASR, if they reported experiencing a parental TBI (see Table 6). Lastly, participants were over three times (3.68) more likely to report dissatisfaction with life, or a SWLS score in the clinical range, if they reported parental TBI, when compared to same-aged norms (see Table 6). These results demonstrate that parental TBI was the strongest predictor of problems with adaptive functioning, externalising problems, and total problems.

**Table 6:** Binary logistic regression predicting likelihood of reporting clinical scores in the Adult Self Report (ASR) and Satisfaction with Life Scale (SWLS) from Gender, Parental TBI and Sex.

Predictor	<i>b</i> (SE)	Wald, df	OR	[95% CI]
<i>ASR – Adaptive Functioning</i>				
Gender	1.03, 0.71	2.08, 1	2.79	0.69, 11.21
Parental TBI	1.84, 0.88	4.34, 1*	6.27	1.12, 35.26
Self TBI	-18.60, 10590.98	0.00, 1	0.00	0.00, 0.00
<i>ASR – Substance Use</i>				
Gender	-0.87, 0.78	1.22, 1	0.42	0.09, 1.96
Parental TBI	-0.08, 1.09	0.01, 1	0.92	0.11, 7.85
Self TBI	0.55, 1.11	0.24, 1	1.73	0.20, 15.23
<i>ASR – Internalising</i>				
Gender	-0.42, 0.29	2.07, 1	0.66	0.37, 1.16
Parental TBI	0.83, 0.56	2.26, 1	2.30	0.78, 6.84
Self TBI	0.45, 0.60	0.56, 1	1.57	0.48, 5.14
<i>ASR – Externalising</i>				
Gender	-0.13, 0.55	0.06, 1	0.88	0.30, 2.58
Parental TBI	2.37, 0.58	16.60, 1*	10.72	3.43, 33.56
Self TBI	-0.92, 1.17	0.62, 1	0.40	0.04, 3.92
<i>ASR – Total Problems</i>				
Gender	-0.36, 0.34	1.11, 1	0.70	0.36, 1.36
Parental TBI	1.86, 0.56	11.00, 1*	6.41	2.14, 19.20
Self TBI	0.19, 0.65	0.08, 1	1.21	0.34, 4.29

*SWLS – Total Score*

Gender	-0.09, 0.37	0.06, 1	0.91	0.45, 1.87
Parental TBI	1.30, 0.52	6.19, 1*	3.68	1.32, 10.25
Self TBI	0.35, 0.66	0.28, 1	1.42	0.39, 5.16

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Statistical significance: \*  $p < 0.05$

Note:  $b$  is unstandardized regression coefficients

## **Chapter Five: Discussion**

### **Overview of Findings**

This study investigated whether reported childhood parental TBI exposure (age <18) predicted problems, poor adaptive functioning and lower satisfaction in adulthood, compared to adults who did not report such exposure. This is the first study to examine long-term adult outcomes following reported parental TBI in childhood. Results provide some support for our hypotheses. Respondents who were affected by parental TBI in childhood showed increased long-term problems and reduced satisfaction with life in adulthood compared to same-aged norms. Additionally, there was a significantly higher proportion of respondents meeting clinical diagnostic criteria for overall problems, externalising problems and life satisfaction by those who reported exposure to parental TBI in childhood compared to normative samples. These findings suggest that individuals affected by parental TBI in childhood are at a greater risk of experiencing long-term adverse outcomes in adulthood such as increased problems and reduced satisfaction with life. Contrary to hypotheses, there was no significant difference in scores or the proportion meeting clinical criteria for adaptive functioning, between both groups. Due to limited sample sizes, the interactive effects of gender or self-TBI and parental TBI were not able to be examined. Consistent with previous studies, exposure to parental TBI in childhood was a risk factor for clinical levels of psychopathology (problems, adaptive functioning and satisfaction with life) compared to same-aged norms.

### **Childhood Parental TBI Exposure and Adult Outcomes**

As predicted in hypothesis one, the analysis revealed higher internalising, externalising and total problems scores, as well as lower reported satisfaction with life, for those affected by parental TBI in childhood. Results showed that 70% of the respondents in the Parental TBI group reported clinical scores for total problems, as compared to 25% in the control group. Additionally, 57% of those exposed to parental TBI in childhood met clinical criteria for satisfaction with life, compared to 18% of the normative sample. The largest difference was reported for externalising behaviours

where 41% of those exposed to parental TBI in childhood were found to have clinical scores as opposed to 6% of same-aged norms. Contrary to our prediction, there was no significant difference in adaptive functioning or substance use scores between groups. Furthermore, the difference in the proportion of each group meeting clinical criteria for internalising behaviours, substance use and adaptive functioning was not statistically significant.

Results are consistent with several studies which reported adverse effects for children, following parental ABI, more broadly. This includes depressive symptoms (Uysal et al., 1998; Visser-Meily et al., 2005), increased stress level or anxiety (Coppock et al., 2018; Sieh et al., 2010; van de Port et al., 2007), elevated post-traumatic stress disorder symptoms (Keiffer-Kristensen et al., 2011), emotional distress (Redolfi et al., 2017) and behavioural difficulties (Pessar et al., 1993; Redolfi et al., 2017; van de Port et al., 2007; Visser-Meily et al., 2005). However, as the present study is the first to assess adult outcomes following parental TBI exposure in childhood, it is not directly comparable to existing parental brain injury literature which examines the impact of parental TBI on children (age <18).

