# Hearing from Children:

# Exploring Children's Experiences of Parental Traumatic Brain Injury

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A thesis submitted to Auckland University of Technology in partial fulfilment of the requirements for the degree of Master of Health Science (MHSc)

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# Table of Contents

# List of Tables

# List of Figures

# Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institute of higher learning.


Signed:                                        Date:          29 November 2016

Alexis Channon

# Related Publications

Channon, A., & Kayes, N. (2013). Considering the impact of parental brain injury on children within the family: A review of the literature. In *New Zealand Rehabilitation Conference: Connecting, Living, Rebuilding*. Nelson, New Zealand, 8-10 March 2013.

# Acknowledgments

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# Ethical Approval

Auckland University of Technology Ethics Committee granted ethical approval for this research on 17 June 2014 (ref: 14/109).

# Definitions of Terms

**Brain Injury:**  The position adopted within this thesis is that 'acquired brain injury (ABI)' refers to any brain injury caused by events after birth (by, for example, stroke, aneurysm, brain tumour, or traumatic brain injury).  While, 'traumatic brain injury (TBI)' specifically refers to injury caused by sudden trauma to the brain from an external mechanical force (by, for example, a fall, road traffic incident or assault).

**Parental Injury:**  The term 'parental injury' has been used to describe *being a parent who is living with the consequences of significant injury*.  In relation to the focus of inquiry, 'parental ABI' describes any parent who is living with the consequence of ABI and 'parental TBI' refers to any parent who specifically has experienced TBI.

**Whānau:**  Whānau is a term used within teo reo Māori (the language of the indigenous population of New Zealand) referring to extended family, or a family group, which includes networks who are closely related (socially, economically and spiritually).  While at times used interchangeably with 'family', the meaning of 'whānau' is based upon a Māori and a tribal worldview and is acknowledged to be more complex than a direct translation (Walker, 2011).  Where appropriate, terms relating to 'family and whānau' or 'family/whānau' have been used within this thesis to recognise the New Zealand context and its people.

# Abstract

This study explored the experiences of children living in the context of parental traumatic brain injury (TBI) within New Zealand.  Brain injury can impact a person's participation in their regular social roles within the family, compromising their wellbeing, and the quality of life of others within the family.  Available evidence emphasises the importance in attending to the needs of adult relatives of acquired brain injury (ABI) patients who may be experiencing issues of depression, burden and loss after injury.  Children living within the family context after ABI, however, appear to be overlooked.  A literature review completed as part of this thesis highlighted a relatively small and heterogeneous sample of studies that have investigated the perspectives of children living in the context of parental ABI to date.  Findings of these studies demonstrated children are impacted by parental ABI, experiencing a sense of shock and loss after the event, and also taking on active roles to try and support, cope and make-sense of family life after injury.

The current study drew on an interpretive methodology, using hermeneutics, to explore children's narratives about their experiences of life after parental TBI. Children were regarded to be the experts and gatekeepers of knowledge about their experiences.  Seven children, from five families, chose to participate within the study.  Interviews conducted with children acknowledged their rights, needs and capabilities as research participants.  A range of data collection methods were used, drawing on a 'toolkit' of interview techniques that could be tailored to the individual requirements of each participant.  Both data collection and analysis were informed by an understanding of experience as *lived*, with a focus on the lifeworld existentials of *lived space, lived body, lived time* and *lived relation*.

The findings were constructed into themes that could provide insight into aspects of children's experiences.  Analysis identified how children faced an *altered sense of being 'at home'* when living in the context of parental TBI.  Children's stories revealed how parental TBI impacted upon many of the taken-for-granted expectations in the home; they experienced disruption to the roles individuals performed and the ways in which their family usually interacted together with

changes to the presence, availability and mood of both their injured and non-injured parent. These experienced *changes to family cohesion and rhythms* meant children faced new (and changing) expectations, opportunities and constraints in their home with regard to their play, behaviour and interactions with their siblings and parents. Where there were changes to usual family-life, there were also responses and adaptations. Children shared examples of the accommodations they made in order to respond to the new (and at times scary, confusing and frustrating) behaviours and expectations that injury brought into life at home. They played an active role in supporting their parents and contributing to efforts to regulate family life by *attuning and adjusting to new ways of being as a family*.

The study findings support and extend existing research on the topic, drawing attention to the impact parental TBI has on children in the home, and also their efforts to influence and moderate the impact of injury on their parents. Children's accounts highlighted the significance of *home as a 'special space experience'*, which is altered when TBI intrudes on family life, introducing change and uncertainty. The work of recovery involves renegotiations of the space of home as a family. Children are actively engaged in interdependent, reciprocal relationships within the family system and their position needs to be acknowledged. Adopting a whole family approach within the context of adult rehabilitation, which includes taking notice of children, has the potential to offer support to the family as a whole, and also the possibility of enhancing recovery for the individual with TBI.

# Chapter One: Introduction

This study investigates children's experiences of living in the context of parental traumatic brain injury (TBI).  Literature relating to recovery and adaptation following TBI consistently highlights that the impact extends beyond the injured person to their families, notably adult relatives such as spouses, parents and siblings (e.g. Kreutzer, Mills, & Marwitz, 2016; Lefebvre, Cloutier, & Levert, 2008; Marsh, Kersel, Havill, & Sleigh, 2002; Moules & Chandler, 1999).  However, the potential impact of TBI on children within such family systems remains largely overlooked, with their voices rarely heard in research.  This study aims to give voice to those children living in the context of parental TBI within Aotearoa/New Zealand (NZ), by hearing directly from them about their experiences, understandings and perspectives of life after parental injury.

 This chapter provides background to the study.  It begins by offering an account of the researcher's assumptions and interest in the topic.  It then introduces the context for the study discussing the impact of TBI on the individual and in connection with others as part of a family system, providing the rationale for the focus of the research inquiry.  The chapter concludes with an overview of the structure of the thesis.

## Exploring the Unseen: Personal Reflections

I have a long-standing interest in the rights and wellbeing of children and adults who experience disability.  I came to rehabilitation research, and post-graduate study, from a background supporting disabled children and families, with a passion, and belief, that better outcomes must be possible.  I was afforded opportunity to engage in post-graduate study and on introduction to the area of childhood studies, I reflected upon my own understandings and interest in children and conceptualisations of childhood.

I have always found children to be great company; I enjoy the fun and creativity that can be expressed through play with children.  I find children great teachers and value the education working with children has given me, both about myself personally as well as life more broadly.  In my experience, children can be very

insightful; their desire to learn, test and make sense of the world can open up new ways of seeing and understanding, especially the taken for granted of the everyday.  My work experience has been marked by the lived experiences of children whose lifeworlds confront assumptions of childhood as a time of innocence and carefree certainty.  I have admired the strength, resilience and fight of the children I have worked with, many of whom have faced challenges through disability, poverty, abuse or neglect.  I have also been frustrated by the added 'fight' required for children and their parents/carers in negotiating the systems and structures in place designed to offer support.

Post-graduate study provided the space and resource to critically examine some of the social and political contexts that shape the environments I have worked in with children.  The process of reviewing literature and critically discussing issues introduced new language, concepts and theories through which I could articulate (to myself as much to others) some of the questions I had been left with in practice; broadening my understandings, challenging my assumptions and generating yet more questions.  Discussions with peers highlighted some intriguing differences between the priorities, expectations and constraints of practice for a range of clinicians working within rehabilitation.  Unlike work with children, rehabilitation work with adults appeared more focused on the individual and the one-to-one interactions between clinician and patient.  Thus, I became aware that the goal of family engagement I regarded as a pre-requisite for work with children in the community was not something I could assume to be universal across rehabilitation practice with adults.

I reflected on my own research practice in which I was working as a Research Assistant on a clinical trial assessing an intervention for adults after TBI.  I became aware through the assessments that the presence of children within these families was largely unseen.  My visits were planned to support the participant's needs, often occurring at a time of day that held the least distractions and when the individual would be least fatigued; notably when other family members were out at work or children were at school.  I also observed that although careful consideration had gone into the selection of measures that could tap into meaningful outcomes for each person, the majority relied on a deficit-focus.  Such measures appeared more orientated toward identifying issues at the level of the

2

individual as opposed to looking at outcomes associated with their connections with others within their family systems. Within the more open or qualitative components of the assessments, or general conversation during the visits, participants would share examples of the wider impact of their injury on themselves *in relation* to others within their lives. Such ideas were often repeated in conversations held with significant others who were also invited to participate in the research. Later, I would have opportunity to qualitatively interview adults with TBI, and their significant others (adult relatives or friends), about their experiences of recovery and adaptation after injury, and once again concern for the wider impact of their injury on loved ones was a frequent topic, especially where people were experiencing issues with mood, emotional regulation and altered sense of self. Injured people also emphasised the significance of support from family and whānau members within their recovery stories. Family and whānau were described as offering a sense of purpose in recovery and contributing to the injured person's ability to adapt to life after injury.

These reflections, through postgraduate study and research practice, left me questioning whether paying greater attention to children living within the context of TBI could offer new insights to inform rehabilitation practice and support families and whānau in their recovery process. I wondered what we might be able to learn from listening to children and hearing their interpretations of the everyday worlds of recovery and adaptation after parental injury. I wondered what systems and structures are in place to support children living in the context of parental TBI, and whether more was needed to ensure their wellbeing is safeguarded and their resilience fostered.

## Context for the Study

When a person's life is affected by the onset of illness or injury, it does not solely impair physical function. As contemporary views of health and rehabilitation recognise, impairment affects a person's ability to engage with their environment, perform their tasks of everyday living and participate in their regular social roles (World Health Organisation, 2001). The tasks and social roles people perform are interconnected with others and as such disability becomes an experience that is shared with those around them, including their family (Rolland, 1999).

3

Recognising that disability exists in context, therefore, is essential in the study of health and wellness after TBI.

**Disabling TBI and Rehabilitation: A Family Affair**

The importance of recognising the role of family within the rehabilitation process is increasingly highlighted within international literature and accordingly is recommended as a core component of best practice for TBI rehabilitation within NZ (ACC & New Zealand Guidelines Group, 2006). The guidelines for the clinical management of TBI emphasise the need to provide information and support to family and whānau, acknowledging their role within the rehabilitation team and enabling their inclusion within care-planning and goal-setting. Within the NZ context, the significance of family and whānau in rehabilitation is further emphasised by cultural values. Holistic views of health seen in Māori culture regard taha whānau (family health) as a *requirement* to wellbeing (Durie, 1998). A similar view is shared by Pacific communities, captured within 'Ala Mo'ui, the Ministry of Health's pathway for Pacific wellbeing (Minister of Health & Minister of Pacific Island Affairs, 2010). Valuing families is a key principle and the importance of family is recognised as offering care and support, as well as providing identity, status and honour. The consideration of such values serves to highlight the significance of attending not only to the family's central position within the rehabilitation team, but also to the patient's position and role within their family.

**The Patient as a Parent**

The patient's position as a family member requiring an increased level of care and support is readily acknowledged, but their position as an individual within the family who may themselves be relied upon to care and support others receives less attention. A key role that a patient may be performing within a family is that of a parent, on whom children depend for their care and protection and for whom children reciprocate love and care. TBI characteristically affects younger adults (especially males) during child-rearing years, with peak incidence in NZ reported within the 15-30 year age group (ACC & New Zealand Guidelines Group, 2006). As such, many individuals with TBI may be positioned within their family context as a parent and must adjust to this role with the consequences of brain injury.

Little is known about the incidence of parenting with a TBI, but a report from the UK indicated 32% of people surveyed with TBI had dependent children under the age of 18 years (Stilwell, Hawley, Stilwell & Davies, 1997, as cited in Edwards, Daisley, & Newby, 2014). Furthermore, there appears to be limited consideration of the combined impact of parenting and TBI, with little literature on the topic and a lack of targeted rehabilitation supports (Morriss, Wright, Smith, Roser, & Kendall, 2013). From what is known (discussed further in *Chapter Two: Literature Review*) individuals appear to struggle with their parenting roles after acquired brain injury (ABI), feeling both physically and emotionally absent from their children, and stress the need for more rehabilitation focused towards supporting family life.

From a family systems perspective (Rolland, 1999), in order for rehabilitation to offer such support to parents after TBI it must recognise the intertwined nature of the injury, individual and family-life. Rolland emphasises the need to look beyond a focus solely on the individual and their condition, and instead address the *"interface of any chronic condition and the family"* (p. 243). The model recognises that the health and wellbeing of individual members of a family has the potential to compromise the healthy functioning of the system as a whole. Also, importantly from a strengths-based perspective, that the family system and reciprocal relationships offer a significant resource post-injury, with potential for resilience building and growth.

Accordingly, as members of a family system, children form part of the rehabilitation context and consideration of their needs and influence is a necessary part of looking at recovery and adaptation after TBI. Yet, as will be demonstrated in the succeeding chapter, there is a very limited pool of evidence focused on children living in the context of parental TBI. This research study aimed to respond to this greater need for understanding about children's experiences after parental TBI.

## Focus of Inquiry

Positioning children as active agents of their lives and the gatekeepers of their life stories, this study worked *with* children to explore their perspectives of life after

parental TBI and address the research question: *'what are children's experiences of living in the context of parental TBI?'*.

This research aims to add to knowledge of children's understandings and sense making of life after parental TBI. Data was collected through interviews tailored to the needs of the individual child, using a toolkit of data collection methods. Data was analysed using a hermeneutic lens to explore the meanings of children's constructed accounts. By exploring children's accounts in this way, this study aims to offer insights into their lived experiences after parental TBI for those working to support families after brain injury.

## Structure of the Thesis

*Chapter Two: Literature Review* will offer a critical review of the current state of knowledge relating to children's experiences of living in the context of parental TBI. It will present a comprehensive review of the literature, appraising the evidence and offering a rationale for the current study.

*Chapter Three: Methodology and Methods* will introduce the underpinning theoretical perspectives guiding this research, including the positioning of children as active agents of their lives. It will provide a rationale for the methodology and methods selected, detailing the approaches used for recruitment, data collection and analysis. The chapter will offer a robust account of the ethical considerations made throughout the design and application of this study.

*Chapter Four: Findings* will present the key ideas that children shared in relation to their experiences of living in the context of parental TBI. Children's quotes will be offered to support the themes presented and to ground the discussion within the data.

*Chapter Five: Discussion* will discuss key study findings in relation to the reviewed literature. Extending the hermeneutic lens toward the application of findings, it will consider the meanings of children's experiences for the context of rehabilitation practice. It will identify the study limitations and offer suggestions for further research.

# Chapter Two: Literature Review

This chapter provides a summary of literature relating to children's experiences of parental TBI.  It opens with discussion of the known impact of TBI on individuals and their adult relatives and considers the role of parenting after ABI.  The chapter then offers a critical review of available evidence; identifying, appraising and synthesising study findings looking first at literature exploring the impact of parental ABI on children and then at studies exploring children's experiences.  The chapter concludes by considering the current scope of knowledge available to inform rehabilitation policy and practice within NZ.

## Disabling Brain Injury

TBI is a leading cause of disability internationally, affecting thousands of New Zealanders each year (ACC & New Zealand Guidelines Group, 2006; Feigin et al., 2013).  Following TBI, individuals can experience a range of persistent difficulties in physical, cognitive and emotional functioning, impacting their participation in previous social and employment roles (Lefebvre et al., 2008).  This disabling impact of TBI serves as a predictor for low quality of life after injury (von Steinbüchel et al., 2010).  Rehabilitation interventions are often designed to maximise quality of life after injury, aiming to optimise an individual's participation and wellbeing and reduce stress on the family (Wade, 2005).

For a person with TBI, restriction in participation of normal social roles in the family can compromise wellbeing and in turn, can affect the quality of life experienced by other members of the family.  It is recognised that adult relatives of injured individuals are at risk of adverse consequences to their own health and wellbeing, with emotional difficulties (including depression) and burden reported for family carers after the brain injury (Lefebvre et al., 2008; Marsh et al., 2002; Moules & Chandler, 1999).  Symptoms frequently inherent in brain injury, such as changes to personality, behaviour and emotional affect coupled with heightened levels of agitation, aggression, depression and/or social withdrawal can be particularly challenging for carers to manage.  Furthermore, the change in relationship that occurs with the adoption of a caregiving role can be further

compounded by financial strain and reduced social support that result from the injury (Ergh, Rapport, Coleman, & Hanks, 2002).

## Parenting with Brain Injury

Studies that have explored the experience of parenting after ABI have found the injured person's impairments and perceptions of their competencies impact their ability to cope with the demands of parenting.  Edwards et al. (2014) found parents with ABI were worried about the impact of their impairments on their children, felt a loss of equality in their parenting roles and experienced difficulties in finding ways to contribute as a parent, feeling like *"an absent parent"* (p. 1703). They felt a loss of the roles they would normally play within their children's lives, being both physically and emotionally absent.  This was also a theme shared in Kitzmüller, Asplund, and Häggström (2012), who explored the lived experience of families of stroke survivors and described the sense of 'absent presence' felt by parents after brain injury.

In both studies, participants were reported to have negative perceptions of themselves as parents, with a reduced sense of competency.  Similar accounts were also evident in interview discussions with fathers with ABI (including TBI) who described a sense of failure in their parenting roles (Morriss et al., 2013).  Injured fathers were described as struggling with the demands of parenting, with physical and cognitive impairments limiting their abilities to participate in everyday activities with their children.  This led to frustrations and stress, contributing to family tension.  For those participants who sustained their injury while already in parenting roles, they struggled to recall or implement previous parenting knowledge and skills.  They had lower tolerance levels and were quick to get angry, which resulted in the use of ineffective strategies (including punitive measures) and increased frustrations.  The non-injured parent often needed to intervene, which at times led to more stress or feelings of failure on the part of the injured parent.  The combined impact of the resulting impairments of the injury, together with environmental changes (such as loss of work), impacted participants' sense of identity and how they perceived themselves as parents (Morriss et al., 2013).  It was observed that their negative perceptions of their parenting roles had an impact on the whole family system.  The additional

8

demands and burden placed on the functioning of the family created stress, with the non-injured parent taking on an increased sense of responsibility for the family.

The participants' accounts in Morriss et al. (2013) stressed a need for more rehabilitative guidance in terms of their parenting roles, and emphasised the importance of family life, and family support, on recovery. Kitzmüller et al. (2012) captured the idea that interviewees regarded family as a 'lifebuoy' and were essential to survival and recovery after ABI. Family relationships were described as supporting a will to live when facing severe post-stroke depression. Similar accounts were shared in Edwards et al, where participants emphasised that knowing they had a role to play in their children's future was a motivating factor in recovery, as was being supported to be able to actively participate in their children's lives (Edwards et al., 2014). Parents valued seeing their children's growing strength and resilience through their recovery. Equally, they acknowledged the important role their children played in supporting and encouraging them, as one participant remarked being with his children had a *"profound affect on my mental world"* (p. 1705). The participants' accounts highlighted the potential rehabilitation support that could be harnessed by attending to a patient's role as a parent, and children's roles within the family, in order to aid recovery after ABI. They demonstrate that the goal of maximising quality of life would benefit from focusing beyond just the individual, or *independent living per se*, and instead consider the person in their context, looking at others with whom a patient lives in *connected*, *inter-dependent* ways.