Findings of the current study are consistent with research examining the long-term effect of parental illness on affected children. In work by Wong et al. (2009), 59% of participants reported adverse consequences in adulthood following parental cancer exposure during childhood. Despite differences, the specific adversities following parental TBI are analogous to parental cancer due to the persistent nature and sudden onset of the illness, resulting in altered parenting and reduced parental attention (Moore et al., 2015). Long-term effects included feelings of loss and void (22%), negative changes in outlook on life (15%) and negative impact on personal relationships (11%) (Wong et al., 2009). Similarly, Metcalf, Arch and Greer (2017) found that experiencing parental cancer during childhood predicted higher reported anxiety during young adulthood. Results of the present study are consistent with previous research and provides further evidence for the

psychological functioning of children affected by parental traumatic brain injury as well as the long-term outcomes following exposure to parental illness in childhood.

### **Parental TBI in Childhood as a Predictor of Adult Clinical Psychopathology**

As predicted in hypothesis three, the occurrence of parental TBI in childhood significantly predicted clinical levels of problems (externalising and total problems), adaptive functioning and satisfaction with life in early adulthood. However, parental TBI did not significantly predict internalising symptoms or substance use.

The current study is the first to examine parental TBI in childhood as a predictor of clinical psychopathology in adulthood. The systematic review in previous chapters cites one study (four papers referring to different time points of the same longitudinal study) assessing long-term outcomes of children following parental ABI (Sieh et al., 2010; van de Port et al., 2007; Visser-Meily, Post, Meijer, Maas et al., 2005; Visser-Meily, Post, Meijer, van de Port et al., 2005). Analyses looked at risk factors for specific outcomes in children following parental stroke such as stress, behavioural problems and overall functioning. Due to the lack of a control group, parental stroke occurrence was not investigated as a risk factor, however, other adversities following parental ABI were used to predict poor long-term (2-months to 3-years) functioning of affected children (Sieh et al., 2010; van de Port et al., 2007; Visser-Meily, Post, Meijer, Maas et al., 2005; Visser-Meily, Post, Meijer, van de Port et al., 2005). Additionally, limited research has been conducted examining the adult outcomes of parental illness in childhood with none examining the predictive nature of parental illness for clinical outcomes in adulthood. For these reasons, it is difficult to compare consistency of past findings to the results of our study.

### **Strengths and Limitations of the Current Study**



Following the discussion of the contribution of findings to existing literature, some strengths of the current study can be noted. Our research is the first to examine the psychological and adaptive outcomes of adults who have reported parental TBI in childhood, compared to normative samples. It is also the first to assess parental TBI exposure in childhood as a predictor for clinical psychopathology in adulthood, adding to the limited literature base exploring the effects of parental TBI on children. Recruitment was disrupted due to COVID-19 and the study did not meet sample size requirements based on our power calculations (see pg. 41). Although the study was underpowered, we still found significant differences in problems and life satisfaction between groups with moderate to large effect sizes. However, it is possible that other associations may have been missed. A methodological strength is the use of a control group and the retrospective design, allowing for the establishment of comparative data for measures and timing of events. Actively inquiring about both positive and negative outcomes allowed for a more holistic view of the effect of parental TBI on affected children and demonstrates consistency between study aims and methods. Sampling bias was reduced by inclusion of children of parents who had more than one TBI or more than one caregiver with TBI, as well as individuals from all family dynamics. Volunteer participation was encouraged by ensuring anonymity and confidentiality and through the provision of credits, reducing volunteer bias. Other strengths of the present study include the high participation rate as well as the use of standardised measures which have received consistent empirical support for their reliability and validity.

Whilst informative, these results must be considered within the limitations of this study. Though the rate of TBI within this study (6.72%) exceeds population estimates of parental TBI in childhood, due to recruitment interruptions, the parental TBI sample was quite small (Niemela et al., 2014). However, previous estimates of parental TBI may be smaller as only biological parents were examined, rather than nominated caregivers as in the present study (Niemela et al., 2014). This limited the ability to conduct secondary analyses such as possible interaction effects of gender. Previous

findings have shown significantly higher stress levels in females compared to males following parental ABI and significantly more behavioural disorders in males [66.7%] than females [23.5%] (Redolfi et al., 2017; van de Port et al., 2005). Though studies have shown differences in psychological functioning following parental brain injury, based on gender, sample size limited further investigation of gender effects on long-term adult outcomes following parental TBI in childhood. In addition, the small parental TBI sample size meant that though it was actively inquired about, the risk factor of living with the parent with TBI at the time of injury and post-injury could not be assessed. Though measures were taken to help reduce bias, the use of a volunteer university sample may underestimate pathology in both groups and limits the generalisability of findings. Additionally, the disproportionately high rate of females in both the normative (82.4%) and parental TBI group (72.5%) is reflective of the university sample used, though limits generalisability compared to more balanced samples. Finally, only one type of measure (self-report) was used for data collection which may not provide an entirely accurate portrayal of psychopathology and limits generalisation of research to samples using clinical measures of data collection.

One possible factor impacting results is the difference in personal TBI history between groups. Those who were affected by parental TBI in childhood were more likely to have suffered traumatic brain injuries of their own, compared to the norm sample. As previously noted, removal of individuals who reported self-TBI from the parental group did not alter significant differences between groups, though effect sizes were slightly reduced. However, studies have shown that males are more likely to suffer from TBI than females, meaning that our study likely underestimates the true rate of self-TBI in both groups, due to the majority female sample. Additionally, the effect of COVID-19 on the mental health of students is unknown. In the parental TBI group, 70% met the clinical diagnostic score for internalising behaviours, however, this was not significantly greater than the normative sample who reported 48% meeting clinical scores. As data was gathered during the early stages of the COVID-19 pandemic/lockdown in New Zealand, students may have reported elevated levels of

anxiety and depression, accounting for the high proportion of students meeting clinical criteria for the internalising problems in both samples (refer to Figure 1, pg. 50). It is also possible that the pandemic resulted in poorer psychological functioning and reduced satisfaction with life, in both the parental TBI and comparative sample, elevating the rate of psychopathology reported by both groups.