## Exploring the Impact of Parental TBI on Children

In considering connectivity and interdependence, it becomes necessary to look at the impact of parental brain injury on children also. Where there are injured and non-injured parents needing to adjust to the impact of disabling TBI on family life, including their changed capacities as parents, there are also children needing to cope with such changes in relation to their position as children within the family context. A child's position within a family is dynamic and variable, shaped by the culture of family life, as well as society more broadly. Children depend on the adults in their lives for their care and protection; they are positioned with less

power than the adults around them and are directly impacted by any decision-making that affects the adults within their lives (Ministry of Social Development, 2002). As a consequence, rehabilitation policy and practice targeted toward the injured (and non-injured) parent has the potential to (inadvertently) impact upon any children within the family context and contribute to their position of vulnerability. Therefore, consideration of the needs of the injured and non-injured parent must extend to the child living in the context of parental TBI.

Studies considering the impact of parental illness or impairment on children have, to date, been predominantly concerned with the relation of childhood risk and resilience to future health outcomes in adulthood, marginalising their experiences as relevant only to the role children will serve as 'future adults' in society (Gladstone, Boydell, & McKeever, 2006). The review offered here purposefully set out to understand what is currently known about the impact of parental TBI on children, currently living in the life-stage of childhood and adolescence, recognising its importance as a period of life in its own right. Effort to explore the impact of parental TBI on children needed to recognise the complexity of childhood experience, acknowledging children's agency as well as vulnerability. Children are not only vulnerable and shaped by their experiences, but are also actively involved in shaping their worlds, through their thoughts, actions and the roles they hold (Alderson, 2005). Children contribute to family life and take on reciprocal roles of love and care towards their parents and others in the family. Greater understanding of the roles that children play in the family context after parental TBI, including the ways they may themselves seek to impact life and support the family, could offer unique insights to aid the development of rehabilitation practices that meet the needs of the whole family during recovery and adaptation after injury.

The literature review for this study intended to identify the scope of the current literature-base considering parental TBI from children's perspectives. However, preliminary searches highlighted a very limited pool of studies specific to parental TBI, with the majority including a broader sample of parental ABI. As such, the inclusion criteria were extended to include parental ABI more broadly in order to gain understanding from children living in closely comparable contexts.

The literature search was undertaken in two stages.  As background to this master's study, a literature review[1] was undertaken to explore the impact of parental ABI on children (primary review).  This literature search was repeated and updated for inclusion within this thesis (secondary review).  The primary review attempted to capture the breadth of literature available on the topic and therefore sought to include all original research, regardless of methodology.  On the basis of the primary review findings, the secondary review was more targeted toward qualitative evidence to a) reduce heterogeneity to enable synthesis of findings in a meaningful way, and b) because qualitative papers were considered to be more explicitly relevant to the focus of inquiry for this study, with its aim to explore children's experiences of living in the context of parental TBI.

The same systematic search strategy was applied to both the primary and secondary review.  Details of the selection and appraisal processes, alongside inclusion criteria, are outlined below.  The findings of each review are then presented in turn.  To avoid unnecessary duplication, discussion of the primary review findings offered below focuses on the included quantitative studies rather than the full data set (of quantitative and qualitative studies) originally included.  The secondary review then offers a synthesis of findings across qualitative studies.

**Search strategy**

Both the primary and secondary search drew on principles of systematic review to guide the definition of key terms for the search strategy, with consideration primarily focused on the *population* (children)*, intervention/variable of interest* (parental ABI) and *outcome* (impact) components of the PICO framework (Schardt, Adams, Owens, Keitz, & Fontelo, 2007).  Initial scoping of literature showed there was limited consistency between studies in the terminology used to describe the concept of 'parental ABI'.  This was problematic within databases and search results, which were rarely able to distinguish between the parent and child as the individual with ABI.  To aid the search process, proximity search restrictions were used alongside Boolean phrasing.  The scoping searches demonstrated that when

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[1] The results of the primary review were presented to a rehabilitation audience at the NZ Rehabilitation Conference, in Nelson, 2013.  (See Appendix A for a copy of the poster.)

using proximity searching the variable of interest component (i.e. parental ABI) was sufficient in generating results, making terms relating to 'population' and 'outcome' redundant; the population concept of 'children' was already encapsulated within the idea of 'parent' and terms relating to 'impact' proved to be too variable to assist the search. Search strategies were adapted according to the database requirements, using phrases such as "("TBI" N5 parent*) OR ("TBI" N5 mother*) OR ("TBI" N5 father*)". The online searches were conducted within EBSCO Health Databases and SCOPUS (primary search in 2012; secondary search in 2016).

**Inclusion and exclusion criteria**

Articles were required to be:

1. published in a peer-reviewed journal;
2. in English;
3. reporting on analysis of original data relating to children living in the context of parental ABI, exploring:
   (a) the impact of parental ABI on children [primary review];
   (b) children's experiences of parental ABI (with data collected directly from the child) [secondary review].

The definition of children 'living in the context of parental ABI' purposively sought evidence in relation to children currently in the life-stage of childhood and adolescence, and therefore studies referring to retrospective experiences of 'grown-up' children were excluded. The definition, however, was intended to capture the complexity of the context for children and therefore study participants were not required to be *physically living with* the injured parent for inclusion. Finally, it was recognised that a paucity of literature may exist on the subject matter, therefore no additional exclusion criteria were applied and a wide publication timeframe (from 1990 onwards) was used.

Article titles and abstracts were reviewed to determine potential eligibility, and where this provided insufficient detail full-text copies of the papers were sought. In addition, supplementary hand searching of included articles reference lists was used to highlight any further relevant papers. Where no full-text copy of the article

was available (in English), the reference was excluded on the grounds that it could not be screened, which is recognised to be a potential limitation of the search process.

**Data extraction, synthesis and appraisal**

After the initial screening process, each selected article was read in full, to confirm eligibility. Data relating to the general characteristics of the study was extracted into a spreadsheet, specifically: study location; aims/focus of inquiry; theoretical perspective/methodology; methods; ethics; participant details; main findings and conclusions (guided by principles from The Joanna Briggs Institute, 2008). In addition, review comments were added in relation to the critical appraisal, conclusions that could be drawn and relevance to the review question. A process of diagramming was used to capture and explore key ideas reported across studies to aid data synthesis.

Articles were appraised on the basis of the paper's methodological position. Ultimately the primary assurance sought was that the specified aims of inquiry could be supported through the selected methodology and subsequently by the methods chosen for data collection and analysis. All papers were appraised to consider the congruence between the stated aims, presented findings and conclusions drawn. Qualitative papers were assessed for internal consistency and rigour, seeking a transparent account of the methods employed and sufficient support of findings with raw data (Ballinger, 2006). For the papers using quantitative methods, reliability and validity of results was considered in relation to the study design and the appropriate reporting of statistical data, seeking clearly defined significance levels, sufficient description of measures used and statistical tests applied.

**Researcher Reflexivity**

Throughout the review process I was mindful of my own pre-understandings that I brought to the process of data extraction, synthesis and interpretation. Alongside my skills and experience as a qualitative researcher, I also bring experience of supporting families living with disability and personal understanding of growing up in a family with experiences of serious illness. As such, I kept a reflective

journal as a space to record developing understandings, explore pre-understandings and critically reflect on the topic.

**Primary Review: Search Results**

The results from the primary review highlighted a relatively small (n=12) and heterogeneous literature base in terms of methodological approach, scope and purpose.  One notable limitation of the search was that three potentially relevant studies could not be retrieved as full or translated texts and therefore could not be reviewed for inclusion (Oppenheim-Gluckman, 2011; Oppenheim-Gluckman, Marioni, Chambry, Aeschbacher, & Graindorge, 2005; Urbach, Sonenklar, & Culbert, 1994).

Broadly, the sample of studies captured three clusters of work aiming to:

1. explore children's experience of parental ABI (Butera-Prinzi & Perlesz, 2004; Charles, Butera-Prinzi, & Perlesz, 2007; Harlow & Murray, 2001; Harris & Stuart, 2006);
2. measure specific outcomes related to children's psychological and physical health (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011; Pessar, Coad, Linn, & Willer, 1993; Sieh, Meijer, & Visser-Meily, 2010; Uysal, Hibbard, Robillard, Pappadopulos, & Jaffe, 1998; van de Port, Visser-Meily, Post, & Lindeman, 2007; Visser-Meily, Post, Meijer, Maas, et al., 2005; Visser-Meily, Post, Meijer, van de Port, et al., 2005); and
3. generate theory of children's coping after parental ABI (Moreno-Lopez, Holttum, & Oddy, 2011).

While the studies offered universal agreement that parental ABI appears to impact on children, the breadth of approaches adopted across such a small sample of literature made the synthesis of study findings challenging.

Taken as a whole, the reviewed evidence underscored the importance in considering children in the context of parental ABI, with research from all three areas of work offering insight into the impact on children.  However, the lack of consistency across reviewed studies in terms of theoretical and methodological positions created difficulty in drawing meaningful interpretations from the data as a whole, with contrasting (or largely unclear) philosophical or theoretical

underpinnings directing a wide range of research.  Other authors have drawn similar conclusions (Tiar & Dumas, 2015) and highlighted the potential benefit of a unifying conceptual model for drawing conclusions across study findings.  As detailed above (p.11), the refined search strategy (within the secondary review) takes account of this finding by focusing on studies with more closely aligned epistemological position, looking at the qualitative evidence.  Therefore, discussion here will focus on the quantitative studies (listed within cluster 2 above), which sought to measure outcomes related to children's wellbeing after parental ABI.  A summary of the reviewed quantitative studies, including study aims, design, findings and critical appraisal, is offered within Table 1 below.

**Table 1: Primary Literature Review Papers**

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Kieffer-Kristensen et al. (2011) <br><br>*Denmark* | To explore children's post-traumatic stress symptoms (PTSS) and psychological functioning after parental ABI. | Not stated | n=55 families (with at least one child 7-14 yrs).<br><br>Parental ABI group (n=35 families); <5yrs post injury.<br><br>Comparison group: diabetes (n=20 families); <5yrs post diagnosis. | Self-report measures (child and adult) | Children found to be at risk of developing PTSS following parental ABI. Almost half of children of parent with ABI (46%) had significantly elevated levels of PTSS compared to 10% of children within comparison group. These symptoms were under-reported by parents.<br><br>Parents of children within ABI group reported more behavioural/emotional problems for their children than standardised norms, but not significantly different from comparison group. | Strengths: consistency between aims and study design (methods); standardised measures used (Danish versions available); child self-report measures used; inclusion of data comparison group in addition to published norms (culturally representative normative data available, i.e. for Danish population).<br><br>Limitations: sampling (small sample size; potential sampling bias, restricted inclusion criteria: only two parent families were included). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Pessar et al. (1993)<br><br>*USA* | To explore the effects of parental TBI on children's psychological functioning and behaviour. | Not stated | n=24 families<br><br>Parental TBI; 16-84 months post injury. | Self reports (adults only) | Negative behaviour change was reported for most children and this was correlated with reduced parenting performance of both parent with ABI and the spouse.<br><br>Depression in the non-injured parent was seen to be associated with poorer outcomes for children. | Strengths: consistency between aims and study design (methods).<br><br>Limitations: sampling (family defined as 'married couple' only); data collection and measures (children's perspectives not sought and most self-reports relied on proxy reporting of non-injured parent in relation to parent with ABI; non-standardised measures/use of measures; sub-scales of self-reports used in isolation, determination of 'substantial change' on measures not clearly accounted for). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Sieh et al. (2010)* *Netherlands* | To explore early risk factors for long-term stress in children after parental stroke. | Not stated, although analysis underpinned by stress theory. Longitudinal study. | n=29 families (44 children). Parental ABI; 3 yrs post stroke. | Self reports (child and adult) | Children's reports of elevated stress correlated with child's gender (girls more at risk) and parent reports of depressive symptoms and marital dissatisfaction. Strongest correlation observed for depressive symptoms reported by parent with ABI. | Strengths: consistency between aims and study design (methods); standardised measures (clear description of use of measures and their reliability/validity); child self-report measures used; consideration of ethics demonstrated. Longitudinal study; cross reference of data available for T1 (entry to rehab), T2 (2mths after discharge of rehab), T3 (1yr post stroke), T4 (3yrs post stroke); explanation provided re participants excluded/lost to follow up at this timepoint (T4). Limitations: sampling (small sample size; participants excluded on basis of marital breakdown); data collection and measures (marital dissatisfaction only measured for spouse, crude measure of functional disability used). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Uysal et al. (1998) *USA* | To explore: parenting skills of individuals with TBI and their spouses; the effects of parental TBI on children; the effects of parental TBI on levels of depression. | Not stated | n=32 families (with at least one child; 7-18yrs). Parental TBI (n=16 families); mean time post injury 9.3 yrs. Comparison group: parents without TBI (n=16 families). | Self reports (child and adult) | Children of parent with TBI experienced more symptoms of depression than comparison groups, as did parent with TBI. No differences found in terms of children's behavioural problems between the two groups. Children perceived non-injured parent as less involved in parenting and both parents as having more 'lax control'. | Strengths: consistency between aims and study design (methods); inclusion of comparison group; perspectives of child sought; thorough reporting of measures used, with clear use of data to support findings. Limitations: sampling (small sample size; restricted to two-parent families where child living at home). No distinction made regarding parents whose TBI pre-dated parenthood. Limited description of method of data collection and ethical considerations, especially in relation to the inclusion of children |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| van de Port et al. (2007)* <br><br> *Netherlands* | To explore caregiving, behaviour problems and stress in children 3 years after stroke. | Not stated. Longitudinal study. | n=29 families (44 children; 10-21yrs). <br><br> Parental ABI; 3 yrs post stroke. | Self reports (child and adult) | Most children supported their parents with care and mobility tasks (66%), reported increased responsibility (72%) and maturity (81%). <br><br> Some behaviour problems reported for children. <br><br> High stress in children was associated with female gender, as well as depression, limitation in activities of daily living and life satisfaction of the parent with ABI. | Strengths: consistency between aims and study design (methods); majority of measures used were standardised; child self-report measures used. Part of longitudinal study; some comparative data available from earlier timepoints (see Sieh et al.,2010). <br><br> Limitations: sampling (small sample size; limited explanation given regarding participants lost to follow up from prior study, Visser-Meily et al., 2005). Data collection and measures (non-standardised measure for perceived benefit – measure did not distinguish between no change and negative change; not all measurement data presented/discussed; no comparative data for stress or some patient measures). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Visser-Meily, Post, Meijer, Maas, et al. (2005)*<br><br>*Netherlands* | To explore: support given to children during inpatient rehabilitation after parental stroke; what determinants predict children's adjustment 2 months after discharge. | Not stated. Longitudinal study. | n=55 families (77 children; <18yrs).<br><br>Parental ABI; <6mths post stroke. | Self reports (child and adult) | Half of children received support (defined as one or more consultation with rehabilitation staff member or attending full-day therapy).<br><br>Support children received during parent's rehabilitation was related to parent's disability, but not health status or behavioural difficulties children were experiencing.<br><br>Children's health and psychological functioning related to the health of the non-injured parent's level of depression and strain. | Strengths: consistency between aims and study design (methods); methods); majority of measures used were standardised; child self-report measures used. Part of longitudinal study; baseline data available for study of correlations. Ethical processes reported.<br><br>Limitations: sampling (small sample size; inclusion criteria limited to children with two parent families only); data collection (crude measurement of support from rehabilitation staff; children's perspectives regarding need for support not ascertained; measures for parent with ABI primarily focused at impairment level, e.g. depression not measured). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Visser-Meily, Post, Meijer, van de Port, et al. (2005)* <br><br> *Netherlands* | To explore: changes in children's functioning (including depression, behaviour and health) 1 year after parental stroke; which factors can predict course of functioning. | Not stated. Longitudinal study. | n=71 children (number of families not specified in follow-up study). <br><br> Parental ABI; 12mths post stroke. | Self reports (child and adult) | Improvements were observed in children's functioning at 1-year post stroke compared to data at admission to rehabilitation and two months post discharge. <br><br> Children's functioning at the start of the rehabilitation served as a predictor for functioning at 1-year post. <br><br> Levels of depression and non-injured parent's perception of relationship also served as predictor for children's functioning. | Strengths: consistency between aims and study design (methods); standardised measures; child self-report measures used; ethical processes reported. <br><br> Limitations: sampling (small sample size; inclusion criteria limited to children with two parent families only). Outcomes measured (data collected for parent with ABI primarily focused at impairment level, e.g. depression not measured). |

*Papers refer to different time points of same longitudinal study*

*Measuring the impact of parental ABI on children's wellbeing*

All included studies measuring the outcomes relating to children's psychological and physical health provided findings that suggested children might be at risk of their own adverse health outcomes and called for more attention to support their needs.

Multiple areas of impact were reported across studies, with findings that children living in the context of parental ABI displayed behavioural difficulties (Pessar et al., 1993; van de Port et al., 2007; Visser-Meily, Post, Meijer, Maas, et al., 2005; Visser-Meily, Post, Meijer, van de Port, et al., 2005), elevated stress (Sieh et al., 2010; van de Port et al., 2007), depressive symptoms (Uysal et al., 1998; Visser-Meily, Post, Meijer, Maas, et al., 2005) and increased levels of PTSD symptoms (Kieffer-Kristensen et al., 2011). However, there were some conflicting findings between studies regarding the type or degree of difficulties experienced as well as the role of injured parent and non-injured parent outcomes as predictors for child outcomes.

Some studies indicated the injured parent's level of impairment or depressive symptoms was associated with greater risk of negative outcomes in children (e.g. Pessar et al., 1993; van de Port et al., 2007), but others found no significant correlation between these variables (e.g.Sieh et al., 2010; Visser-Meily, Post, Meijer, Maas, et al., 2005). Greater consistency was shown across studies between children's outcomes and those of the non-injured parent. A number of studies showed the non-injured parent's scores of depressive symptoms, experienced strain or perception of marital relationship predicted issues relating to child's mental health and behavioural issues (Pessar et al., 1993; Sieh et al., 2010; Visser-Meily, Post, Meijer, Maas, et al., 2005; Visser-Meily, Post, Meijer, van de Port, et al., 2005).

*Appraising the evidence: Strengths and limitations*

The quantitative studies were able to offer insight into the potential risk for children in terms of the outcomes captured across studies. However, due to the lack of theoretical basis guiding most of the research, it is difficult to determine whether the issues selected for measurement are the most meaningful or

important to study, either from a conceptual basis or from children's own understandings and experiences. Furthermore, a wide range of outcomes were assessed across the studies. It was positive to note that many studies sought data directly from children using self-report measures, but some level of proxy reporting (for both the child and injured parent) was evident across studies. Finally, a number of studies used non-standardised measures. Using standardised measures would not only have offered greater assurance of the validity and reliability of results obtained, but also would have provided more opportunity for comparison between studies using the same measures.

A number of other design limitations were consistently noted across studies that restrict the generalisability of findings. Sampling issues appeared across many studies, with small sample sizes, reliance on convenience sampling, and restricted inclusion criterion noted. For example, many studies had narrow definitions of family, restricting who was eligible for inclusion (e.g. two parent households or married couples) and those measuring change over time also excluded families where parents had since separated or had secondary injuries (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). While strict exclusion criteria offers control to the experimental design, it limits the applicability of study findings across the population as it does not reflect the lived reality of families after ABI, who are known to experience relationship issues when living with the consequences of brain injury (Kreutzer et al., 2016)

Significant associations were found across studies, with some findings (such as the impact of non-injured parent's wellbeing on children's outcomes) repeated across studies and providing direction for further exploration. However, in general, there was still a lot of unaccounted variance within reported data. Many studies were cross-sectional, limiting ability to draw causal inferences from the data. Furthermore, it is possible that pre-injury variables may account for some of the variance but capturing meaningful pre-injury data is a challenge inherent in this type of injury research. Some studies did make effective use of comparison groups, such as the inclusion of families diagnosed with diabetes within the last five years (Kieffer-Kristensen et al., 2011). This allowed for useful exploration of the significant differences noted in measured outcomes between different populations.

While aetiology of brain injury, and timeframe post injury, was a factor of some designs (for example, the studies by Visser-Meily et al looking at children's adjustment to parental stroke), other studies did not have this as a focus of interest (e.g. making no distinction if brain injury predated parenthood or occurred in the child's lifetime in Uysal et al., 1998) and therefore did not explore the potential impact of these factors on children's outcomes.

Knowledge of whether the ABI predates the child's birth or has occurred in their lifetime, as well as the type (and severity) of injury, level of ongoing impairment and time since injury, are potentially salient issues that could be useful to inform rehabilitation practice. As it stands, studies were not able to offer much insight into how these factors accounted for variance within findings, and so potential differences relating to, for example, the cause of injury (and associated population characteristics) could not be explored.

As a whole, the quantitative studies related to a relatively small body of work and a small number of children, with 4 of the 7 publications referring to studies discussing the same group children at different time-points (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). Studies examined populations with cultures and healthcare contexts quite different from NZ, being conducted in Denmark, The Netherlands and USA. When looking at supporting domestic rehabilitation practice through the application of evidence-based practice caution must be taken to consider the differences that may exist due to the political context of healthcare as well as cultural factors. The health disparities that exist for Māori and Pacific populations within the NZ context emphasise the need for cultural competence at all levels of healthcare practice, which includes the application of evidence-based practice in brain injury rehabilitation (ACC & New Zealand Guidelines Group, 2006).

**Refining the Focus of the Search**

The results of the primary review emphasised the need for a more robust theoretical-base for research aiming to explore or address the impact of parental ABI on children. As such, the space for more inductive exploration of the topic was highlighted, providing the potential to gain greater understanding about children's

experiences and possible areas for future study (including areas where measurement or intervention may be best directed).

As indicated above (p.11), an updated review (secondary review) was undertaken, refining the search criteria according to epistemological assumptions of this thesis, with specific consideration of the positioning of children and the type of knowledge sought as 'evidence'.  The secondary review specifically acknowledged children's agency, placing value on their knowledge and ability to offer their own perspectives of the meanings they construct from their life experiences (Christensen & James, 2008; Docherty & Sandelowski, 1999).  Therefore, it prioritised examination of the findings from qualitative studies, aiming to gain understanding of children's constructions of their experiences and sense making, from their perspectives.  Once again, studies were appraised for their strengths and limitations, and ideas found across studies synthesised.

**Secondary Review: Search Results**

As outlined above (p.12), SCOPUS and EBSCO Health Databases were searched for peer-reviewed qualitative literature.  Papers were required to be available in English language and published from 1990 onwards.  All results were subjected to the revised screening process, and were required to report on qualitative data, collected directly from the child, about their experiences of living in the context of parental ABI.  Potentially relevant articles were retrieved for full text review.

The primary review identified five qualitative studies relating to children's experiences of parental ABI and the secondary review identified an additional study.  After the refined criteria had been applied, with a particular focus on qualitative studies exploring children's own constructions of their experiences, two papers were excluded on the basis of ineligible data.  The studies were excluded as the data was not sourced directly from the child; having been collected from a parent and clinician (Harlow & Murray, 2001), and (within a mixed-methods study) from families, within an intervention (Charles et al., 2007).  Therefore, in total, four papers were deemed eligible for inclusion.  All four sought to gain understanding of children's experiences in the context of parental ABI; one was a pilot study conducted with children prior to therapeutic intervention (Butera-Prinzi & Perlesz, 2004); one interviewed children with PTSD symptoms

(Kieffer-Kristensen & Johansen, 2013); two were focused on adolescents, exploring their experiences (Harris & Stuart, 2006) and the role of social support (Moreno-Lopez et al., 2011).  A summary of the reviewed qualitative studies, including study aims, design, findings and critical appraisal, is provided within Table 2 below.

**Table 2: Secondary Literature Review Papers**

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Butera-Prinzi and Perlesz (2004)<br><br>*Australia* | To explore children's experience after parental ABI. | Phenomenological framework | n=4 children (7-12yrs)<br><br>Parental ABI; 2-4 years post injury | Semi-structured interviews<br><br>Observations<br><br>Self-report measures (child and parent without ABI) | Coping and adjustment following parental ABI was challenging for children, especially in relation to parental personality and behavioural changes following ABI.<br><br>(Measures did not reveal clinically significant concerns, but risk factors were indicated.)<br><br>Some positive coping strategies reported. | Strengths: stated aims supported by methodology; data gathered over extended timeframe (6mths).<br><br>Limitations: methods appear incongruent with methodology (use of measurement data inconsistent with philosophical perspective). Some ambiguity between focus of inquiry as research study versus case report from clinical intervention. Limited discussion re: methods of interviewing children. Some use of supporting data for identified themes, but limited (and sources of data not clear, i.e. interview vs clinical observation). Limited description of ethical considerations. Sampling (non-diverse sample; all families seeking counselling). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Harris and Stuart (2006)<br><br>*South Africa* | To explore adolescents' experience after parental TBI. | Phenomenological framework (specifically existential-phenomenological psychology framework) | n=4 adolescents (17-19rs)<br><br>Parental TBI; 1.5-7 yrs post injury | Semi-structured interviews | Adolescents experience was unique; they felt sense of responsibility for their parents (parentification), as well as a sense of guilt.<br><br>Experienced initial shock/fright, loneliness and isolation (self and family), changes in family (including sense of loss) and financial implications.<br><br>Participants also experienced positive meaning-making, seeing positive changes in themselves (including maturity). | Strengths: aims of study, philosophical perspective and methodology clearly stated; internal consistency demonstrated. Some diversity within the small sample. Thorough consideration of ethics provided.<br><br>Limitations: limited use of data to support themes. |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Kieffer-Kristensen and Johansen (2013)<br><br>*Denmark* | To explore the experiences of children showing high levels of PTSS after parental ABI. | Phenomenological approach | n=14 children (7-14yrs)<br><br>Parental ABI; <5yrs post injury (mean 3.5yrs) | Semi-structured interviews | Children experienced several losses at different stages after parental ABI, which were suppressed or neglected by children and their parents to protect injured parent.<br><br>Themes related to: initial fear of parental loss; feelings of estrangement from others who did not understand their situation; increase in chores and responsibilities; dealing with a changed parent; and coping mechanisms.<br><br>Children were regarded to take an active role in trying to preserve the family system after parental ABI. | Strengths: aims of study, philosophical perspective and methodology clearly stated; internal consistency demonstrated. Clear description of methods, including content of interview guide and process of analysis.<br><br>Limitations: sampling (only interviewed children showing high levels of distress after parental ABI, on basis of high scores on measure of PTSS). |

| Included Paper | Study Aims | Theoretical Perspective | Participant Information | Data Collection Methods | Reported Findings | Critical Appraisal |
|---|---|---|---|---|---|---|
| Moreno-Lopez et al. (2011)<br><br>*UK* | To build a model of adolescents' response to parental ABI. | Positioned between positivist and constructionist epistemologies as a 'critical realist'; using grounded theory methodology. | n=6 families (9 adolescents, 12-20 yrs; 6 parents)<br><br>ABI 16-49 months post injury | Semi-structured interviews | A model of the process of coping presented.<br><br>Highlighted a process of initial shock, increased protectiveness by adolescents, sense of increased maturity and the role of social support in offering stability/connection to life before parental ABI (including extended family and peers).<br><br>The findings highlighted the importance of the non-injured parents coping on family functioning and the (supportive) role that offspring have within the functioning of the family unit. | Strengths: philosophical perspective, methodology and methods (including analysis) aligned and clearly described; internal consistency demonstrated. Use of theoretical sampling. Clear description of interview schedule provided; themes and generated theory supported with use of data and participant feedback sought. Thorough consideration of ethics provided.<br><br>Limitations: homogeneous sample of participants (n=9), including data from only 6 families (including three sets of two siblings). |

*Exploring children's experiences of parental ABI*

The qualitative studies offered some rich descriptions of children's experiences in the context of parental ABI. In synthesising the study findings, some key themes emerged that underlined the importance in considering children's position within the family after brain injury. Descriptions of children's accounts emphasised the wide-ranging impact of the injury and the array of emotions children reported feeling in the context of parental ABI. Reading across studies, ideas that seemed to repeat included experiences of:

- shock and fright of the event;
- loss (challenges in dealing with changes in the injured parent and impact on relationships);
- support (receiving and providing);
- active coping and sense making.

A summary of these ideas is presented below, incorporating related literature where relevant. Key observations made during the appraisal process are also highlighted.

Three studies described the ***experienced shock and fright of the event*** children felt at the time of parental ABI. In Kieffer-Kristensen's (2013) study, they found the children they interviewed not only had vivid memories from either witnessing or learning about their parent's injury, but also of seeing their parent injured in hospital. They recounted feeling scared, despite maintaining a calm appearance, and worrying their parent may die. Similar ideas were observed in the studies with adolescents who were reported to find the aftermath of ABI a *"frightening and uncertain time"* (Moreno-Lopez et al., 2011, p. 1227), with a participant in Harris and Stuart (2006) explaining that immediately after the accident, and in the early period of recovery, she recalled *"feeling numb"* (p. 50). Moreno-Lopez et al. (2011) suggested that support (especially from extended family) during this period helped young people manage their daily lives and regain a sense of 'normality'. Across studies, participants indicated that the level of support typically changed over time, with support often reducing after the crisis period of parental injury.

The theme of **experienced loss** was common across all studies. The losses children experienced related to the changes they reported observing in their injured parent's behaviour, personality and emotional affect, as well as changes in their relationships with their injured parent and non-injured parent, and others. In the reviewed studies, the changes brought about a range of mixed emotions, with children feeling happy and grateful that the parent they loved and cared for had survived, while also experiencing sadness, anger and frustration toward their injured parent and the changed ways they interacted with them and others around them.

The children's accounts were aligned with themes of loss and identity change seen in qualitative literature exploring the lived experience of recovery after TBI, where injured people themselves report a sense of disconnect with their former selves and social world (Levack, Kayes, & Fadyl, 2010). Similar reports have been noted in studies looking at couples' relationships after TBI, where the theme of loss is equally apparent, with people experiencing the loss of their own identity as well as their shared sense of self, and also their sense of connectedness with the other person (Godwin, Chappell, & Kreutzer, 2014). In the reviewed papers children were dealing with a loss of a person who was still present; their accounts spoke of the fact the person they had known, or the relationship they had previously enjoyed, had gone. As these two participants described:

> *"I basically just feel sad because he's there physically. I suppose I've still got a Dad but he's not my Dad. It's not like I remember him, he has a total personality change, that is not my Dad."*
> (Butera-Prinzi & Perlesz, 2004, p. 89)

> *"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. But I haven't felt I could say this to him or anyone else."*
> (Kieffer-Kristensen & Johansen, 2013, p. 1566)

The ambiguity of the losses the children described were recognised to resonate with the theory of 'ambiguous loss' (Boss, 1999). The framework of 'ambiguous loss' has been applied to research and therapeutic intervention for people after brain injury (Kreutzer et al., 2016) and is useful in describing the confusion caused with the unclear loss of a loved one who is physically still present, but psychologically absent. Reviewed studies highlighted the impact of these losses on

children through the difficulties they experienced in knowing how to manage their uncomfortable feelings (Butera-Prinzi & Perlesz, 2004) or relate to their changed parent (Moreno-Lopez et al., 2011) *"we have clashes because he is just a different person"* (p. 1227).

The changes children reported in relation to their injured parent impacted on their child-parent relationship. Some participants talked about efforts to maintain positive relationships with their injured parent, for example trying to find ways to maintain, or regain, emotional connection with their injured parent through shared activities. A few examples were provided of positive changes children observed in their injured parent, for example improved temperament, being less stressed or home more often, which had positive impact on connectivity between child and parent. However, more commonly reported findings were that children experienced difficulties connecting with their injured parent and coping with the personality, mood and behavioural changes of the 'new' parent. In Moreno-Lopez et al's (2011) study, adolescents recognised the impact their parent's mood had on them and the whole family, as one participant stated, *"when dad is unhappy sets up a horrible atmosphere"* (p. 1228). Issues with reduced tolerance, quick temperedness and aggression appeared especially challenging for participants across studies. In relation to the symptoms of increased aggression, participants in Butera-Prinzi and Perlesz's (2004) study reported experiences of verbal and physical abuse in the home. While no other authors reported similar findings it is noteworthy that the children in their study did not actually disclose these experiences in the research interview sessions themselves, but later in the therapeutic sessions that occurred over time. Their finding highlights the importance is staying vigilant to the topic of family violence, both in research designed to explore the impact of parental ABI on children and in rehabilitation practice with family and whānau.

The review findings also demonstrated that children experienced changes to other significant relationships in their lives. Several themes across studies described positive changes in children's relationships with their non-injured parents, who were most often recognised as being their primary source of support. Children were reported to experience a closer sense of connection with their non-injured parent, who they felt united with in their efforts to work together, supporting each

other after injury.  There was a new sense of appreciation for family, which also extended to closer relationships with siblings and other family members who had rallied around to offer support, including, most notably, grandparents.  However, there were also negative changes observed in terms of the healthy parent's behaviour, stress levels and availability.  In the two studies looking at younger children's experiences, authors highlighted a sense of expressed annoyance from children that their injured parent demanded so much time and attention from their healthy parent, when they had their own needs they wanted addressed (Butera-Prinzi & Perlesz, 2004; Kieffer-Kristensen & Johansen, 2013).

Across study findings themes described children's ***experiences of receiving and providing support*** in the context of parental ABI.  As indicated above, children were frequently reported to have found support in their healthy parent, siblings and grandparents.  Their support came with the shared understanding of experiences of injury, and endured over time.  However, other support networks were seen to be more inconsistent and transient, with studies describing how participants felt estrangement from others who did not show understanding of their situation (Kieffer-Kristensen & Johansen, 2013), and experienced loneliness as a result of reduced socialisation as part of the family (Harris & Stuart, 2006).  Peer relationships emerged as needing extra consideration; they were relationships also impacted by parental ABI and had the potential to be an important source of support for children (especially adolescents) or alternatively a potential source of negative influence for children going through difficult times (Moreno-Lopez et al., 2011).  Across studies, children were seen to be selective in terms of disclosure to friends; it was an active decision and children expressed frustrations when friends did not show understanding (Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2011).

A reciprocal role of support was noted across studies, with findings showing a mutual dependence of support roles within families (Harris & Stuart, 2006).  Children took on extra tasks and chores around the home, and talked about it being a 'natural response' to support the family (Kieffer-Kristensen & Johansen, 2013).  The support was not limited to physical tasks and many children were reported as discussing their efforts to emotionally support the family.  As described, the relationship between the child and non-injured parent was

35

consistently raised as significant to study participants. Children demonstrated that as well as being aware of the impact of the injury on themselves, they were acutely aware of their non-injured parent's suffering. They expressed their worries about their non-injured parent, recognising they were sad, stressed and burdened. Studies reported how children actively sought to protect their parent in order to try and reduce the stress they were experiencing, and try make their 'life easier'. As well as remaining alert to potential stressors, children avoided sharing their own worries or stresses with their parent(s) so as not to make them more stressed, burdened or sad.

A further layer of support considered across studies was the role of information and professional input. Studies stressed that children often did not have access to information, either about ABI generally or their parent's condition. Adolescents in Harris and Stuart's (2006) study highlighted that they could not always talk to their healthy parent about their injured parent's condition, as asking questions could cause further upset. Equally, they recognised at times people were trying to protect them from the seriousness of the event, but the lack of information contributed to anxieties. Similar findings have been reported in literature looking at children's experiences of parental illness more broadly. Such studies have highlighted that in the absence of appropriate information, children can become more worried and try to make sense in their own ways; at times leading to inappropriate allocation of blame with themselves (Kristjanson, Chalmers, & Woodgate, 2004) or their parents (Turpin, Leech, & Hackenberg, 2008); or drawing inappropriate conclusions, such as a parent only enters hospital to die (Mordoch, 2010). In terms of professional input, children in the reviewed studies found staff addressed the adults and didn't seem to notice them (Kieffer-Kristensen & Johansen, 2013) and accordingly they were regarded to be *"left out and invisible"* (Butera-Prinzi & Perlesz, 2004, p. 88). Positive examples of family engagement were also mentioned and this was perceived as supportive to the children involved (Kieffer-Kristensen & Johansen, 2013).

Across studies, positive ideas relating to the ways in which children actively managed their experiences by ***coping and sense making*** were emphasised. Providing support to others, or finding someone with whom to communicate, were both seen as positive coping mechanisms. Positive relationships that were

particularly emphasised were extended family, with the consistency of grandparent support being discussed across a number of studies. Children also highlighted the role family pets could play in offering a level of comfort. A commonly reported coping strategy across studies was the use of distraction. Children used play activities, as well school and leisure time as spaces for respite and distraction, providing time-out from the issues going on at home.

The reviewed papers also described children's meaning making in which their experiences were constructed into positive narratives. Study participants talked about how their experiences had given them a new outlook on life, in which they now looked *"on the bright side of everything"* (Moreno-Lopez et al., 2011, p. 1226) and felt they must *"make every second count"* (Harris & Stuart, 2006, p. 51). Some gave examples of wanting to prioritise family more since ABI, with a new value of their time together, and also felt they had closer relationships with members of their families (Harris & Stuart, 2006; Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2011). Children explained that the sense of duty they felt toward their parents gave them a perspective that was different from their peers, increasing their sense of maturity. While at times this led to frustrations and a sense that others could not truly understand their position, it also provided children the opportunity to learn about their character and contributed to their developing sense of self.