### **Implications for TBI Policy and Rehabilitation Practice**

TBI is a sudden and uncontrollable event which can severely impact the children of affected individuals and results highlight lasting effects of exposure to parental TBI in childhood. Consequently, rehabilitation practices targeted towards TBI-injured individuals and their spouses will likely affect dependent children. This reiterates how consideration of the needs of the injured parent and the healthy spouse should also encompass the dependent children of TBI patients, to lessen adverse long-term outcomes.

One recommendation is that health services should identify their TBI patients who are performing parenting roles and to consider the supports needed to cope with the demands of parenting after TBI. Patients readjusting to their parental responsibilities under new circumstances often stress the importance of rehabilitation in a familial context to ultimately aid familial harmony following parental brain injury (Khan, Baguley & Cameron, 2003). Studies such as Edwards et al. (2014) have reported a lack of services specifically provided for parenting. These findings highlight the opportunity for rehabilitation staff to consider and support the patient's role as a parent during the recovery process. Parenting and child development can be supported through provision of additional care for the injured parent, lessening the burden for uninjured spouses, allowing them the freedom to resume parenting obligations. Frequent contact with health and social services following the discharge of injured parent would allow families the opportunity to request and be provided with additional and ongoing supports. Inclusion of educational components for children may be beneficial to aid understanding and acceptance of the complex nature of brain injury and the 'invisible' problems

that accompany it. Because the social burden of brain injury is enormous, family education and counselling, as well as the ongoing support of patients and their children is essential for the wellbeing of everyone affected. Acknowledgment of children during rehabilitation following parental TBI should also be considered by designers of research and policy, not by health service providers alone. In line with a family systems illness perspective and indigenous worldviews (Durie, 1998; Ministry of Health, 2014; Rolland, 1999), TBI policy and guidelines for clinical practice in Aotearoa/New Zealand, need to recognise the position of children within the context of parental TBI to allow consideration of their needs and to achieve overall well-being for the TBI-affected caregiver.

The current study is the first to examine the predictive nature of parental TBI to clinical psychopathology in adulthood. The specific challenges accompanying parental TBI such as parental mental illness, neglect, parental substance use and parental loss or divorce were found by Green and colleagues (2010) to be strong correlates of psychiatric disorder onset in adulthood. As found with psychiatric disorders, the similar behaviour changes and distress resulting from a parent being affected by TBI have an impact on parenting (Uysal et al., 1998). Further, parental TBI involves both interpersonal and attentional loss as the injured spouse is preoccupied with caring for the injured parent (Kratz et al., 2017; Rolland, 1999). High levels of dysfunction, increased marital stress, violence in the home and financial strain are also commonly reported and depression, anxiety, and substance misuse are common in both the affected and unaffected parent (Charles et al., 2007; Flemiger & Ponsford, 2005; Marsh et al., 2002; Perlesz, Kinsella & Crowe, 1999; Pessar et al., 1993). Overall, many of the specific challenges accompanying parental TBI can be described as adverse childhood events (ACEs) or childhood adversities. The notion that adversities experienced in early childhood are associated with long-term risk for mental illness has been consistently supported empirically. Children who experienced multiple adversities, as seen following parental TBI, have been shown to have an increased risk of anxiety disorders, mood disorders and substance abuse/dependence in adulthood (van der Vegt et al., 2008). Prior studies illustrate the broad spectrum

of adversities faced by families following parental TBI, which may affect children in a variety of ways. The results of this research have confirmed that parental TBI in childhood can be seen as a major risk factor for psychopathology as an adult. As stated in Kinnunen et al. (2018), TBI policy should consider regarding parental TBI as an ACE or childhood adversity.

### **Implications for Future Research**

The present study encompasses and extends the current knowledge relating to children's outcomes following parental TBI by assessing long-term adult outcomes. Whilst implications for rehabilitation practice and policy have been discussed, findings reveal areas that should be addressed in future research.

Due to the small sample size, varied results and being the first study of its kind, additional research is needed to confirm findings. Use of a university population reduces diversity of sample so future studies should look at adults from different educational backgrounds (non-university sample) and from a range of ages (> 18 year old). Despite the higher proportion of self-TBI in those affected by parental TBI compared to the normative sample, the small sample size of the parental TBI group limited the ability to assess whether the people who are affected by parental TBI are at a higher risk of experiencing a TBI of their own. Contrary to TBI prevalence in Aotearoa/New Zealand, there was no statistically significant difference in the proportion of Māori and Pasifika peoples in the parental TBI group compared to the normative sample. These results may be attributed to the small sample size, the use of a university sample or the ethnic demographics of the Canterbury region, emphasising the need for future research to clarify findings and the interaction effect of gender, ethnicity as well as self-TBI on adult outcomes for those exposed to parental TBI in childhood. Future studies could use other illnesses, such as parental diabetes, as an additional comparative group. This would allow examination of the specific stressors associated with parental TBI such as incident-related trauma, loss of attention, changes in parental personality and parentification pertaining to the injured parent,

whilst allowing the observation of differences in adult outcomes between parental TBI exposure, parental illness and normative populations. Future research with less homogenous samples is needed to address the limitations of the current study and to explore the interactive effects of specified variables, on the adult outcomes of those who experienced parental TBI in childhood.

To aid the translation of research to rehabilitation practice following parental TBI, it may be beneficial to explore the viewpoints of health service providers to identify current constraints and potential areas of intervention when considering affected children in the context of TBI. Previous studies have noted that clinicians typically focus on treating the physical manifestations of conditions, with little to no discussion of how the family unit, particularly children, may be adjusting to the changed dynamics. In Rohleder et al. (2017), however, support workers reported observing the difficulties faced by children, particularly when dealing with the changes in personality and the sense of ‘loss’ felt in relation to the brain injured parent. Despite witnessing the hardships experienced by affected children, support workers reported feeling under qualified to support children or to offer parenting support (Rohleder et al., 2017). One support worker stated “they need that emotional support, they need that educational support, they need someone to talk to, they need an outlet, they may need other children to meet with and talk to, I think all bases need to be covered and at different stages” (Rohleder et al., 2017, pg. 205). Another worker mentioned the need for peer support for children following parental TBI, with genuine understanding and empathy, as opposed to the comfort and support they could provide as healthcare workers. This denotes frustration with lack of expertise and limited skill within rehabilitation teams, rather than a lack of consideration for the needs of children affected by parental brain injury. Future research should explore health service providers’ perspectives of work with children affected by parental TBI, to better identify the expertise needed to develop and provide specialized interventions when working with TBI-affected families.

## **Conclusions**

The present study provided insights into the long-term outcomes of individuals affected by parental TBI. This is the first known study to examine adult outcomes following parental TBI exposure in childhood and provides evidence for parental TBI as a predictor of clinical levels of psychological functioning. Future research with larger, less homogenous samples are needed to clarify findings. Additionally, further research is needed to foster the development of family-centred TBI policy in Aotearoa/New Zealand and internationally, and to aid the translation of policies into rehabilitation practices by healthcare services, following parental TBI. This study provides a promising foundation for future research and policy to consider parental TBI as an ACE (adverse childhood experience) and further emphasises childhood as a crucial period for understanding the development of psychopathology.

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## Appendix A: Ethical Approval



### HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson  
Telephone: +64 03 369 4588, Extn 94588  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2019/170

31 January 2020

Lihini Wasundara Mendis  
Psychology, Speech and Hearing  
UNIVERSITY OF CANTERBURY

Dear Lihini

The Human Ethics Committee advises that your research proposal “The Long-Term Effect of Parental Traumatic Brain Injury on Children” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 31<sup>st</sup> January 2020.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to be 'DS' followed by a stylized flourish.

Dr Dean Sutherland  
**Chair**  
***University of Canterbury Human Ethics Committee***



## Appendix B, Section I: Demographic Information

Your age: \_\_\_\_\_

1. Please select your **gender** from the following options

- ☐ Male
- ☐ Female
- ☐ Gender neutral or gender diverse

2. Please select your **ethnicity** from the following options

- ☐ Māori
- ☐ Pasifika people
- ☐ European or NZ European
- ☐ Asian
- ☐ Middle Eastern/Latin American/African
- ☐ Other Ethnicity

## Appendix B, Section II: Parental and Personal Traumatic Brain Injury History

Please read the following definitions and answer the subsequent questions:

- *Brain Injury or Acquired Brain Injury*: A term used to describe all types of brain injury which occur after birth. This includes but isn't limited to stroke, brain tumour, traumatic brain injury etc.
- *Traumatic Brain Injury*: A type of acquired brain injury caused by sudden trauma to the head via an external physical force. This may include incidents such as assault, falls, motor accidents, sports injuries etc.

4. From the following list, please identify the nature of the relationship of your primary caregiver to yourself. Select up to 3 options which are applicable.

- ☐ Father
- ☐ Mother
- ☐ Grandfather
- ☐ Grandmother
- ☐ Step father
- ☐ Step mother
- ☐ Father's partner
- ☐ Mother's partner
- ☐ Brother
- ☐ Sister
- ☐ Uncle
- ☐ Aunty
- ☐ Male cousin
- ☐ Female cousin

5. To your knowledge, was your [*Insert 1<sup>st</sup> primary caregiver here*] ever affected by a traumatic brain injury?

- ☐ Yes
- ☐ No
- ☐ I don't know

[Note: If participants answer 'Yes' to say that the caregiver in the question was affected by TBI, the participants will have to answer the subsequent questions before proceeding.]

6. What was the cause of their TBI?

- ☐ Assault
- ☐ Fall
- ☐ Motor Accident
- ☐ Sports Injury
- ☐ Other
- ☐ I don't know

7. Were you living with the injured caregiver at the time of injury?

- ☐ Yes
- ☐ No

8. How old were you at the time of caregiver brain injury? (insert age or write 'I can't remember') \_\_\_\_\_

[If they answer 'No' or 'I don't know' when asked about the first primary caregiver, individuals will be asked the same question for the rest of their chosen caregivers. Example is as follows.]

9. To your knowledge, was your [*Insert 2<sup>nd</sup> primary caregiver here*] ever affected by a traumatic brain injury?

- ☐ Yes
- ☐ No
- ☐ I don't know

10. To your knowledge, was your [*Insert 3<sup>rd</sup> primary caregiver here*] ever affected by a traumatic brain injury?