*Appraising the evidence: Strengths and limitations*

The majority of the qualitative papers demonstrated rigour in terms of their stated methodology and application of methods, providing clear rationale and description of approaches taken. One study where questions of methodological congruence and ethics remained was the work of Butera-Prinzi and Perlesz (2004) who combined research with a clinical intervention. The paper offered some insightful findings that aligned with the other studies and also highlighted the topic of increased family violence after parental ABI. However, questions remained over the blurred lines between data collected as pre-therapy interviews and through the intervention sessions themselves; how children assented to processes; and how the different data sources (including information from therapy sessions and from parents) were combined for analysis. Despite its limitations, the study draws

attention to the need to consider the relationship between child participant and adult researcher, as well as potential benefits of collecting data over multiple sessions. The study also highlights how information gathered from parents may be useful in providing context for stories shared.

All the reviewed qualitative studies sought the experiences of children who had known their parent prior to ABI, with criteria that the injury must have occurred in the child's lifetime (ranging from 1-7 years post injury across studies). Where restrictions were made about families residing in the same home this was generally limited to the period before the brain injury and so did not exclude families who had since separated. The studies still only refer to the experiences of a relatively small number of children, with all but one study (Kieffer-Kristensen & Johansen, 2013) drawing mainly on experience of older children (from 12 years and over). Greater diversity was seen in the qualitative studies in terms of populations studied with studies taking place in Europe (Denmark and UK), Australia and South Africa.

Two of the qualitative studies purposefully sampled children or families experiencing difficulties after parental ABI. One study invited only those children showing elevated levels of PTSD to participate (Kieffer-Kristensen & Johansen, 2013) and another recruited families seeking family therapy (Butera-Prinzi & Perlesz, 2004). While it is important that children who are experiencing negative outcomes are given the opportunity to participate in research, there is a risk that a bias towards researching problems means that children coping well in similar circumstances may not be given opportunity to share their experiences. From an ethical perspective, some authors have argued that research that takes a problem- or deficit-focused approach to researching children's issues risks increasing prejudice and stigma to groups of children related to the research (Alderson, 2005). Alderson argues that in order to conduct fair research, it is important to also ask children about positive aspects of their lives, exploring their strengths, resiliencies, knowledge and the resources they access. The reviewed studies did all report on positive aspects of children's reported experiences, and one study (Moreno-Lopez et al., 2011) adopted a strengths-based approach by design, seeking adolescent's experiences of coping and accessing support after parental ABI.

# Current Scope of Knowledge to Inform TBI Rehabilitation

The reviewed literature demonstrates a need for greater consideration of children as family members impacted by ABI within current rehabilitation practice, policy-making and research.

Within New Zealand, current national policy in the form of TBI Guidelines is guided by a participation model of practice and calls for practitioners to look at a person's potential to perform significant life roles, such as living independently, driving or returning to work, as well their ability to *"fulfil family roles and maintain personal, sexual and family relationships"* (ACC & New Zealand Guidelines Group, 2006, p. 70).  The policy document also emphasises the long-term strain that may be experienced by family members.  However, it offers limited detail about the types of issues family and whānau may be experiencing or the types of support they may need in performing their roles, including parenting after injury.  In contrast, the TBI Guidelines offer clinicians more detailed information and recommendations in relation to paediatric patients and their family and whānau. The guidelines discuss the impact of the child's injury on parenting function and potential outcomes for the non-injured children within the home (i.e. siblings of injured child).  From the findings of the reviewed literature, many of the highlighted issues for sibling children (e.g. emotional impact, experienced stress, caregiving and long term impact related to parental availability, ability to work or relationship breakdown) would appear to also apply when it is the parent who is injured.  Why the discussion is not extended to consider adults with TBI in parenting roles and their dependent children is not clear, but perhaps is reflective of greater tendency for family-focused models of research and practice within paediatric rehabilitation.

The evidence reviewed suggests children are impacted by parental ABI; being at risk of their own adverse health outcomes and experiencing a wide range of emotions in processing the event and coming to terms with the impact of the injury on their lives.  Qualitative findings provided insights into ways in which family relationships could be better supported to harness the potential for greater resilience, coping and mutual support available within families.  Several studies emphasised the importance of ensuring children were included within discussions

about their injured parent and received appropriate information to support their understanding and coping (Harris & Stuart, 2006; Moreno-Lopez et al., 2011). As a whole, however, the sample of studies remains relatively small and heterogeneous, with research predominately originating in Europe (with no studies from NZ), and few studies focusing specifically on children of parents with TBI as opposed to ABI more broadly. Acknowledging these limitations highlights a need for further research to support the development of evidence-based national policy and to guide rehabilitation practice with family and whānau.

## Summary

This chapter has offered a summary and appraisal of current evidence relating to children living in the context of parental ABI. The synthesis of study findings highlights that parental ABI impacts on children in the family and yet, to date, there appears to be a very limited focus on children's experiences within rehabilitation literature. The current study aims to add to the evidence base to help inform policy design and guide practice. The following chapter *(Chapter Three: Methodology and Methods)* will discuss the study design, outlining the theoretical perspectives underpinning the research and the methodology and method selected to work with children in exploring their experiences of parental TBI.

# Chapter Three: Methodology and Methods

This chapter provides an account of the theoretical, ethical and practical considerations that shaped the current study.  It opens with description of the conceptualisation of childhood guiding this study.  Then it describes the methodology used to explore children's experiences of living in the context of parental TBI, including the positioning of children as research participants.  It then describes the methods used and offers an account of ethical decisions made.

## Conceptualisations of Childhood

The current study was designed in accordance with contemporary conceptualisations of childhood, where children are recognised as active agents within their lives, who have the right to contribute to research on issues relating to their life experiences (Christensen, 2004; Christensen & James, 2008; Woodhead & Faulkner, 2008).  This view reflects the shift away from research that positions children as the *objects* of study, of interest for their role as future adults, or 'human becomings', towards research *for children and with children*.  This position recognises children's status as capable *subjects* and *"already competent participants in their everyday worlds"* (Farrell, 2005a, p. 6; Hood, Kelley, & Mayall, 1996).  As such, childhood is acknowledged to be a unique period of life in its own right and is recognised to be neither fixed nor universal, but socially constructed and contingent on context (Balen et al., 2006; Christensen, 2004; Farrell, 2005a; Woodhead & Faulkner, 2008).  Positioning children in this way raised a number of epistemological, methodological and ethical questions that needed to be considered in designing the study, which are made explicit in this chapter.

## Methodology

### Interpreting Children's Stories

In alignment with the contemporary conceptualisations of childhood introduced, the study methodology was embedded in a social constructionist epistemology (Patton, 2002).  This perspective discounts a belief in objective truth and instead assumes that seeking understanding of an experience relies on accessing the

*meanings* of an experience that have been *constructed* by a person and their interactions within their social world (Crotty, 1998). Accordingly, the study positioned children as the experts and gatekeepers of knowledge about their experiences and recognised them to be *"the best sources of information about themselves"* (Docherty & Sandelowski, 1999, p. 177). The study methodology drew on hermeneutics, using interviews to gather children's narratives about their experiences of parental TBI in order to explore interpretation and sense-making from children's perspectives (Ellis, 2006; van Manen, 1990).

The search for meaning of a lived experience relies on interpretation. Drawing on what van Manen (1990) describes as the *"hermeneutic thrust"* of conversation, the research interviews were regarded to be a collaborative pursuit of sense-making and interpretation. The methodology was guided by the assumption that people often *"best reveal their sense-making and experience narratively"* (Ellis, 2006, p. 112), as it is through stories that people represent, and ultimately construct, the realities of their lives (Riessman, 1993).

Congruent with the epistemological positioning of the research, the search for objective 'truth' of experience was not the goal. The study recognised that we do have *direct access* to another's experience and that narratives are not reflections of experience, but rather are constructions that are *"creatively authored, rhetorical, replete with assumptions and interpretive"* (Riessman, 1993, p. 5). The research process worked with the 'ambiguous representations' of experience as attended to and told by the participant, which in turn were represented in transcription and analysis by the researcher and interpreted when read by the audience (Riessman, 1993). Accordingly, the findings produced through these representations reflect a co-constructed account of children's experiences of parental TBI.

Children's Participation in Research

In acknowledging children's roles as both *experts* and *gatekeepers* of their individual experiences, the study sought to address their rights as well as needs as active participants within research.

*Research for children: Supporting their right to be heard*

Children are recognised as having fundamental human rights, which include the freedom to express their views and opinions, and be heard, on all matters affecting their lives (UN General Assembly, 1989). The reality, however, is that children are rarely given the opportunity to challenge decisions made on their behalf (Lansdown, 1994) and research often fails to talk directly to children about the issues that affect their lives (Carter, 2009). Conducting ethical research with children is *"embedded within our understandings of children and childhood"* (Farrell, 2005b, p. 5). Traditionally discourses have maintained a focus on the risks and vulnerabilities associated with children's research (Carter, 2009; Hood et al., 1996). The process of developing a study that aimed to *engage with* children and assumed their competency, agency and expertise did not diminish concerns for vulnerability, but rather served to extend the responsibilities I held as the researcher (Woodhead & Faulkner, 2008). As researcher, I needed to recognise children's position as research participants, with rights and capabilities. I needed to consider children's *abilities* and *interests* as participants alongside the *context* that informs their vulnerabilities in society.

*Children as research participants: Same, but different*

Respect for participants' unique status as children was considered a core aspect of study design. Children were regarded as capable of acting as reliable informants in the study and consequently shared similar needs and rights as adult participants. However, children are not adults and as research participants they have specific needs that relate to the context in which they live their lives, particularly in relation to issues of power and aspects of their culture (Mauthner, 1997; Morrow, 2005). Children's lives are shaped by dependency as well as agency and constrained by multiple contextual inequalities; children are *physically vulnerable* due to the power that adults have over their lives and are also *structurally vulnerable* due to their cultural position in society that limits their civil status (Lansdown, 1994). Equally, children form a distinctive social group and are more than the *"mere recipients of contextual influences"* but are *"active in the construction and determination of their social lives"* (Irwin & Johnson, 2005, p. 821). They have

their own interests and values, which are *"not necessarily harmonious"* with the adults in their lives (Hood et al., 1996, p. 118).

As an adult researcher I was positioned as an 'outsider' to the child's lifeworld and needed to recognise that listening to children is not the same as giving them true opportunities to be *heard* (Roberts, 2008). Explicit consideration of children's perspectives, values, abilities and interests was required to communicate in ways that not only matched the children's understanding, but also resonated, were sensitive and meaningful (Morrow, 2005). The research process represents a partnership between researcher and participant, whereby both partners have the potential to contribute to the generation and interpretation of data (Farrell, 2005b). The inherent power imbalances that existed within the processes of data collection, interpretation and dissemination within the partnership between (child) participant and (adult) researcher were acknowledged and a process of meaningful reflexivity was required across all stages of the project to avoid the risk of over-privileging the adult perspective. Respect for children's competencies needed to *"become a methodological technique in itself"* (Morrow, 2005, p. 154). I was required to remain cognisant of my position and assumptions throughout the research process to ensure children were allowed to set their own research agenda and actually be heard.

Respect for children, and their rights and needs, guided ethical and methodological decision-making in the study. A detailed account of the approaches adopted in relation to issues of consent, confidentiality, safety, privacy and practices of consultation is provided later in this chapter (see 'Ethics' section below, p.58). Speaking more broadly however, ethical reasoning was regarded to be an active, ongoing process throughout all phases of the iterative design and implementation of the study. The study aimed to gain knowledge that could be of benefit to children and families who experience parental TBI in the future and in doing so sought to avoid any potential harm to those families who participated in the research. To ensure the principle of beneficence was upheld, careful consideration was given to establishing research conditions that provided for children's physical, emotional and psychological safety (Farrell, 2005a). In order to ensure the study was appropriate for each child, the ethical design emphasised the need for flexible and responsive processes that could cater for the specific needs of the individual

participants and the potential *"for innovative and situational problem-solving"* when needed (G. Allen, 2005, p. 18).  Such an approach aligned with the qualitative design of the study, as flexibility is regarded a necessity for data collection methods, whereby interviews *"are event- and data-driven, as opposed to fixed prior to the beginning of a study"* (Docherty & Sandelowski, 1999, p. 178).

# Methods

The selection of appropriate research methods was guided by the overarching study methodology and informed by relevant literature.  The study design was refined through processes of consultation, which provided specific guidance to support recruitment, data collection, analysis and dissemination.

### Research Question

This study aimed to gain understanding of children's experiences when a parent sustains a TBI.  The study sought to answer the research question:

*What are children's experiences of living in the context of parental TBI?*

### Sampling

Children who had experience of parental TBI were purposefully sampled and were eligible to participate if they:

1. were aged between 7-11 years old at the time of the interview
2. had a parent who had had a TBI within the last 5 years
3. lived in the Auckland or Waikato region
4. were able, and willing, to communicate with a researcher, verbally in English, in a research interview.

The definition of parent-child relationship was open to individual family/whānau interpretation and as far as possible guided by the child's definition of their family/whānau.  As such, the parent was not required to be living in the same household as the child nor required to be biologically related to the child to be regarded as parent to the child.

The rationale for the inclusion criteria was based upon the exploratory nature of the study and aspects of practical utility in terms of data collection. The decision to set a timeframe post-injury of five years was guided by the methodology, current evidence regarding TBI recovery and the age range of the children included within the study. Unlike positivist assumptions that emphasise the need for interviews to occur close in time to an event to ensure valid and reliable accounts, the study methodology emphasised the *"revisionist nature of stories"* and importance of passing of time to allow events to become *"storied"* (Docherty & Sandelowski, 1999, p. 181; van Manen, 1990).

Recovery and adaptation after TBI is increasingly recognised to be ongoing for years after injury (Powell, Ekin-Wood, & Collin, 2007) and as such it was deemed appropriate to avoid setting a timeframe post-injury that would be too premature. The limit of five years was made on the basis that the study was situated within a rehabilitation context and interested in gaining insights into how children experience life after parental TBI. Therefore factoring in the age range of participants (7-11 years) a maximum of five years allowed children to have experienced life prior to parental injury. Initially this was paired with a minimum timeframe of 12 months post injury, based on the assumption that this period would give children enough time to reflect on their experiences and have a story they wanted to share, and also be a time when more intensive periods of rehabilitation would have passed to avoid adding burden to families. However, after commencing data collection it appeared these assumptions were misleading, as in fact families expressed keenness to participate within the first year of injury and children had stories they wanted to share. Therefore, in consultation with the ethics committee, this minimum timeframe of 12 months post injury was removed and those interested families were invited to participate.

Acknowledging the limited opportunity children have to contribute to research on topics impacting their lives, the study sought to prioritise the voice of children within this research, specifically younger children aged 7-11 years. The discourses of risk and vulnerability that have traditionally surrounded research with children are argued to have affected children's inclusion in studies differently (Carter, 2009). It has been suggested that *"older children/adolescents are generally seen as more competent and therefore less vulnerable than younger children"* and

consequently more often included in research (Carter, 2009, p. 861).  This bias towards representing the views of more 'adult-like' children was seen within the small sample of studies looking at children's experiences after parental ABI discussed in the previous chapter (*Chapter Two: Literature Review*).  Therefore, the study aimed to increase the representation of younger children's voices in research by designing a project that could take account of potential vulnerabilities, but also recognise competencies of younger children.  The study purposefully sampled (Patton, 2002) children aged 7-11 years who could offer new insights to develop the limited literature base on the topic of parental TBI.

The study aimed to capture diversity of experience across the study sample and recognised that perspectives of children living in urban and rural communities may differ in experience.  The study therefore extended the sampling area beyond the limits of the Auckland region (an urban area) to include the rural Waikato region.  Due to the limits of the project budget, as a post-graduate master's thesis, it was not possible to travel further than these regions for interviews.

The study methodology drew on hermeneutics and sought to explore children's narratives relating to their experiences of parental TBI.  Therefore children were required to be able, and willing, to verbally communicate with a researcher in an interview.  While every effort was made to ensure that the individual needs of children were taken into account at each stage of the research, it was important that children were able to verbally communicate in order to be able to share their perspectives through the data collection process.  Children were required to be able to express their preferences regarding participation, including offer their assent to be involved in the research and how they would like to take part, and needed to be able to talk about their experiences within the interview.

**Recruitment**

As there are no specific support services in place for children living in the context of parental TBI within NZ, a range of recruitment strategies were required to identify potentially eligible participants for the study.

Consultation with the Kawa Whakaruruhau Komiti at the School of Clinical Sciences, AUT University (discussed further below, p.58) emphasised the

importance of whakapapa[2] and building upon existing research relationships within the TBI community to support engagement in the study.  Therefore, the research was discussed within personal and professional networks within the community and through presentations about the topic.  Support was received from a range of TBI service providers and advocacy groups who acted as recruitment localities for the project.  In order to meet the goal of maximising potential diversity of experiences, the study sought to include organisations who support people with different levels of classified TBI severity (e.g. outpatient concussion services; inpatient rehabilitation centres) and those who support people with different levels of ongoing impairment related to their injury (e.g. advocacy groups; community-based support services; residential services).  The study also drew on established research relationships that had been developed through an existing research project (The TBI Experiences Study) ongoing in the Centre for Person Centred Research, which was analysing longitudinal experience of recovery and adaptation after TBI.  This recruitment strategy provided the ability to purposefully sample children toward the upper limit of the timeframe post parental injury, who it seemed were harder to reach through formal support agencies, as service provision had since ended for the injured person.

Families had opportunity to express an interest in participating in the study in a number of ways.  Firstly, potentially eligible families were told about the research by recruiting localities and provided with a copy of the study leaflet (see Appendix B: Study Leaflet).  They were then invited to make direct contact with, or have their details passed on to, the study team.  Secondly, potential participants were given the opportunity to respond directly to advertisements displayed by recruiting localities in-house, online or within newsletters (see Appendix C: Study Advert).  To protect participant's rights to privacy and confidentiality recruiting localities were not informed which families ultimately consented to be interviewed.  Thirdly, families already participating in the TBI Experiences study were contacted directly by myself, as a researcher working on that project.  Thorough ethical and methodological consideration was given to this process and a formal

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[2] Whakapapa in Māori culture refers to genealogy.  Whakapapa links people to their ancestors and all living things, and to the earth and the sky.  (Taonui, 2015)

communication strategy was established, which included the development of a specific telephone script and follow-up letter that were approved by the Principle Investigators of the TBI Experiences Study and AUT Ethics Committee. Full details can be found in the recruitment proposal, which acknowledges and addresses the ethical and methodological considerations made in sourcing recruitment via this method (see Appendix D: Recruitment Proposal, which includes the telephone script and letter).