- ☐ Yes
- ☐ No
- ☐ I don't know

[Note: Following questions pertaining to primary caregiver parental traumatic brain injury, participants will answer the subsequent questions pertaining to their own TBI history].

11. Have you yourself experienced a TBI?

- ☐ Yes
- ☐ No

[Note: If 'yes'. participants answer the following questions or if answer is 'no', they skip to the subsection titled 'FRIENDS'].

12. What was the cause of your TBI?

- ☐ Assault
- ☐ Fall
- ☐ Motor Accident
- ☐ Sports Injury
- ☐ Other
- ☐ I don't know

13. How old were you at the time of your own TBI injury? (insert age or write 'I can't remember')  
\_\_\_\_\_

## Appendix B, Section III: Adult Self Report (ASR) Questionnaire

Please fill out this questionnaire to reflect ***your*** views, even if other people might not agree. You need not spend a lot of time on each question but please be sure to ***answer all questions***.

### ▪ FRIENDS:

14. About how many close friends do you have? (Do not include family members).

- ☐ None
- ☐ 1
- ☐ 2 or 3
- ☐ 4 or more

15. About how many times a month do you have contact with any of your close friends? (Include in-person contacts, phone, emails, texts etc.)

- ☐ Less than 1
- ☐ 1 or 2
- ☐ 3 or 4
- ☐ 5 or more

16. How well do you get along with your close friends?

- ☐ Not as well as I'd like
- ☐ Average
- ☐ Above average
- ☐ Far above average

17. About how many times a month do any friends or family visit you?

- ☐ Less than 1
- ☐ 1 or 2
- ☐ 3 or 4
- ☐ 5 or more

### ▪ SPOUSE OR PARTNERS:

18. What is your relationship status?

- ☐ Never been married
- ☐ Married, living with spouse
- ☐ Unmarried, living with spouse
- ☐ Widowed
- ☐ Married but separated from spouse
- ☐ Divorced
- ☐ Other-please describe: \_\_\_\_\_

19. At any time in ***the past 6 months***, did you live with your spouse or with a partner?

- ☐ No

☐ Yes

[Note: If answered 'yes', participants will answer the following questions. If not, the survey will skip to the following subsection entitled 'FAMILY'].

Please answer the following questions to describe your relationship *during the past 6 months*.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very true or Often True

- |   |   |   |   |
|---|---|---|---|
| 0 | 1 | 2 | A. I get along well with my spouse or partner   |
| 0 | 1 | 2 | B. My spouse or partner and I have been trouble sharing responsibilities                        |
| 0 | 1 | 2 | C. I feel satisfied with my spouse or partner   |
| 0 | 1 | 2 | D. My spouse or partner and I enjoy similar activities  |
| 0 | 1 | 2 | E. My spouse or partner and I <i>disagree</i> about living arrangements, such as where we live. |
| 0 | 1 | 2 | F. I have trouble with my spouse or partner's family  |
| 0 | 1 | 2 | G. I like my spouse or partner's friends  |
| 0 | 1 | 2 | H. My spouse or partner's behaviour annoys me   |

▪ FAMILY:

Compared with others, how well do you:

20. Get along with your brothers?

- ☐ I have no brothers
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

21. Get along with your sisters?

- ☐ I have no sisters
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

22. Get along with your 1<sup>st</sup> primary caregiver?

- ☐ 1<sup>st</sup> primary caregiver is deceased
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

23. Get along with your 2<sup>nd</sup> primary caregiver?

- ☐ 2<sup>nd</sup> primary caregiver is deceased
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

24. Get along with your 3<sup>rd</sup> primary caregiver?

- ☐ 3<sup>rd</sup> primary caregiver is deceased
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

25. Get along with your biological or adopted children?

i. Oldest child

- ☐ Not applicable
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

ii. Second oldest child

- ☐ Not applicable
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

iii. Third oldest child

- ☐ Not applicable
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

iv. Other children

- ☐ Not applicable
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

26. Get along with your stepchildren?

- ☐ I have no step children
- ☐ Worse than average
- ☐ Variable or average
- ☐ Better than average
- ☐ No contact

#### ▪ JOB

27. At any time in the past 6 months, did you have any paid jobs (including self-employment and military service)?

- ☐ No
- ☐ Yes

[Note: If answered 'yes', participants will answer the following questions. If not, the survey will skip to the following subsection entitled 'EDUCATION'].

Please answer the following questions to describe your work experience *during the past 6 months*.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very true or Often True

- |   |   |   |  |
|---|---|---|--|
| 0 | 1 | 2 | A. I work well with others   |
| 0 | 1 | 2 | B. I have trouble getting along with bosses                          |
| 0 | 1 | 2 | C. I do my work well   |
| 0 | 1 | 2 | D. I have trouble finishing my work                                  |
| 0 | 1 | 2 | E. I am satisfied with my work situation                             |
| 0 | 1 | 2 | F. I do things that may cause me to lose my job                      |
| 0 | 1 | 2 | G. I stay away from my job even when I'm not sick or not on vacation |
| 0 | 1 | 2 | H. My job is too stressful for me                                    |
| 0 | 1 | 2 | I. I worry too much about work                                       |

#### ▪ EDUCATION

Please answer the following questions to describe your educational experience *during the past 6 months*.