Potential participants were screened for eligibility. If meeting inclusion criteria, the family/whānau were sent further information about the study in the form of a parent participant information sheet (see Appendix E: Participant Information Sheet for Parents) and a child information sheet (see Appendix F: Participant Information Sheet for Children). The child information sheet (alongside other material prepared for the study) was designed to be as accessible and engaging for potential child participants as possible, respecting their rights as autonomous, active agents capable of making informed decisions about their lives. To support this design process, exemplar documents were sourced through consultation with other childhood and disability researchers and the literature was reviewed for guidance (see for example Alderson, 2005). A useful guidance document from a Young Person's Advisory Group (Medicines for Children Research Network, n.d.) emphasised the design of participant information sheets that consider the presentation of material (including use of colour, pictures and layout) alongside clear, concise content.

To support the creation of shared understandings of language within the research process the information sheet provided basic definitions of the concepts of research and TBI, alongside the more specific information about the study. The information sheet also provided a space for children to write down any questions about the study, with the intention of empowering them to engage in the research process and take an active role in choosing whether to participate (some examples are provided below on p.50). If after reading the information families were interested in being involved, an initial meeting was set up with children and their parent(s) to go over study information before scheduling an interview.

## Consent and Assent Processes

The initial meeting offered children and parents the chance to meet with me, as the researcher, directly and to ask any questions about the research face-to-face. The study was designed to allow sufficient time for information about the research process to be clearly explained to parents and children, in a way that was responsive to the individual needs of the different family/whānau members. Both parental consent and children's assent to participate was sought. Most children raised their own questions during the initial meeting and some had used the space on their information sheet to note down their queries. Their questions related to practical aspects of the interview (such as *"do I have to draw?"*) as well as enquiries about the overall intended impact of the study (such as *"how is this going to benefit other children?"*; see further examples in Figure 1 below). Children's questions demonstrated their competency to act as informed participants within research, showing reflection and insight on the process.



**Figure 1: Examples of questions children asked about the study**

Parents provided their consent for their children's involvement in the research, but ultimately children's views held decisional weight also. The decision to take part therefore needed to be shared by both the parent and the child and this message was clearly reinforced through the information sheets and in the process of talking about the study. Parents were required to give their consent for their children to participate and children were asked to give their assent if they were happy to be involved (see Appendix G: Consent Form and Appendix H: Assent Form). For those families recruited through the TBI Experiences study, parents were also asked if they would provide consent for data to be shared between the two studies for potential secondary analysis in the future. Consent and assent was considered an ongoing process within the research, where, as the researcher, I was responsible for watching for cues that children were happy to be involved and comfortable during the interview process (Alderson, 2005).

The underlying assumptions outlined above (p.43) relating to children's positioning within the study were made as transparent as possible to families considering participating in the research. Children and their parents were advised that the study was interested in children's perspectives of their experiences, which included their thoughts, opinions and ideas, and it was explained that there were no right or wrong answers within the research interview. The interviews were designed as 'guided conversations' (van Manen, 1990) and children were informed that they were 'in charge' of what was discussed, allowing them to address the salient points of their experience of living in the context of parental TBI. As such children could chose not to answer any question during the interview, as well as raise any issue they felt important. Both children and parents were informed that they had the right to withdraw from the study at any time, without having to provide a reason.

**Data Collection**

Collecting meaningful data through qualitative research interviews with children was recognised to be a collaborative process that relied on engagement with the family/whānau as a whole. A child's position within a family/whānau is the context that shapes their experiences. Therefore, the existing relationships, power dynamics and loyalties inherent within interdependent family/whānau life needed

to be acknowledged (Teachman & Gibson, 2013). The early consultation work undertaken emphasised the importance of establishing positive research relationships and this was incorporated into the design of the study, which prioritised the need to create working relationships with the child and also the parent (Irwin & Johnson, 2005). The initial meeting with the family/whānau as a whole was included as the first step in establishing trust and rapport with children and their parents, talking together to ensure transparency. The openness of the conversation was intended to allow children to see that their parents were happy to talk with me, as the researcher, and also, by extension, that their parents were happy for them to talk to me. This was deemed important in supporting children to feel comfortable discussing issues relating to family/whānau life with an 'outsider', especially in a context where children are often encouraged to be wary of strangers (Morrow, 2005). This idea was explicitly discussed through the process of talking about children's rights and their control of the interview conversation and parental consent/child assent (as outlined above). Parents were forthcoming in supporting this process, reinforcing to their children that they should feel free to be open and honest about their experience and explaining that they should not worry that what they say may upset or offend their parents.

Ellis suggests that in seeking to make sense of another's experience, *"one uses everything they know to inform interpretation"* (Ellis, 2006, p. 115). As researchers cannot necessarily have access to the day-to-day social worlds of participants, she suggests that pre-interview meetings can therefore be useful in developing a *"backdrop"* that can be used to inform interpretation of children's accounts of their experiences. Within the study, the initial meeting was used to gather valuable contextual information in relation to the child, their family/whānau and their shared experiences of the injury. As well as the collection of basic demographic information (such as age, family/whānau make-up, severity of parental injury and on-going impairment), the session also proved to be a useful opportunity for parents to share their own stories, discussing the impact of the injury on themselves and family/whānau life. This was helpful in that as well as providing contextual information to inform the research interview it also gave parents the opportunity to be heard, enabling the return visit to focus solely on children's narratives. The initial meeting also helped to establish the child's capabilities and

preferences to enable the interview to be tailored to their interests and needs. The contextual information shared within this session (and the interviews) was recorded as field notes and used as orientation within the interview and data analysis, prompting questions to explore in more detail in order to help make sense of children's accounts.

As the researcher I was responsible for supporting the participant to remain orientated to the topic during the guided interview conversation, working collaboratively to construct shared understandings of experience (van Manen, 1990). Accordingly, a strict interview schedule, with set questions, was avoided within the study and instead a customisable interview guide was developed that could be tailored according to the child's needs (taking account of their age, stage and interests) and responsive to the ideas they raised. The guide consisted of a pre-interview 'warm-up activity' alongside a series of potential prompts and activities that could be used to support the conversation between researcher and participant. This approach was aligned with research that advocates for a *"toolkit of interview techniques"* that the researcher can draw on in relation to the participant within the interview (Teachman & Gibson, 2013).

To support the construction of their narratives, children were given the option of using drawing as a form of expression in addition to written and spoken word in order to share their experiences. Drawing was recognised to offer children a 'constructive process' by which they could craft and make sense of their experience in conversation with the researcher:

> Drawing involves more than simply forming images; it is equated with the capacity to think and feel. Young children's drawings open a window into their realities and how they shape these. As Cox (2005: 124) notes, the constructive process of drawing helps children to 'purposefully bring shape and order to their experience, and in so doing, their drawing activity is actively defining reality, rather than passively reflecting a "given" reality'. Through drawing and talking, children come to not only 'know' reality, they 'create' it. (Wright, 2011, p. 159)

Rather than regarding the final artefact as a source of interpretation, the focus was the research conversation that occurred through the act of drawing and telling (Carter & Ford, 2013; Horstman, Aldiss, Richardson, & Gibson, 2008; Teachman &

Gibson, 2013).  The process of drawing served as a tool for communication within the research interview in order to support the aim of finding shared meanings of language (Ellis, 2006).  Not all children chose to participate in arts-based methods and other techniques (discussed below) were used to support children to elaborate, in their own words, on their narratives in order to ensure interpretation remained grounded within the child's perspective and their lived experience.

Issues of power were considered at all times within the interview to support the research conversation.  Interviews took place within a location of the child's choosing in the home, they were invited to select who they would like to be present during the conversation and were told they had free access to the research equipment, including art materials and the audio recorder.  To 'warm-up' to the idea of sharing stories, a game of 'talking cards' (Australian Catholic University, n.d.) was played in which a series of question cards were laid face-down in front of the researcher and participant, with each person taking turns to select a card at random to ask each other.  The cards contained sentence starters that needed to be completed, with examples such as *'if I could have any super-power I'd choose…'*; *'the person who makes me laugh the most is…'*.  The game acted as an ice-breaker and chance to build rapport and provided further contextual information about the child, giving indications of their communication style as well as preferences, values and interests.  The game also gave participants the chance to act as the interviewer and increase their comfort in answering questions, showing they were in control of the answers (including elaboration) they provided on topics raised within the collaborative interview process.

As stated, the interview format was not structured around a fixed set of questions.  Instead a basic framework for the interview was developed using van Manen's writing on lifeworlds as a source of reflection (van Manen, 1990).  The idea that *"the temporal dimensions of past, present and future constitute the horizons of a person's temporal landscape"* proved a useful concept to give shape to the interview structure (van Manen, 1990, p. 104).  Open questions were devised as starting points to consider the topic; broadly focusing on what life was like before parental TBI, at the time of the injury, since the injury and currently, looking to the future (see examples provided below).  Alongside this a range of possible prompts and activities were considered.  This 'toolkit' of potential interview techniques

54

included the use of: 'draw and tell' activities and poster design, generation of 'word salads' and thinking about children's 'top tips' and 'wish lists' (Australian Catholic University, n.d.; Carter & Ford, 2013; Horstman et al., 2008; Teachman & Gibson, 2013).  So, as an example, the series of questions used in one interview started broadly by asking *"Can you tell me what your dad's been like since he had his injury?"*.  The participant explained her dad had been a bit angry and to prompt her to elaborate on this discussion, follow up (open) questions were offered, which included *"And what does he do when he's 'a bit angry'?"* and *"what do you do when he gets angry?"*.  When generating questions or prompts I was mindful of trying to use the participant's own words when seeking further elaboration or explanation to avoid, as far as possible, pre-empting interpretations of their meanings.  Within interviews children often made their preferences for activities clear, for example in this case telling me it would be *"easier to tell you"* than draw about her experiences.

Prior to the interview, information gathered within the initial meeting was used to consider potential questions that may be appropriate for the child and their context.  These evolved through the warm-up activities and interview itself in response to the topics raised by the child, as illustrated in the example above.

Interviews aimed to begin with open questions to give children the opportunity to freely narrate, followed by more directed questions (where required) to elicit more information (Docherty & Sandelowski, 1999).  Questions were intentionally aimed at exploring positive aspects of their experiences as well as negative (Morrow, 2005).  Some children responded well to open questions and prompts such as *"tell me more about…"* or *"what happened next…"*, while others needed more direction, gradually building their narratives by answering a series of closed questions on a topic or story they raised.  The 'word salad' activity, where children would write down or describe whatever words came to mind when thinking about a selected topic (such as the time since their parent's injury), proved especially useful as a starting point to conversation within several interviews.  Some children were also keen to use drawing to support their narratives.  The interview process involved remaining sensitive to the accounts discussed.  Children were given opportunity to redirect conversation if they seemed keen to move on but also offered reassurance and prompts where appropriate to expand further on topics

raised. On the whole, interview conversations came to natural conclusions and after being asked if there was anything else they wished to talk about in relation to their parent's injury, children were invited to turn off the recorder. On two occasions, the debriefing conversation after the interview prompted additional ideas; so the recorder was turned back on to document the discussion.

**Data Analysis**

The process of making sense of children's experiences began with the initial meeting with the child and their family/whānau. Contextualising the child in their family/whānau and learning about their shared experiences and motivations to participate in the research was important to support the collection of data for the purposes of analysis. The concurrent processes of data collection and analysis followed a pattern of movement indicative of the hermeneutic circle (van Manen, 1990), with movement between the part and whole. The process involved considering specific experiences of the child's story and then broad ideas across their account, alongside exploration of the unique aspects of each participant's story in relation to all the participants' accounts. Meanings of the participant's experiences were also reflected upon in relation to the context of the lifeworlds of children more broadly. After the first family/whānau consented, each subsequent family-meeting and interview was situated in the context of the ongoing interpretation of the previous participant's story.

The observations and reflections made within and immediately after research meetings and interviews were recorded as field notes and incorporated into the material used for analysis. As discussed earlier, the act of transcription was recognised to be a process of representation, constructing an account of the experiences shared within the interview conversation (Riessman, 1993). Effort was made to transcribe not only the spoken word, but also an indication of the intent of the speaker in the context of the conversation to ensure this was apparent on the written page used for analysis. The transcribed interviews were constructed into analysis material by combining the verbal stories with photographs of the visual representations created (artwork or written words) alongside the field notes that served as the contextual 'backdrop' for the child's account. Transcripts were then read and re-read, reflected upon and discussed

with the supervisory team to become acquainted with the stories shared and deliberate upon interpretations made. The *"art of writing and rewriting"* was a core part of this process (van Manen, 1990, p. 32). The initial reflections and ideas were recorded as analysis memos, which were incorporated into early writing on the study findings, which served to support additional data collection and analysis and the re-writing of early ideas in the context of subsequent reflection and interpretation.

The study aimed to construct a thematic account of children's experiences in the context of parental TBI based upon the stories participants shared. Rather than assuming such information could offer generalisations across the entirety of the experience, the themes generated were intended to offer 'aspects' of the phenomenon that may be used to guide fuller understanding of the experience:

> Themes are the stars that make up the universes of meaning we live through. By the light of these themes we can navigate and explore such universes. (van Manen, 1990, p. 90)

Essential to the construction of these themes was the need to keep the perspective of the child, and their lived experiences, central. The analytical reading of the participant's accounts was guided by van Manen's writing on explorations into children's lifeworlds (van Manen, 1990). Each transcript was read as a whole for salient points and then re-read with reflection on the lifeworld existentials of lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). The reading was concerned with reflecting on the child's stories in relation to their *lived experiences* of space, body, time and relation with others and how this could support the overall understanding and interpretation of their experience as a whole. Once again, the pattern of movement between part and whole was demonstrated as key ideas relating to each existential were highlighted for each participant and written out and used as a tool to reflect on their story as a whole. The hermeneutic circle was further reflected as these ideas were drawn together to read across all the children's transcripts, comparing and contrasting ideas relating to the existentials between each of the participants. The existentials offered a lens through which to focus on different aspects of the child's lived world. Overlap of ideas was deemed inevitable as the existentials *"can*

*be differentiated but not separated"* (van Manen, 1990, p. 105). Looking for these points of convergence, as well as the differences, within and between participants enabled the thematic structure of the findings to be constructed.

# Ethics

As introduced earlier in the chapter (p.43), respect for children guided all ethical and methodological decision making within the study. The study received ethical approval from the Auckland University of Technology Ethics Committee (see Appendix I: Ethical Approval).

## Consultation Processes

The potential vulnerabilities of children and family/whānau involved in the study were considered alongside their rights and needs as study participants. The study aimed to work in meaningful ways with children and families, and as the researcher I drew on a wide range of literature, my own experience, the expertise of the study supervisory team and consultation work to guide this process.

Recognising that Māori are over-represented in TBI statistics (Feigin et al., 2013), the study drew on the guidelines from Te Ara Tika (The Pūtaiora Writing Group, 2010) to inform ethical decision-making in relation to supporting Māori, both as intended participants for the study and in terms of potential outcomes from the study. Prior to ethical approval, consultation was sought with Māori through the Kawa Whakaruruhau Komiti to ensure safe cultural practice of the research. The committee offered opportunity for constructive critique of the proposed study design to support Māori participation, as well as gain general feedback on the research.

Additional consultation work was undertaken with a child and adolescent psychiatrist and researchers with specific expertise researching children and families experiencing health issues or family/whānau violence. The consultation processes supported areas of the study where specific knowledge was required, including consideration of engagement with children and families in research; development of appropriate research materials; and management of potential safety issues.

**Privacy, Confidentiality and Safety**

The ethical principles of privacy and confidentiality were discussed with children and their families at the time of acquiring consent/assent. With respect for privacy, children were invited to choose where the interview should take place and the level of privacy they would like in discussing their ideas (MacNaughton & Smith, 2005). Their permission was sought for the researcher to record the interview conversation. To ensure confidentiality, children were allocated an identification (ID) number used in place of their name and all personal information collected (including names, contact information) was stored in a separate location, away from study data. This process was explained to children and they were shown their ID number and invited to select a pseudonym that could be used in study reports.

Confidentiality, and its limits, was discussed with the child and parents together to ensure a transparent process. It was important that parents were fully informed that their child's narratives would be treated confidentially and the specific details of their stories would not be shared with anyone outside of the study team, including them as parents, unless any concerns were raised (Cuskelly, 2005). Equally, it was important that children were clear about the limits of confidentiality that could be assured to them in talking to me as a researcher. It was stressed that they should feel free to discuss anything they wanted, but to do so with understanding of the responsibility I would have if they raised any issues that were of concern, either in relation to them personally or others. I explained that if I was concerned about any issues they raised then it may be necessary for me to raise these with other adults who may be able to offer support. Children were told that, wherever possible, this would be discussed with them first, giving them the opportunity to have the discussion themselves. To support this process a clear 'safeguarding children' protocol was developed in accordance with guidance from the consultations processes and literature related to child protection and research ethics with children (Child Youth & Family, n.d.; David, Tonkin, Powell, & Anderson, 2005). A core part of this protocol was the researcher responsibility for transparent communication with children and their families, as well as the opportunity for debriefing and supervisory support after meetings with

participants.  A copy of safeguarding protocol is included within the overarching 'Safety protocols' developed for the study (see Appendix J: Safety Protocols).

Talking about experiences of parental TBI was recognised to be a sensitive topic that could elicit emotional reactions from children and indeed children (and parents) did, at times, become distressed during conversations.  During the course of the interviews effort was made to provide reassurance to their responses and follow their cues when deciding whether to offer support in continuing, or moving on from, the conversation.  Children were given the opportunity to debrief after the interview, to talk about how they found the process and to think about their own wellbeing.  To aid this process, children were given a copy of the 'support information' booklet designed for the study (see Appendix K: Support Information Booklet), which contained a resource list which included details of free, confidential telephone counselling services for children.  Parents were also given a copy of this information booklet for their reference.

**Data Ownership**

The importance of upholding the individual and collective mana[3] of research participants was considered through consultation with various parties.  The study acknowledged that while children had given permission for their stories to be shared for research, they had not given up ownership of their narratives (Ball, 2005; MacNaughton & Smith, 2005).  Permission was sought from children to take photographs of their artwork and written material (including questions on information sheets and their assent forms) that could be taken away as evidence. Children were then given the opportunity to keep original copies of the research work.

**Giving Back**

Children were presented with a voucher for a retail store to the value of $20 and a certificate of appreciation to acknowledge their contribution to the research and

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[3] In Te Reo Māori, mana is a concept that speaks of *"prestige, authority, control, power, influence, status, spiritual power, charisma - mana is a supernatural force in a person, place or object"* (Mana, n.d.)

thank them for sharing their stories and experiences (see Appendix L: Certificate of Appreciation).