Please answer the following questions to describe your work experience *during the past 6 months*.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very true or Often True

- |   |   |   |   |
|---|---|---|---|
| 0 | 1 | 2 | A. I get along well with other students         |
| 0 | 1 | 2 | B. I achieve what I am capable of               |
| 0 | 1 | 2 | C. I have trouble finishing assignments         |
| 0 | 1 | 2 | D. I am satisfied with my educational situation |
| 0 | 1 | 2 | E. I do things that cause me to fail            |

28. Do you have any illness, disability or handicap?

- ☐ No  
☐ Yes - If yes, please state: \_\_\_\_\_

29. Please describe your concerns or worries about family, work, education, or other things?

- ☐ No concern  
☐ I have some concerns:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

30. Please describe the best thing about yourself:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## DESCRIPTIVE SECTION

Below is a list of items that describe people. For each item, please circle 0, 1 or 2 to describe yourself ***over the past 6 months***. Please answer ALL items as well as you can, even if some do not seem to apply to you.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very true or Often True

- |     |   |   |   |   |   |
|-----|---|---|---|---|---|
| 1.  | 0 | 1 | 2 | - | I am too forgetful  |
| 2.  | 0 | 1 | 2 | - | I make good use of my opportunities                                   |
| 3.  | 0 | 1 | 2 | - | I argue a lot   |
| 4.  | 0 | 1 | 2 | - | I work up to my ability   |
| 5.  | 0 | 1 | 2 | - | I blame others for my problems  |
| 6.  | 0 | 1 | 2 | - | I use drugs (other than alcohol and nicotine) for nonmedical purposes |
| 7.  | 0 | 1 | 2 | - | I brag  |
| 8.  | 0 | 1 | 2 | - | I have trouble concentrating or paying attention for long             |
| 9.  | 0 | 1 | 2 | - | I can't get my mind off certain thoughts                              |
| 10. | 0 | 1 | 2 | - | I have trouble sitting still  |
| 11. | 0 | 1 | 2 | - | I am too dependent on others  |
| 12. | 0 | 1 | 2 | - | I feel lonely   |
| 13. | 0 | 1 | 2 | - | I feel confused or in a fog   |
| 14. | 0 | 1 | 2 | - | I cry a lot   |
| 15. | 0 | 1 | 2 | - | I am pretty honest  |
| 16. | 0 | 1 | 2 | - | I am mean to others   |



- |     |   |   |   |   |  |
|-----|---|---|---|---|--|
| 17. | 0 | 1 | 2 | - | I day dream a lot  |
| 18. | 0 | 1 | 2 | - | I deliberately try to hurt or kill myself                    |
| 19. | 0 | 1 | 2 | - | I try to get a lot of attention                              |
| 20. | 0 | 1 | 2 | - | I damage or destroy my things                                |
| 21. | 0 | 1 | 2 | - | I damage or destroy things belonging to others               |
| 22. | 0 | 1 | 2 | - | I worry about my future                                      |
| 23. | 0 | 1 | 2 | - | I break rules at work or elsewhere                           |
| 24. | 0 | 1 | 2 | - | I don't eat as well as I should                              |
| 25. | 0 | 1 | 2 | - | I don't get along with other people                          |
| 26. | 0 | 1 | 2 | - | I don't feel guilty after doing something I shouldn't        |
| 27. | 0 | 1 | 2 | - | I am jealous of others                                       |
| 28. | 0 | 1 | 2 | - | I get along badly with my family                             |
| 29. | 0 | 1 | 2 | - | I am afraid of certain animals, situations or places         |
| 30. | 0 | 1 | 2 | - | My sexual relations with others are poor                     |
| 31. | 0 | 1 | 2 | - | I am afraid I might think or do something bad                |
| 32. | 0 | 1 | 2 | - | I feel that I have to be perfect                             |
| 33. | 0 | 1 | 2 | - | I feel that no one loves me                                  |
| 34. | 0 | 1 | 2 | - | I feel that others are out to get me                         |
| 35. | 0 | 1 | 2 | - | I feel worthless or inferior                                 |
| 36. | 0 | 1 | 2 | - | I accidentally get hurt a lot, accident-prone                |
| 37. | 0 | 1 | 2 | - | I get in many fights   |
| 38. | 0 | 1 | 2 | - | My relations with neighbours are poor                        |
| 39. | 0 | 1 | 2 | - | I hang around people who get in trouble                      |
| 40. | 0 | 1 | 2 | - | I hear sounds or voices that other people think aren't there |
| 41. | 0 | 1 | 2 | - | I am impulsive or act without thinking                       |
| 42. | 0 | 1 | 2 | - | I would rather be alone than with others                     |
| 43. | 0 | 1 | 2 | - | I lie or cheat   |
| 44. | 0 | 1 | 2 | - | I feel overwhelmed by my responsibilities                    |
| 45. | 0 | 1 | 2 | - | I am nervous or tense  |
| 46. | 0 | 1 | 2 | - | Parts of my body twitch or make nervous movements            |
| 47. | 0 | 1 | 2 | - | I lack self-confidence                                       |
| 48. | 0 | 1 | 2 | - | I am not liked by others                                     |
| 49. | 0 | 1 | 2 | - | I can do certain things better than other people             |
| 50. | 0 | 1 | 2 | - | I am too fearful or anxious                                  |
| 51. | 0 | 1 | 2 | - | I feel dizzy or lightheaded                                  |
| 52. | 0 | 1 | 2 | - | I feel too guilty  |
| 53. | 0 | 1 | 2 | - | I have trouble planning for the future                       |
| 54. | 0 | 1 | 2 | - | I feel tired without good reason                             |
| 55. | 0 | 1 | 2 | - | My moods swing between elation and depression                |
56. Physical problems without knowing the medical cause
- a. Aches or pains (**not** stomach or headaches)
  - b. Headaches
  - c. Nausea, feel sick
  - d. Problems with eyes (**not** if corrected by glasses)
  - e. Rashes or other skin problems
  - f. Stomach aches
  - g. Vomiting, throwing up
  - h. Heart pounding or racing
  - i. Numbness or tingling in body parts
- |     |   |   |   |   |  |
|-----|---|---|---|---|--|
| 57. | 0 | 1 | 2 | - | I physically attack people               |
| 58. | 0 | 1 | 2 | - | I pick my skin or other parts of my body |
| 59. | 0 | 1 | 2 | - | I fail to finish things I should do      |