## Summary

This chapter provided an overview of the assumptions underpinning the research design, including the positioning of children as active agents of their lives.  It outlined the study methodology and methods used to explore children's experiences of living in the context of parental TBI.  It detailed the different approaches taken at each stage of the research process to ensure that children's voices were heard.  The results of the analysis will be presented in the subsequent chapter, *Chapter Four: Findings*, giving voice to participants' experiences after parental TBI.

# Chapter Four: Findings

The harmony and comfort of 'home' is rocked when TBI shows up at the door; the injury acts as an intruder into family life, causing a ripple that shifts the flow of the whole family unit.

Each of the participants in this study had a unique story to tell of their experience of parental injury. Their accounts talked of disruption precipitated by TBI; of negative and positive change; and of their efforts to regulate family life. This chapter serves as the opportunity to hear from children about their experiences and will explore the findings of the research in detail. Firstly it will describe the participants who took part in the study. Then it will discuss the themes constructed through analysis of children's data, exploring how children appeared to experience an *altered sense of being 'at home'* after parental TBI. It will consider how the interconnected ideas relating to *changes to family cohesion and rhythms* and *attuning and adjusting to new ways of being as a family* contributed to this interpretation of children's experiences after parental TBI.

## Participant Characteristics

Nine children from seven families were invited to participate in the study. All nine met the eligibility criteria and opted to be present for a first meeting at their home to hear more about the study. Of the nine, seven children (including two sets of siblings) chose to take part. Two children opted not to participate. In one family, the parents were keen for their daughter to participate, feeling passionate about the importance of the topic and the significance of the contribution she could make to the study based on their family experience. However, the child explained that her previous experiences of talking to people (professionals) had been unhelpful and so could not see benefit in participating. In another family, one child ('Holly') was keen to participate, but her brother was not.

Further details of the participants are presented in Table 3 below. Children were invited to select their own pseudonym for the study and these names have been used throughout the thesis to maintain participant confidentiality.

The interview processes reflected the fluid and responsive nature of the study. Children chose where in the home they wished to be interviewed, with one participant selecting to move between rooms as the interview progressed. All children opted to be interviewed away from their injured parent and some, but not all, chose to have their non-injured parent available (in the background or with them) while discussion took place. While it was emphasised that the interview was about hearing the children's stories, parents were not prevented from contributing and at times they asked their own questions of their children's experiences, which offered further insights. Although sibling pairs were given the option to be interviewed together, all took part individually.

**Table 3: Participant Characteristics**

| Participant | Contextual Information |
|---|---|
| **Madderson (8yrs)** *Female; Māori/NZ European* <br><br> **Tomohawk (11yrs)** *Male; NZ European* | **Living arrangements:** Madderson and Tomohawk live together with their mum (45yrs; NZ European) and dad (46yrs; NZ European/Māori) in a semi-rural setting. <br><br> **Injured parent: Dad (11 months post):** (self-reported) closed concussion as a result of a sports-related incident (exposure to mechanical force). Received inpatient care at hospital (few days) only (i.e. no admission to rehabilitation centre). At time of interview receiving ongoing community rehabilitation support. Continues to experience disabling difficulties with fatigue, headaches, sensory sensitivity, mood and personality changes. <br><br> **Work status:** Prior to injury dad worked in full-time paid employment and was beginning a return-to-work trial on reduced hours. At the time of interview, mum had seen the work doctor who had signed her off work. |
| **Rose (8yrs)** *Female; NZ European* <br><br> **Hard Core (9yrs)** *Male; NZ European* | **Living arrangements:** Rose and Hardcore live together with their mum (38yrs; NZ European), dad (41yrs; NZ European) and older sister (17yrs) in an urban setting. <br><br> **Injured parent: Dad (4 years, 2 months post):** mild TBI as a result of a fall. (Self-reported) some loss of consciousness; delayed concussion. No longer in receipt of rehabilitation support. Experienced issues relating to memory, fatigue and regulation of mood, which have improved with adaptations over time. <br><br> **Work status:** Both parents work full-time. Father changed role following injury. |

| Participant | Contextual Information |
|---|---|
| **Holly (11yrs)** *Female; NZ European* | **Living arrangements:** Holly lives with her mum (50yrs; NZ European), dad (57yrs; NZ European) and brother (9yrs) in a rural setting. She has two grown-up sisters who live independently. Holly's brother, although eligible, declined to participate. **Injured parent: Dad (3 years, 8 months post):** mild TBI as a result of a road traffic incident. (Self–reported) Glasgow Coma Scale score of 14; some loss of consciousness. No longer in receipt of rehabilitation support. Has been able to return to previously enjoyed activities, but with changed capacities and experiences ongoing issues with fatigue, memory and mood. **Work status:** Both parents self-employed; father works full-time. |
| **Ava (10yrs)** *Female; NZ European* | **Living arrangements:** Ava and her older brother (13yrs) live part-time with their mum (52yrs; NZ European) and part-time with their dad in an urban setting. **Injured parent: Mum (5 months post):** (self-reported) mild TBI as a result of exposure to mechanical force. At time of interview receiving ongoing community rehabilitation support. Continues to experience difficulties with cognitive fatigue, headaches and slow processing. **Work status:** Prior to injury mum worked in full-time, paid employment. Since TBI she has returned to work on reduced hours. |
| **Riley (9yrs)** *Female; NZ European* | **Living arrangements:** Riley lives with her mum (42yrs; NZ European), dad (41yrs; NZ European) and younger brother (6yrs) in an urban location. Her brother was not eligible to participate in the research. **Injured parent: Dad (11 months post):** (self-reported) severe TBI; injured as a result of a sports-related incident (fall). Received inpatient care at hospital and a rehabilitation centre (5weeks). At time of interview receiving ongoing community rehabilitation support. Continues to experience difficulties with memory, fatigue and anxiety. **Work status:** Prior to injury dad worked in full-time paid employment; at time of interview voluntarily completing some part-time hours. Mum works 30 hours a week in paid employment. |

# Experiences of Parental TBI: An Altered Sense of Being 'At Home'

Each participant's story of parental TBI was unique to them and their family/whānau.  Analysis explored the meanings of children's lived experiences in order to construct a thematic representation of their experiences.  van Manen's existentials (van Manen, 1990) were used as the lens to consider points of convergence, as well as difference, within and between participants' experiences.  Analysing children's lifeworlds in this way offered insights into the ways in which they spoke about: the spaces they inhabited; their bodies (and their parents' bodies); their experiences of past, present and future; and their familial relationships, in the context of parental TBI.

The thematic structure of the findings offers, as van Manen (1990) suggests, the *stars to navigate* the children's data and explore the meanings of their experiences.  The interpretation that children appeared to experience *an altered sense of being 'at home'* when living in the context of parental TBI forms the central, guiding thesis of the study.  The construction of this overarching idea is scaffolded by the inter-relating themes that emphasise the *changes* children experienced in family life after parental TBI and the ways in which they actively *attuned and adjusted* to these new ways of being as a family (see Figure 2 below).  Accordingly, this chapter will seek to share the ideas captured within these sub-themes to explore the meaning of being *at home* after parental injury.

**Changes to Family Cohesion and Rhythms**
- Home as a place of safety and knowing
- Home as a place of rhythm and routine
- Home as a place of connection

**Attuning and Adjusting to New Ways of Being as Family**
- Home as a place of negotiation

**An Altered Sense of Being 'At Home'**
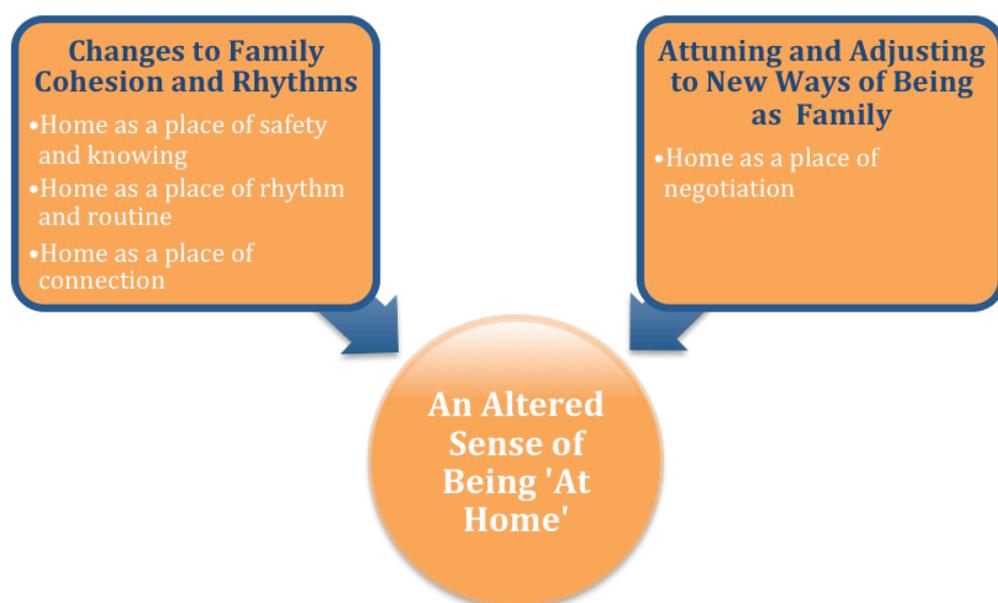
**Figure 2: Thematic overview**

# The Sense of Being 'At Home'

*Felt space* captures the idea that the *"space in which we find ourselves, affects the way we feel"* (van Manen, 1990, p. 102).

> […] 'Home' is not simply a residence but a way of being-in-the-world, a spatial metaphor for our relationship to places (Manzo, 2003), and an embodied experience of existence within the world (Svenaeus, 2001).   (Moore, Carter, Hunt, & Sheikh, 2013, p. 152)

Home, as an experience of space, is special and symbolises more than the physical presence of a building; it is connected to our sense of self and how we experience the world.  *"Home is where we can **be** what **we are**"* (van Manen, 1990, p. 102). The sense of being 'at home' is not bound by being within a literal space, but instead refers to the way of 'being-in-the-world' that makes us feel at ease and free to be ourselves.  It is a place where we can experience a sense of belonging and control, as well as safety and predictability (Moore et al., 2013; van Manen, 1990).

Children's accounts highlighted that the sense of ease and comfort associated with being 'at home' within family life altered after parental TBI.  Their sense of 'being-in-the-world' was disrupted, experiencing uncertainty and dis-connection.  They faced a number of *changes to family cohesion and the day-to-day rhythms* and routines of life.  This shift toward a sense of feeling 'not at home' was seen to be challenging, with accounts of sadness and worry coming through in the children's stories.  However, with time, it also provided opportunities for new meaning making and perspectives as they *attuned and adjusted to new ways of being as a family*.

## Changes to Family Cohesion and Rhythms

### Home as a Place of Safety and Knowing

Children explained that parental TBI brought about sudden changes to their injured parent, which in turn affected the whole family.  As Tomohawk explained:

*Tomohawk: As soon as dad got the head injury, like I said, it was almost like a switch had been flicked or something, then all of a sudden we had to get used to this new system in like a day or two. […] Otherwise he was getting so angry and stuff.*

The injury caused unexpected disruption to the flow of family life, introducing *"a lot of chaos I could say"* where before there was predictability. The rhythms of family life are unique within any home. They support a sense of cohesion within the family unit, which operates as a co-ordinated system of (often unspoken) routines, rules, expectations, roles, interactions and behaviours. Children's accounts highlighted that parental injury shifted routines, changed roles, rules and expectations, and brought about interactions and behaviours that were new and confusing; contributing to a sense of being 'not at home'.

*Uncertainty and fear of loss*

The stories children shared indicated the period immediately after the incident was a scary time. They described that when they heard the news of the injury, or saw their parent injured, that they felt *"Sad. Freaked out. Scared."* (Holly) *and "in shock"* (Madderson). Holly recounted what her dad was like when she saw him at the scene of his accident:

Holly: *He was on the ground and had tonnes of towels on him, so I didn't really see the bottom of his body, but I saw his head and it was just blood everywhere.*

Holly's vivid account of her father's injury, more than three and a half years prior, painted a picture of chaos, but also support. She described the support her and her brother had received from strangers (*"there were really nice old people who took us into their car"*) as well as her mum, who remained *"pretty calm"* throughout. Holly explained that the early days after her father's injury was a worrying time. She would get upset *"just thinking about it"* to the point that sometimes she felt like she was *"going to throw up"*, fearful that her dad would not return from hospital:

Researcher: *[...] And what were you mainly worried about?*

Holly: *That he would never be able to come back [...]-He'd have to stay in a hospital [...]-Cos he was pretty old – 50 something.*

She explained how her mum would reassure her, telling her *"he'd be alright"*, and she would stop crying, but then she would start to *"think about it more"* and get upset again. Hardcore and Riley echoed similar worries of parental loss and each discussed fears they had had at the time of the accident that their parent may die.

*Researcher: Did you feel worried?*

*Hardcore:    Sort of*

*Researcher: What were you worried about?*

*Hardcore:    That he might die.*

TBI disrupted the taken-for-granted predictability of life, introducing uncertainty. While not all children brought up the topic of potential loss and death, those who did kept their discussion to a minimum and suggested it was not a topic they wished to focus on or found easy to talk about.  In Riley's case her account was framed somewhat positively when she explained that seeing her dad in the rehabilitation centre had been quite *"scary but also quite relieving"*; relieving as he *"didn't die"*.

Home as a place of safety and knowing was disrupted by the sudden nature of TBI, which brought new requirements into children's day-to-day lifeworlds.  Riley's description of visiting her father as an inpatient in hospital, and then the rehabilitation centre, drew attention to the *dis*comfort involved in navigating new spaces, which were alien and *"scary"*.  Seeing her dad in hospital was particularly difficult as it was scary *"just like seeing him in that state"*, vacant and unable to communicate with them (*"he was only really able to make sounds"*).  She thought it was a good thing that she got to see her dad in hospital and rehabilitation, but also highlighted how seeing him in such foreign environments was worrying.  *"All hospitals"*, she explained are *"really scary [...] they make me scared, cos like it's just like their nature"*; as did the rehabilitation centre, which she explained was a scary place to visit because of *"how the other people acted"*.  Her report spoke directly of the experience of *felt space* and the sense of *un*ease introduced by being within spaces that, by 'their nature', seem to hold inherent characteristics that are unsettling.

*Changes to the known parent*

The unsettling experience of seeing a parent injured included changes in the way they looked and acted.  Rose recounted seeing her father soon after he was injured and drew a picture from this time.  She explained it was a 'confusing' time as they tried to piece together what had happened when he came home with a mark on his

head and *"yucky stuff"* (vomit) on his shoes.  She said that he just *"didn't look right"* (see Figure 3).
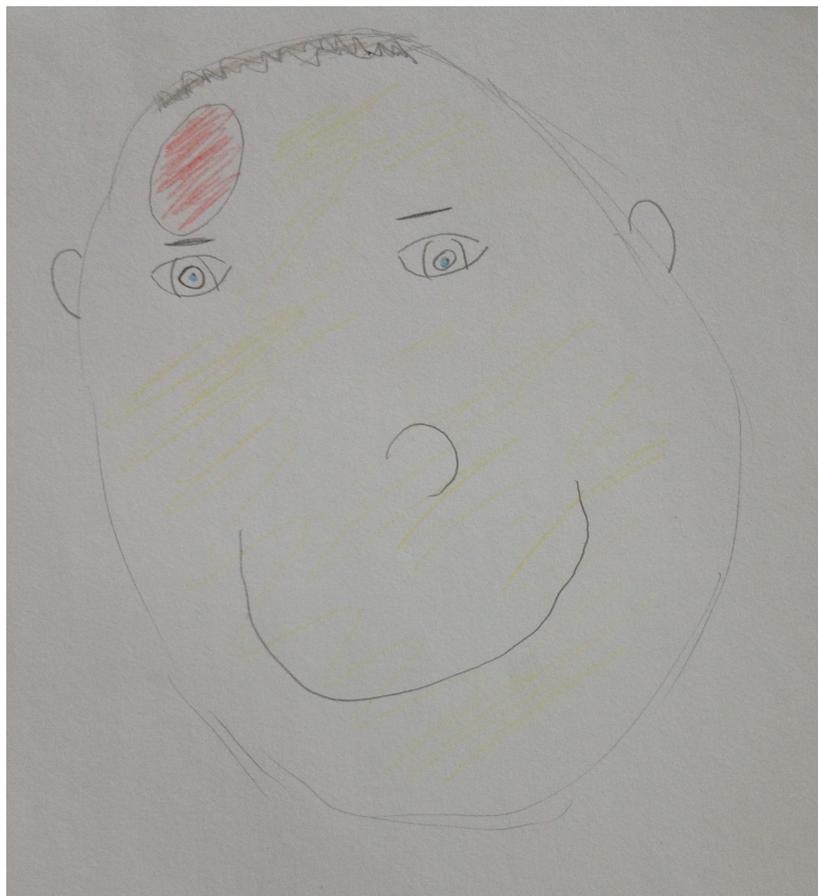


**Figure 3: Rose's dad**

Riley's discussion of her dad's altered appearance in the early weeks after injury was similar.  She struggled to find the words to describe how he looked different but said that as he recovered in the rehabilitation centre his appearance changed and *"his face just got back to normal"*.  Children's perceptions of change to the embodied parent were evident in their discussion, with the sense that the way in which the children *knew* their parent was altered from the injury.   Children were attuned to how their parent *should **be*** in the world and the injury disrupted this sense of understanding.

Children's stories illustrated that their parent's altered appearance encompassed the changed ways in which they acted that were not 'right' according to their 'normal' ways of being.  Hardcore recounted that after the injury his dad acted like a *"dumb drunk person"* – *"he acted weird [...] like he was nuts"*.  His sister, Rose,

commented further saying how their dad *"used to act strange"*, explaining he could be silly and also *"quite a bit mean"*.

Some behaviours, while bizarre, were not of great concern to children who saw them more as a source of amusement.  For example, Ava described some of *"silly things"* her mum did some time after her TBI, including serving her breakfast on two separate plates (see Figure 4):
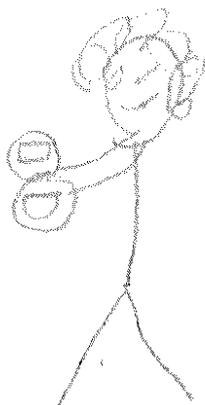


**Figure 4: Ava's breakfast**

*Ava:*          *Well, in the weekends sometimes she brings me breakfast and so she brought my breakfast on two plates – it was one piece of toast [laughs] and it was on two plates, cut in half.*

Other behaviours were more confusing for children, as Rose recounted when she described her father's difficulties with word finding:

*Rose:*          *He would say one word and then he'd change it to another word, so he didn't understand what he was saying.*

*Researcher: Ah OK.  Can you think of any examples?*

*Rose:*          *Like he said…he would say "hi" and then he would say "bye".*

*Researcher: Right OK.  And how was that for you when he did that?*

*Rose:*          *I didn't know what he meant, if he was saying hi or bye, cos I was only small.*

Rose's extract draws attention to her interpretation of her father's impairment, whereby she appears to attribute some of the confusion in communication to her own lack of understanding being *"only small"* at the time.  It speaks to the belief that ordinarily a child (as the *smaller* person) may expect their parent (as the

71

*bigger* person) to help them to understand. Rose's account shows that this expectation can be challenged after parental injury, contributing to a sense of unease in terms of knowing how to interact with their changed parent.

Rose's interview discussion of her dad's difficulties extended this sense of discomfort in interactions when she described how after his injury her dad *didn't know who she was.*

Rose: *He would say one name to – like [name] to me and that's my big sister's name and he would call my big sister Rose, or he would call my brother Rose. He would keep getting the names mixed up so he didn't know if he was calling one, cos like he'd go "Rose" and I'd come and he said "no, [says clearly/slowly] Rose" and he meant my… so we didn't know if it was, um, who he wanted.*

She not only found it confusing that her dad could not differentiate between her and her siblings, but also upsetting. She felt angry that she wasn't recognised by her father for her place of significance within the family:

Researcher: *[…] Why did it make you feel angry?*

Rose: *Cos my name's Rose and no-one el…and I'm the only Rose in this family.*

For Rose, the change in the dad she knew seemed to be matched by change in how her dad knew her. The changes that children described of the parent they *knew* appeared to alter their sense of being *at home* with their parent, whose behaviour they could no longer rely on as predictable. As a result, children appeared to experience an *altered sense of ease to be themselves*, creating uncertainty in how they should interact with their injured parent or act within the home.

One area this changed level of predictability was most pronounced was in terms of the impact of anger management issues after TBI. The majority of children discussed changes to their injured parent's level of tolerance and ability to manage their mood. For Tomohawk, the father he knew before his injury as a *"quiet"* person, who *"wouldn't get angry at us"*, became someone who was quick to lose his temper and would get *"so angry"*. As alluded to at the beginning of the chapter (p.67), Tomohawk's experience of his father's injury was like a *"switch had been flicked"* and TBI resulted in sudden changes to the parent he knew. This was true

for Holly too, who explained her father's issues with anger management came about as suddenly as the accident itself:

Holly:      He got pretty angry pretty quick [...] And, yeah, he just get stressed. And he would shout a lot, and get tired [...] And he still gets it now.

In Holly's case, the immediate behavioural changes she saw in her father after his injury had endured over the years of his recovery. Although she reflected that *"he's a bit improving"*, there was a degree of acceptance, or resignation, that the changes in how her dad acted was something she had learnt to live with.

*Changes to family cohesion*

Children gave examples of how issues with anger impacted their interactions with their injured parents, and changed dynamics within the family, creating tension and sadness. Children were not only aware of the impact on themselves, but recognised the impact on their non-injured parent, who tried to shield them from their injured parent's changed behaviour and anger issues.

Holly:      He would shout at us, a lot. If we did one thing wrong. And he hadn't asked us not to or anything. He'd just shout at us.

Researcher: How did that make you feel?

Holly:      Sad, yeah.

Researcher: Yeah

Holly:      And especially if mum left us alone with him and we had no one to go to.

Holly's account demonstrated a sense of injustice in trying to make sense of her father's anger, which she felt was often directed at her (and her brother) and was a disproportionate response to their behaviour. Rose too appeared to experience similar feelings in relation to her dad's behaviour. She sounded sad when she explained how her dad was *"really mean to us"* after his injury and would *"always tell us off and stuff"*. Rose said she didn't understand why he got 'grumpy' and felt that he directed his 'grumpiness' toward her rather than others in the family; *"he'd be mostly grumpy with me [...] I brought him food and water and stuff but he didn't want it. So he started getting grumpy with me."* Rose's mum added that Rose was

around her dad more than her siblings and made a lot of effort to try and help him, and *"he would just get frustrated"*.

The other two younger children in the study, Riley and Madderson, both raised the topic of mood changes after injury in response to the opening question of their interviews. It appeared to be another topic that was not necessarily easy to discuss. Madderson swiftly redirected the conversation elsewhere, but did return to the topic later in the interview when her mum was present. She brought up issues relating to her dad's anger and 'grumpiness' and talked about the support they had received when they saw her dad's therapist as a family. Madderson explained that the therapist was there when they needed help *"working things out"*, as someone who could support if *"maybe there might be like anger issues, or like, if there's been a fight or something and we can't get over it"*.

The older children who brought up the topic of anger in their interviews highlighted the *protective role* of their non-injured parent during times of conflict. Holly's statement above described how she felt saddest when her mum left them alone with their dad, with no-one to go to. Holly explained her mum would tell their dad to stop and he would listen. Tomohawk's narrative told how his mum would take the *"blame from dad"* in order to lessen the level of anger directed towards him and his sister.

> Tomohawk: She gets…takes a lot of…like a little bit of blame from dad, like, if I'm up a bit later because she was helping me with my project, dad would say 'he needs to go to bed' and later he'd talk to her or something, or that gets her stressed out. And sometimes if us kids do something she'll take the cop and stuff. I think… she told me the best thing to do… the best thing she can do for herself and that those times is just like say yes to everything, cos like, if you say no to something, it gets daddy angry and things carry on.

Tomohawk recognised that his mum had also been impacted by his dad's new behavioural difficulties and that this protective role added to her sense of stress.

**Home as a Place of Rhythm and Routine**

In his interview Tomohawk demonstrated insight into the tension that these issues put on his parent's relationship and the disruption it caused to the normal rhythms of family life.

*Tomohawk: there's chaos between, sometimes, between mum and dad have problems because dad of course has got the brain injury, so he either can't understand something properly or he's in a zone where he wants to be so organized for like maybe like little things and it sort of gets mum a bit stressed in some things.*

For Tomohawk, his father's sudden need for a new level of order in the home and issues with anger management changed the normal flow of family life, introducing 'chaos' into the home.

The feeling of being *at home* represents a sense of predictability, comfort and ease. Tomohawk's description of life after parental TBI as a place of *"chaos"* sits in sharp contrast to this. His account described the impact of TBI on relationships within the home as well as the familiar patterns, roles and responsibilities of family life. The changes to the rhythms and routines contributed to a sense of being *not at home*.

Interestingly, however, Tomohawk stated that as well being *chaotic*, a positive outcome was that life was also *"more organised"* since his father's injury. The seeming paradox of these two statements was not unique to his narrative and several children talked about 'good and bad' changes following parental TBI. The co-existing experiences speak of the complex and dynamic nature of the experience, whereby life after parental injury is not static and in making sense of their experiences positive narratives begin to emerge.

For Tomohawk, there were positive aspects of the changes that had occurred as a result of TBI. He appreciated how, owing to his dad's new need for order, life had become more 'organised'. He liked that they were now always early for things, meaning he no longer had to be embarrassed arriving late to events and got to spend more time socialising with his friends before school. He said it had also been *"quite fun"* having his dad at home more, he had enjoyed being able to play with him and go on runs together, where before they *"didn't have time for that"*. Madderson's account agreed, as, she felt *"the good thing about the head injury is we get to see him [dad] all the time".*

Ava spoke positively of the new sense of independence she had gained as a result of the changed routines and roles within the home that had occurred at the time of her mum's injury:

*Ava:*        *I think it made me a little bit more independent. […] Yeah, cos sometimes I would just moan that I was hungry and then she [mum] would like suggest certain foods to me, but…now I just get up and go grab some food.*

Rose, too, highlighted that the management of some TBI symptoms could be simultaneously positive and negative. In her description of her dad's issues with fatigue and resulting need for sleep, she spoke of both frustrations and benefits in terms of how they experienced time together post injury. She said it was *"annoying"* how he would agree to read to her, but then *"would go to sleep before he could"*. However, she also felt it was *"kind of good"* that he was getting more sleep and was at home more, as before his injury *"he had to wake up really early in the morning to go to work, so we didn't get to see him"*. Her account highlighted how changes from adaptations made over time in recovery, such as the need to change work roles, were also regarded positively:

*Rose:*        *So it was quite good after he had gone cos he swapped jobs to [place] and we got to see him more often because he came home earlier and he went to work later and he could drop us off […].*

The changes to family rhythms meant they could spend more time playing together, where before she felt "*we didn't get to see him – he always had to work"*.

Changes to the *lived space* of home, as a *shared* space experience, went hand-in-hand with changes to the *lived relations* between children and their parents. Hardcore made similar observations to his sister, saying since his father's injury they had more opportunity to play together. *"[Dad is] a lot more playful […] sometimes he can freak me and Rose out a bit, because he lifts us up and nearly makes us touch the roof"*. When asked if he felt that his dad's new level of playfulness was a good thing or a bad thing, Hardcore replied *"kind of both"*. He said it was 'kind of' a bad thing *"cos sometimes he can freak us out"*, yet it was also 'kind of' a good thing *"cos sometimes it's quite fun"*. The change in the way in which their father interacted with them was fun, but also a little scary. The behaviour was not typical of the *role* they knew of their father, being more impulsive and risky, which was fun but also did not reflect the predictable behaviour they had come to understand in their *lived relation*, as parent and child. As van Manen (1990) describes, the *special lived relation* of parent to child is *"charged with personal significance"*, through which *"the child experiences a fundamental sense of*

76

*support and security"* (p. 106). Hardcore's account speaks of a change in the sense of *trust* he had in his father as being *in control*, altering the sense of support and security experienced through their relational experience.

Again the account speaks of the complexity of the experience, where some changes after parental TBI were not necessarily regarded to be solely negative or positive and indeed could be both at the same time. Indeed positive outcomes of one aspect of change could be offset by the negative outcomes of the same change. For example children discussed positive outcomes associated with having their injured parent at home more, but at the same time spoke of negative outcomes associated with the changed roles and routines, especially in relation to the stress they observed on their non-injured parent.

*Concern for the non-injured parent*

Tomohawk recognised the stress his mum experienced as a result of dealing with changes that had resulted from his dad's injury. In his interview, he spoke of his parent's role reversal with his mum being at work more and changes to the usual roles and responsibilities performed in the home;

> *Tomohawk: [Dad has] become like mum, where he sort of like stays at home and cleans and stuff and he'll sort things out. He still sort of… at home he does do a bit of work, but not too much. And yeah, mum's going to work every so often.*

The experienced changes after parental injury created new demands for time and resources. Additional roles performed by the non-injured parent did not only relate to paid employment, but the ways in which they were described as trying to shield the children from the injured parent's aggression. For Tomohawk, as highlighted above (see p.75), he observed the tension that the residual impact of the injury had on his parent's relationship. Both Tomohawk and his sister noted that these new demands had taken a toll on their mum's wellbeing; she was described by Madderson as being really *"tired"* and Tomohawk as being *"sick a bit"* now herself. In the pre-interview session, their mum explained how she was not coping and had just been signed-off work by the doctor herself.

As Tomohawk's account demonstrated, TBI impacted the rhythms of family life. The altered presence of who was *in the home* contributed to these changes to roles,

responsibilities and routines of family life; which changed over the course of recovery. Initially the need for inpatient care meant the injured parent was required to *stay away from the home*, in hospital or rehabilitation. Later, once discharged, the demand for rest and recovery meant the injured parent had to *stay at home more than usual*. These changes impacted who was physically present in the home and placed additional demands on family life, altering the *felt space* of home, as shared *interpersonal space*. Like Tomohawk, other children recognised these experiences as being stressful for their non-injured parent.

Holly explained that the early period after her dad's injury was not only scary but was also difficult for the impact it had on family life. *"Mum got stressed a lot because dad wasn't there"*. The family had to add in regular visits to the hospital to see their father, alongside the usual chores associated with managing the home and livestock that remained despite their dad's absence. Holly saw the impact of this on her mum and stated *"sometimes [mum] got really annoyed and stressed and she would just slam doors and let it all out"*.

Riley also recognised that her mum, the non-injured parent, bore a lot of stress during the more acute phase of recovery:

*Researcher: How do you think it's been for your mum?*

*Riley: Stressing.*

*Researcher: Stressing, yeah. And what makes you think it's stressing?*

*Riley: I don't know just like organising the family and yeah [on edge of crying]…*

*Researcher: Organising the family as in your dad, you and your brother?*

*Riley: [Brother] yeah.*

*Researcher: OK. How does she have to organize?*

*Riley: School, work, um, money.*

*Researcher: So do you think she has to do it more on her own now? At the moment?*

*Riley: No, not any more.*

*Researcher: Not any more, but at that time?*

*Riley:*        *Yeah.*

Holly and Riley both described how their families received support from others (including wider family) who helped out with practical aspects of home-life such as provision of meals and support to look after them and their siblings.  The children recognised that this support was helpful for their respective families.  However, this practical support, as Riley illustrates below, did not make up for the disruption to family cohesion caused by the injury over this acute phase.

## Home as a Place of Togetherness and Connection

The connectivity of the family unit was impacted by not only Riley's dad's absence from the home (staying as an inpatient), but also her mum's absence:

*Mum:*        *I wasn't here a lot was I sweetie?*

*Riley:*        *[Sounds sad] No.*

*Researcher:*  *Where was mum?*

*Riley:*        *At the hospital, or at [rehabilitation centre], or at work, or something like that.*

The emotion during this interview conversation was palpable.  Riley spoke to her mum, as well as me as the interviewer, when she explained that the absence of both her parents from the home *"was a little bit"* hard; saying that she *"just missed them a little bit"*.  Riley recounted that her mum would get home after she had gone to bed and so she would only see her very briefly in the day.  Riley revealed the impact of her mother's absence on her in showing empathy for her brother's experience;

*Researcher:*  *And how do you think it was for [brother]?*

*Riley:*        *Well I guess it was hard as well for him cos he didn't really have anyone to talk to either*

In her dad's absence, Riley's mum was also less available for her and her brother.  Her mum's typical role as someone who offered support and reassurance to the children was disrupted by the challenges of managing parental injury and Riley felt she didn't have anyone to talk to during this time.  Her conversation emphasised that the emotional support normally offered by her mum was not easily substituted.  Over the acute phase of recovery she missed having her mum

available, as the person she *wanted* to talk to, where having others available was not necessarily the issue. In addition to the actual absence of their non-injured parent from the home, children experienced a sense of reduced availability due to the stress they could see that their parents were also experiencing after TBI.

Similar to Riley, Madderson shared a conversation with her mum about how she had found her reduced availability difficult since her dad's injury. She explained that it was hard to find a good time to talk with her mum; aware of the pressure she was under:

Mum:      *Do you feel like you've ever really wanted to talk to mum about dad's head injury?*

Madderson: *Well I did want to, but you never let me, cos you're like 'arggghh…' it's always a school day when I try to talk to you and I always think it's the wrong time, but… You just don't let me get time to talk, so, I just…*

Mum:      *So is there anything you want to ask me now? I'm happy for you to ask me*

Madderson: *I have asked you one question though…*

Mum:      *Yeah?*

Madderson: *But, like… when is dad's brain injury going to end?*

Mum:      *[Sighs as says] yeah.*

Madderson: *Is this the last year? Or is it the next year is it going to end?*

Mum:      *That's a really good question, like, I'm really glad that you asked me that.*

Madderson: *Cos I'm wondering.*

Mum:      *OK. So with head injuries we don't know.*

Madderson: *Cos they said in two years it would end.*

Mum:      *They did.*

The conversation revealed how Madderson wanted to talk with her mum in order to help process the event and make sense of what the injury meant for the future. The uncertainty introduced from TBI extends beyond the concern of loss in the acute phases of recovery and extends into *wonderings* about the future. As Madderson's question demonstrated, making sense of recovery after TBI is a

challenging process.  Parental TBI introduced new anxieties into daily life as children experienced, with awareness, uncertainty and change in family life, roles and connectivity after injury.

**Coming Back to the Whole: Altered Sense of Being 'At Home'**

Home as a place of safety and knowing; rhythm and routine; and togetherness and connection changed as a result of parental injury.  The ease and comfort associated with being 'at home' shifted when children experienced the sudden, confusing and frightening event of parental TBI.  It altered the familiarity of daily life, the spaces they navigated and how they *knew* their parent(s).  Children's narratives showed how initial disruption caused a shock to their sense of being 'at home' with their injured parent, as the familiarity of the person they *knew* as their parent was altered after TBI.  Their parent's behaviour was *"strange"* to them, and they were left questioning what was *not right* about their parent, both in terms of appearance and behaviour.

Their stories also demonstrated that with time a process of attunement and adjustment enabled children to become more familiar with new aspects of their parent's behaviour and personality, allowing them to get to *know* their changed parent(s) and adjust to new ways of being as a family.

## Attuning and Adjusting to New Ways of Being as a Family

**Home as a Place of Negotiation**

Parental injury changed family cohesion and rhythms and impacted how children felt and the ways in which they would normally act, and interact with others, in the home.  Children's accounts demonstrated they *adapted* their behaviour in order to *accommodate* the changes and *regulate* the disruption to family life.  Tomohawk's opening extract (p.67) spoke of the sudden changes they saw in their father after injury and the equally immediate need to respond, having to *"get used to this new system in like a day or two"*.  Tomohawk highlighted that there was abrupt change in terms of his dad's expectations of how they should act within the home, whereby *"all of a sudden, he expected this and that, he expected us to do all these things"*.  Like other children in the study, Tomohawk's narrative showed that he was not a passive bystander to these changes, but instead took steps to make

sense, monitor and adapt behaviour accordingly, attuning to the injured parent and adjusting to the *"new system"*.

*Seeking harmony*

The process of attuning and adjusting to life after parental injury was regarded to relate to an effort to find harmony and restore the sense of being *at home*. The early phase of parental injury was challenging for children, disrupting their sense of understanding and ease at being-in-the-world. Children's accounts appeared to demonstrate how they attuned to the welfare of the family system, putting their own needs aside, recognising a call to keep going and soldier on. Riley explained she managed to 'fight through' by telling herself *"it will all get better"*. Similarly, Tomohawk explained the time *"was a bit hard but, we managed to get through it"*, stating there wasn't really anything that helped him, he *"just sort of had to push through everything"*.