60.	0	1	2	-	There is very little that I enjoy
61.	0	1	2	-	My work performance is poor
62.	0	1	2	-	I am poorly coordinated or clumsy
63.	0	1	2	-	I would rather be with older people than with people my own age.
64.	0	1	2	-	I have trouble setting priorities
65.	0	1	2	-	I refuse to talk
66.	0	1	2	-	I repeat certain acts over and over
67.	0	1	2	-	I have trouble making or keeping friends
68.	0	1	2	-	I scream or yell a lot
69.	0	1	2	-	I am secretive or keep things to myself
70.	0	1	2	-	I see things that other people think aren't there
71.	0	1	2	-	I am self-conscious or easily embarrassed
72.	0	1	2	-	I worry about my family
73.	0	1	2	-	I meet my responsibilities to my family
74.	0	1	2	-	I show off or clown
75.	0	1	2	-	I am too shy or timid
76.	0	1	2	-	My behaviour is irresponsible
77.	0	1	2	-	I sleep more than most other people during day and/or night
78.	0	1	2	-	I have trouble making decisions
79.	0	1	2	-	I have a speech problem
80.	0	1	2	-	I stand up for my rights
81.	0	1	2	-	My behaviours is very changeable
82.	0	1	2	-	I steal
83.	0	1	2	-	I am easily bored
84.	0	1	2	-	I do things that other people would think are strange
85.	0	1	2	-	I have thoughts that other people would think are strange
86.	0	1	2	-	I am stubborn, sullen or irritable
87.	0	1	2	-	My moods or feelings change suddenly
88.	0	1	2	-	I enjoy being with people
89.	0	1	2	-	I rush into things without considering the risks
90.	0	1	2	-	I drink too much alcohol or get drunk
91.	0	1	2	-	I think about killing myself
92.	0	1	2	-	I do things that may cause me trouble with the law
93.	0	1	2	-	I talk too much
94.	0	1	2	-	I tease others a lot
95.	0	1	2	-	I have a hot temper
96.	0	1	2	-	I think about sex too much
97.	0	1	2	-	I threaten to hurt people
98.	0	1	2	-	I like to help others
99.	0	1	2	-	I dislike staying in one place for very long
100.	0	1	2	-	I have trouble sleeping
101.	0	1	2	-	I stay away from my job even when I'm not sick or not on vacation
102.	0	1	2	-	I don't have much energy
103.	0	1	2	-	I am unhappy, sad or depressed
104.	0	1	2	-	I am louder than others
105.	0	1	2	-	People think I am disorganised
106.	0	1	2	-	I try to be fair to others
107.	0	1	2	-	I feel that I can't succeed
108.	0	1	2	-	I tend to lose things
109.	0	1	2	-	I like to try new things

- |      |   |   |   |   |  |
|------|---|---|---|---|--|
| 110. | 0 | 1 | 2 | - | I do not identify as the gender at which I was assigned at birth                 |
| 111. | 0 | 1 | 2 | - | I keep from getting involved with others   |
| 112. | 0 | 1 | 2 | - | I worry a lot  |
| 113. | 0 | 1 | 2 | - | I worry about my social relations with individuals who I'm sexually attracted to |
| 114. | 0 | 1 | 2 | - | I fail to pay my debts or meet other financial responsibilities                  |
| 115. | 0 | 1 | 2 | - | I feel restless or fidgety   |
| 116. | 0 | 1 | 2 | - | I get upset too easily   |
| 117. | 0 | 1 | 2 | - | I have trouble managing my money or credit cards                                 |
| 118. | 0 | 1 | 2 | - | I am too impatient   |
| 119. | 0 | 1 | 2 | - | I am not good at details   |
| 120. | 0 | 1 | 2 | - | I drive too fast   |
| 121. | 0 | 1 | 2 | - | I tend to be late for appointments   |
| 122. | 0 | 1 | 2 | - | I have trouble keeping a job   |
| 123. | 0 | 1 | 2 | - | I am a happy person  |

124. ***In the past 6 months***, about how many times per day did you use tobacco (including smokeless tobacco)? \_\_\_\_\_ times per day.

125. ***In the past 6 months***, on how many days were you drunk? \_\_\_\_\_ days.

126. ***In the past 6 months***, on how many days did you use drugs for nonmedical purposes (including marijuana, cocaine, and other drugs, except alcohol and nicotine)? \_\_\_\_\_ days.

#### **Amendments:**

Adaptive Functioning Section (pg. 76-77):

Q22-24: Amended to include nominated caregiver options.

Descriptive Section (pg. 82, 86):

Q30: Originally phrased as 'my social relations with the opposite sex are poor'

Q110: Originally phrased as 'I wish I were of the opposite sex'

Q113: Originally phrased as 'I worry about my social relations with the opposite sex'

## **Appendix B, Section IV: Satisfaction with Life (SwL) Questionnaire**

Below are five statements which you may agree or disagree with. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest with your responding.

- 7 – Strongly agree
- 6 – Agree
- 5 – Slightly agree
- 4 – Neither agree or disagree
- 3 – Slightly disagree
- 2 – Disagree
- 1 – Strongly disagree

- \_\_\_\_\_ In most ways my life is close to my ideal.
- \_\_\_\_\_ The conditions of my life are excellent.
- \_\_\_\_\_ I am satisfied with my life.
- \_\_\_\_\_ So far I have gotten the important things I want in life.
- \_\_\_\_\_ If I could live my life over, I would change almost nothing.

## Appendix C: Participation Information Sheet



Department of Psychology  
Telephone: +6433692074  
Email: [[lihini.mendis@pg.canterbury.ac.nz](mailto:lihini.mendis@pg.canterbury.ac.nz)]  
[18/09/2019]  
HEC Ref: [Enter when approval given for your study]

### **Long-term Effect of Parental Traumatic Brain Injury on Children. Information Sheet for Participation.**

Hello and thank you for taking the time to consider participating in my study.

My name is Lihini Mendis and I am currently a student at the University of Canterbury, partway through my Masters in Child and Family Psychology. The purpose of the current research is to investigate the effect of parental traumatic brain injury on dependent children. Thousands of New Zealanders every year are affected by traumatic brain injury (TBI) and face several difficulties following injury, affecting their ability to take part in previous relational, occupational and physical roles. Despite such outcomes after injury, few studies have explored the impact of TBI on dependent children of TBI patients. This study aims to explore the outcomes of adults who lived with parents with TBI as children (under the age of 18 years old) compared to same-aged norms.

You have been offered the opportunity to take part in this study as it intends on utilising adult students from the University of Canterbury. If you choose to take part in this study, your involvement in this project will be to fill out a self-report online questionnaire and should take approximately 30-40 minutes. The survey will ask for details about your life skills, character and satisfaction with life, over the past 6 months. You will also be asked about demographic information and information pertaining to both your caregivers' and your own TBI history.

All disclosed information will remain anonymous as identifying information (such as your name or Student ID) will not be collected. The questionnaire will inquire about potential problems and your state of mind over the past 6 months. I understand that this may cause discomfort for some individuals. If you wish to participate in this study and experience any discomfort at any stage, please feel free to contact the following support services. This list of services will also be provided at the end of the survey.

*Lifeline* – A free confidential crisis helpline service which offers brief counselling support in all areas of concern.

24/7 Helpline: 0800543354 or Free text HELP to 4357

OR

*Need to talk* – A free service for New Zealanders who are feeling anxious, overwhelmed or may need to chat to someone.

You can free call or text 1737 at any time.

OR

You may wish to visit the Psychology Centre on campus.

Located at Level 1, Geography Building, University of Canterbury (Arts Road Entrance)

You can call them on +6430693777 or email them at [psychclinic@canterbury.ac.nz](mailto:psychclinic@canterbury.ac.nz)

Participation is voluntary and you have the right to withdraw by closing the browser at any time while completing the survey. However, once you have completed the questionnaire and it has been submitted, withdrawal is no longer a possibility due to the anonymity of the data.

The results of the project may be published, but you may be assured of your privacy in this investigation. All data will be securely stored on a password protected personal device and will be kept in locked storage at the University of Canterbury and will only be accessed by myself or my supervisors. All raw data will be destroyed after 10 years, however, the thesis itself is a public document and will be available through the UC Library.

Please indicate to the researcher via the email provided above if you would like any further information prior to participation or you would like to receive a copy of the summary of the results of this project.

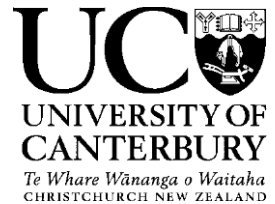
The project is being carried out by Lihini Mendis as a requirement of a Master's in Psychology, under the supervision of Randolph Grace and Audrey McKinlay, who can be contacted at [audrey.mckinlay@canterbury.ac.nz](mailto:audrey.mckinlay@canterbury.ac.nz)

She would be happy to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)).

Once you have read this information sheet, if you wish to participate in the study, please complete the Consent Form (to follow).

## Appendix D: Online Consent Form



Department of Psychology  
Telephone: +6433692074  
Email: [lihini.mendis@pg.canterbury.ac.nz](mailto:lihini.mendis@pg.canterbury.ac.nz)

### **Long-term Effect of Parental Traumatic Brain Injury on Children. Consent Form for Participation.**

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary and I may withdraw at any time without penalty, until the questionnaire has been submitted.
- ☐ I understand that any information or opinions I provide will be kept anonymous to the researcher and that any published or reported results will not identify the participants of this study. I understand that a thesis is a public document and will be available through the UC Library.
- ☐ I understand that all data collected for the study will be kept in password protected electronic form and will be destroyed after ten years.
- ☐ I understand the risks associated with taking part and how they will be managed.
- ☐ I understand that I can contact the researcher Lihini Mendis [email: [lihini.mendis@pg.canterbury.ac.nz](mailto:lihini.mendis@pg.canterbury.ac.nz)] or supervisor Audrey McKinlay [email: [audrey.mckinlay@canterbury.ac.nz](mailto:audrey.mckinlay@canterbury.ac.nz)] for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch [[human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)].
- ☐ If I would like a summary of the results of the project, I can contact the researcher Lihini Mendis via email (as above).
- ☐ By checking this box, I agree to participate in this research project and continuing to the survey constitutes consent.

*Please check all boxes within this consent form prior to gaining access to the following section of the project.*