Children's narratives highlighted that *over time* they supported the process of seeking harmony within the home by tuning in to new ways of knowing and connecting as a family. Their accounts provided examples of the ways in which they monitored their parent's appearance and behaviour in order to make judgements as to how they may be feeling or likely to act. They then adapted their play and behaviour accordingly, to accommodate the needs of the injured parent. Those children who discussed their parent's issues with mood shared how they coped by removing themselves from the situation, going to their own rooms when conflicts arose. Holly, for example, said that when her dad became angry and shouted at them she would go to her *"room and sit down, lie down"*, both to get out of his way and also to give herself some space. Tomohawk also told how he would retreat to his room, or go outside, to avoid becoming entangled in *"the mess"* of arguments. He shared that, like his mum had said above (p.74), the best approach when his father lost his temper was to avoid escalating issues and instead would try to *"keep up with him"*, in order to appease him:

*Tomohawk: Well when it gets to that stage, I just do everything dad says (soft laugh) [...] I just try and do that and keep up with him and then, yeah, or sort of stay in my room or something if it was at home and just do things, just do stuff that I want to do.*

Similarly, when Riley spoke about her dad's anger issues, she recounted that she too would remove herself from the situation and usually go to her room.  She explained that she did this to try and help defuse the situation, to *"give everybody some space"* and found it worked as when she returned things would have calmed down.

Children's accommodations of their injured parent's needs were not without frustration.  Children's accounts spoke of a sense of dictated changes to the ways they were able to *be* within their own homes, normally the space "*where we can **be** what **we are**"* (van Manen, 1990, p. 102).  In her interview, Madderson describes this sense of not being 'at home', in her own home:

Madderson:   *We just never got to have time to play and you always said… we always get to play inside and you always said 'oh you have to play outside' and we love playing inside.  And then you said oh we have to take…if there was something inside you said we have to take it outside, cos once when me and [Tomohawk] were playing rough and tumble and…or if we were playing with the balls and we start going a bit crazy and start yelling you would say (whispers) 'get outside!'…*

Mum:       *Yeah*

Madderson: *And…*

Mum:       *And why do you think I said that?*

Madderson: *[Sounding impatient] Because dad has a brain injury.*

Mum:       *And how does that make you feel?*

Madderson: *Um, I feel kinda like we're never allowed inside.*

The extract captures the tension that the disruption and required adjustments created for Madderson.  While she understood her dad's new demands for a quiet recovery space, simultaneously she still wanted to enjoy the opportunity to play without constraint, where she chooses within her home.  The restrictions placed upon her previously enjoyed freedoms altered her sense of being 'at home' in her play and contributed to the impression she gave of almost feeling barred from her home - *"I feel kinda like we're never allowed inside"*.

*New knowings*

Children's accounts provided insights into the dynamic nature of their understandings and experiences of parental TBI over time. Strategies they used to cope with the changes in life at home appeared to be different as recovery, and life, moved on. Their narratives related to how they made sense of their past, present and future, discussing future with a sense of uncertainty, resignation or hope, some highlighting changes to their outlook and perspectives on life.

The insights children shared related to their individual family/whānau experiences. Participants were dealing with a range of parental impairments, at different stages of recovery (from five months to over four years post injury). In Ava's case, for example, she did not report her mum had any issues with mood or anger management after her injury five months prior. She felt minimal impact from her mum's issues with memory, explaining it had been *"ok"* as she had *"just gotten used to it after a while"*.

This idea of 'just getting used to' parental changes was repeated across participant's narratives, however while the same phrase was used by participants, it's meaning was not universal across accounts. In Holly's case, for example, her description emphasised a level of resignation about the lack of potential for future improvement as she observed that her father's impairments (of fatigue and forgetfulness, as well as anger issues) had endured over the three and a half years since his injury. In terms of his difficulties with anger, she explained that she had just *"got used to it"* now and rather than removing herself from the situation sometimes found it helpful to shout back at him. Her change in strategy in dealing with her dad's behavioural issues appeared to suggest a changed way of being *at home* with her dad, who she now *knows* in new ways and is more comfortable, or willing, to confront, rather than avoid.

For Tomohawk and Riley, their dads' injuries had both occurred 11 months prior to interview and they shared similar accounts of issues with anger, which although were ongoing, had improved over time. They both spoke about their hopes for continued improvement. Alongside their parent's own journey of recovery and adaptation to their impairments, Tomohawk's and Riley's accounts highlighted how they became more attuned to the needs that resulted from the impact of

84

injury and therefore better able to respond in helpful ways. With time, they were more able to spot the triggers for symptoms or situations that may result in anger and knew to adapt their behaviour accordingly. For example, Tomohawk explained, that he had *"sort of got used to the routine"* that surrounded their dad's injury and stated it was less chaotic now that their dad was more aware of the support he needed from them to manage his symptoms and help control his issues with mood.

Tomohawk: *No, he's better… he can control his anger now, and he tells us to sort of lower our voices or something or lower noise down or something like music or something, he'll say it's too loud – I've got a headache, turn it down.*

It appeared, that over time, Tomohawk had learnt that it was best to try and *listen* to his dad and do what he asked, as this helped his dad to manage his symptoms and behaviour and thus avoid conflict. He stated his advice to other children would be to do what their parent says, warning that otherwise it *"doesn't conclude very well"*, especially in the early stages;

Tomohawk: *I would probably say just listen – listen a bit more and um yeah don't get…don't try and wind him up or anything, just sort of listen to what he says…just listen pretty much.*

By tuning in to his dad's needs, Tomohawk was better able to predict his father's behaviour and thus regulate the impact on him, supporting efforts to bring harmony into the home.

Madderson too showed that she had learnt to 'read' her father's presentation to assess how he was feeling. She used his appearance and behaviour to judge how he was, noting that she could tell if he was well by the activities he was doing (e.g. house chores, work). She explained she felt he had been looking better recently as before *"he was always pale when he came back"* but *"now he has his colour back"*. Riley, too, described how, over time, she had learnt to read her father's body for cues as a way of predicting his behaviour. She spoke about the improvement she had seen in her dad and shared that he no longer got angry like he used to (*"like angry angry!"*). Riley and her mother joked together about how they knew when her dad was about to lose his temper, as he would get his *"angry face"*.

Mum: *Like I'll say to Riley 'oh did he get his 'angry face'?'*

| Riley: | [laughs] |
|---|---|
| Mum: | So yeah, and we both...we know if things...like look at each other and go - |
| Riley: | 'Time to leave'. |

They both demonstrated what the 'angry face' looked like and discussed how it not only offered an understood signal just between the pair of them, but also served as a source of shared humour. It appeared to provide an opportunity for Riley and her mum to connect and share in making light of the situation together. Other children talked about how their families used humour as a way of coping with the changes brought about after parental injury. Children described nicknames and jokes about the injured parent that they shared with their non-injured parent, as well as those that they shared as a family to recount behaviour or experiences, which retrospectively they could laugh about together. Constructing and retelling stories together created shared understandings and representations of their realities (Riessman, 1993). The process appeared to offer families a way of taking control of the narratives of their experiences, serving to support connection within the home.

*Taking active roles to support and (re)connect*

Connectivity within the family was important to children. They actively attuned to their parent's needs not only to regulate the impact of changes on themselves, but also as a way of supporting their parents after injury. Children provided examples of the ways they tried to actively respond to their parent's needs by offering practical help around the home. For example, Rose explained how she tried to look after her dad by taking him food and water and telling him to stay in bed and rest. Ava, too, described how her and her brother supported their mum after her injury by helping to make dinner. Tomohawk shared that he thought it was important *"to help a bit more with things, like maybe if it was the dishes or just...taking the washing out"* to support the family. This assistance was also intended to relieve the strain experienced by the non-injured parent. Holly, for example, shared how her mum had asked for some help and she enjoyed the opportunity to take responsibility for shifting the family's livestock. Rather than describing such roles

as burdensome, children appeared keen to be able to offer some assistance to their families after parental TBI.

Children also revealed other, more subtle ways they tried to support their parents. In an example provided by Madderson, she described a time when her dad was getting headaches, and struggling to sleep in the day, and how she tried to help him by *"sleeping with him"*. Although less explicit, these forms of support were equally purposeful in intent, and were described in children's efforts to monitor, and protect, their parents. Children appeared concerned for their injured parent's wellbeing in new ways after TBI. Both Tomohawk and Madderson spoke about a new level of family monitoring that occurred in regard to their dad's absence from the home, whereby they had a heightened sense of awareness in terms of how long he had been out, for fear that it could mean he had re-injured himself. Similarly, Rose shared her experience of wanting to remain close to her dad after he was injured so she could check that he was OK:

*Rose:*        *I stayed home instead of going to daycare.*

*Researcher: Oh did you? Why did you stay home?*

*Rose:*        *Because I wanted to stay and help my daddy to make sure he was OK.*

Children's discussions challenged assumptions of typical roles between parent and child, demonstrating care, support, and even protection for their parents. In another example of this, Madderson drew pictures of activities she enjoyed doing with her dad, before and after his injury. Through the process of drawing and talking she described some limitations her father's injury had placed on some activities, but she also shared adjustments she herself had made to their activities. As she drew, she narrated about her and her dad's enjoyment of tree climbing together (see Figure 5 below)*.* She explained that prior to his injury, they climbed trees *"really high"* together and when she got scared, he would have to help her to climb down. She said when they went tree climbing recently they *"didn't climb it very high"* as she chose not to go very high so as to not risk her father having to help her; *"I didn't want my dad to help me, if I went too high, because he could fall, because his brain injury […] we don't want another head injury".*

**Figure 5: Madderson climbing a tree with her dad**

Few children spoke about specific support they received or strategies they used to support themselves. Children were selective about who they spoke to about what was going on at home, saying they avoided talking to peers or teachers for different reasons: they weren't sure they could trust them; they didn't feel they would truly understand; or that when they were away from home they just tried to forget about it. Some children said that it might have been helpful to have opportunity to talk with other children going through similar experiences to their own. Riley mentioned that she found interacting with pets was a form of support as it relaxed her, as did focusing on creative hobbies.

In their interviews, Tomohawk and Riley discussed having had some engagement with professional supports in relation to their dads' injuries, but with equally

mixed results.  Tomohawk explained that his initial experience with a psychologist *"wasn't the greatest experience"*.  He recounted how he felt she was *"aiming everything"* at him, telling him, in *"not the nicest of tones"*, that he needed to be understanding of his dad's injury and had to help him.  Tomohawk contrasted this with a second, more positive experience with psychologists at his dad's rehabilitation service who were *"good listeners"*.  He explained they didn't just *"tell you what you're doing wrong or what you need to do, they ask"*.  Riley also found her experience with the psychologist was too focused on telling, providing her with information about the brain.  When asked if it had been helpful seeing them she replied *"sort of, I guess, well if I wanted to become a brain scientist, then yeah"*, she stated it would have been more helpful to know *"how he would react to certain things"*.  Through their interviews, children demonstrated how they were engaged in their own processes of making sense of the injury, trying to tune in and adjust to new ways of being as a family.

## Summary

As the themes have highlighted, children experienced change to the usual, familiar rhythms shaping family life, and after parental injury were required to tune in to adjust to these changes.  Ordinarily, the rhythms of family life offer comfort in their predictability and shared understanding.  The familiar routines, roles, rules and expectations shape an experience of ease with daily life, providing a sense of being 'at home'.  The children's narratives revealed ways in which the changes and adjustment following parental TBI altered this sense of ease and comfort, appearing to leave children, at times, feeling *not 'at home'* in their lives at home with their families.  Once again, the stories children shared demonstrated that while challenging, the experienced discomfort also brought the possibility for new insights as they found new ways of being as a family.

For some children, the altered sense of being 'at home' following parental TBI appeared to provide space for reflection and insight going forward.  Riley explained that the experienced disruption to family life after TBI had provided a new sense of perspective.  The altered sense of being 'at home' had resulted in a positive outcome.  Riley described feeling a greater sense of connection to her family as a result of their shared experiences over the last 11 months:

*Riley:*        *I guess that like just the separation of all of us has sort of like brung us closer together.*

*Mum:*        *Yeah, definitely - a stronger family unit.*

*Riley:*        *Yeah, like we realize how much we'd miss each other.*

In this chapter, the interpretation that children experience *an altered sense of being 'at home'* after parental injury has been explored, drawing on the voices of children living in the context of parental TBI.  In the next chapter (*Chapter Five: Discussion*), these findings will be discussed within the context of relevant literature.  A critical consideration of potential implications for clinical research and practice will be offered, followed by acknowledgement of the strengths and limitations of the research and directions for future research.

# Chapter Five: Discussion

The aim of this study was to explore children's experiences of living in the context of parental TBI in order to inform how we might better work with families after brain injury. This study has found that children experienced an altered sense of being *at home* after parental TBI. The themes highlighted that children experienced changes to family cohesion and rhythms and took an active role in tuning in and adjusting to new ways of being as a family.

This chapter will discuss the findings in relation to existing research, exploring the implications for clinical and research practice within rehabilitation. It will review the strengths and limitations of this study, alongside suggestions for future research.

## Hearing from Children: Insights Gained

The current study set out to explore what could be learned from listening to children and hearing their interpretations of the everyday world of recovery and adaptation after TBI by asking them about their experiences of living in the context of parental TBI. Consistent with my previous experience, I found hearing from children offered new ways of seeing and understanding. Their accounts not only offered insight into their experiences as children living in the context of parental TBI, but also presented ideas that, as I will elucidate, relate more broadly to new ways of seeing the *shared spaces* of recovery for all people after TBI.

The study findings support and extend previous research exploring children's experiences of parental ABI. They draw attention to the impact parental injury has on children in the home, and also their efforts to influence and moderate the impact of injury on their parents. Children's stories heard within this research resonate with those reported earlier (within *Chapter Two: Literature Review*) and similarly spoke of experienced shock, uncertainty and loss, and active roles of support and sense making (Butera-Prinzi & Perlesz, 2004; Harris & Stuart, 2006; Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2011). The message from existing research that parental ABI impacts upon children within the home is echoed by the current study. This study's findings extend existing understandings,

showing children's experiences of living in the context of parental TBI relate to an altered sense of being *at home* with their family. Children experienced sudden change to the ease in *knowing* who their parent was after injury and how they should *be in relation* to them. They experienced change to the usual, predictable flows of *lived time* as a family, and were required to navigate *new spaces*, while simultaneously encountering a sense of disruption to the *shared space of home*. Children were not passive bystanders of these experiences, but were actively involved in reciprocal roles of support to find *new ways of being as a family* after parental TBI.

Children's accounts illuminated the significance of home as a 'special space experience' (van Manen, 1990). The approach of purposefully taking notice and reflecting on lived space, alongside the other existentials, allowed for an enriched understanding of the meaning of *home* and *at-homeness* for children after parental TBI. The discussion offered below seeks to examine the significance of home as a special space experience, as reported by children, and, by implication for the adults with whom children share relational and physical space.

## The Special Space Experience of Home

> Home refers to an inner space and is an area of security and peace. Home is a space in which we are protected, hidden and safe; it is a space that is familiar, and a space into which we can withdraw and be ourselves. (Norlyk, Martinsen, & Dahlberg, 2013, p. 4)

The space experience of home is considered special as it is the place we can feel most comfortable and free to *be what we are* (van Manen, 1990); where we can feel most 'at home'. Yet, as the current study has illustrated, the home (as a lived experience) is dynamic and not always experienced in this way. For the children within this study, the experience of home changed in the context of parental TBI, influencing how they felt and how (and who) they could be.

### The Felt Space of Home

The understanding of home as a special space experience relates to how it is *felt* as a space. Home, characterised by the sense of at-homeness, is a space *known intimately*; it is the place where one can feel a *freedom to be*; can rest and

*regenerate*; have a sense of *possession, control and privacy* and experience '*warmth*' of atmosphere (Seamon, 2015, p. 84).

> Attachment to home is associated with the experience of *at-homeness* – the taken-for-granted situation of being comfortable and familiar with the world in which one lives his or her day-to-day life. (Seamon, 2015, p. 79)

The *changes to family cohesion and rhythms* discussed by children altered their experiences of the felt space of home. Home as a place of safety and knowing instead became a space of fear and uncertainty as children coped with the shock of the TBI event. Their accounts echoed those reported by other authors who have explored experiences of children living in the context of parental illness and impairment. Across different contexts, studies have shared children's accounts of shock, fear and anxiety when illness or injury threatens the stability and security of daily life (e.g. Ahlström, Skärsäter, & Danielson, 2011; J. Allen & Oyebode, 2009; Clemmens, 2009; Davey, Tubbs, Kissil, & Niño, 2011; Garley, Gallop, Johnston, & Pipitone, 1997; Helseth & Ulfsæt, 2003; Stiffler, Barada, Hosei, & Haase, 2008).

Studies looking at children's experiences of parental cancer, for example, have described themes that discuss *"a world turned upside down"* (Stiffler et al., 2008, p. 935), where young people's lives are *"unravelled"* by parental diagnosis (Clemmens, 2009, p. 573), with illness taking a position as the new *"permanent resident"* in the household (Davey et al., 2011, p. 82) *"ruling the family"* (Helseth & Ulfsæt, 2003, p. 358). Their accounts demonstrate how parental diagnosis, and the uncertainty it entails, intrude on life and create an *"unpleasantness of home"* (Stiffler et al., 2008, p. 936). The themes seem to highlight comparable experiences to children's within the current study, where home (as the place *known intimately,* with a sense of privacy and control) is challenged as illness, uninvited, takes 'residence' and governs daily life.

For patients, illness is regarded to have *"the power to radically change an individual's lifeworld"*, disrupting the individual's being-in-the-world (Norlyk et al., 2013, p. 8). In their study exploring experiences of lived space, they found patients felt more able to be themselves at home (in comparison to 'alien' hospital environments), but even the 'familiar and kind' space of home could become

'problematic' due to restrictions caused by illness. The space of home was seen to change in the context of illness, becoming *"overwhelmed by discomfort and insecurity"* (p. 5). Similar observations have been made for adults recovering after ABI, where the significance of home as part of one's identity has been emphasised. Home is not static, but fluid and like one's identity is "*constantly re-positioned and re-produced over time"*. After stroke, people experience abrupt, sudden changes in their personality and *"struggle to accommodate their changed selves in an unchanged house, which does not feel like home anymore"* (Meijering, Nanninga, & Lettinga, 2016, p. 36).

The children's accounts in the current study demonstrate the experience of disruption to one's lifeworld and the sense of being *not-at-home* in the home is not limited to patients themselves. The 'overwhelming discomfort and insecurity' extends to others with whom the patient shares physical and personal space. The sense of home as a *"safe haven"* (Carroll, Morbey, Balogh, & Araoz, 2009, p. 545) changed in the context of parental TBI, as the *feeling* of home as free and familiar became uncertain for children. Home as a place of *uncertainty* appeared to create a sense of *not-at-homeness*, as parental TBI made children confront fears of parental loss and required them to navigate new, 'scary' places (such as hospitals and rehabilitation centres).

In their study looking at the notion of home in experience of hospice day care, Moore et al. (2013) describe patients' fear of entering hospice. Their fears related to those seen in the current study, which underscored how clinical settings such as hospitals and rehabilitation centres (like hospices) can hold inherent characteristics that, 'by their nature', are *scary* and have assumed meanings (for example, as a place to die). In contrast to health professionals who may feel *at home* in such settings, for the sense of professional identity associated with place (Heath et al., 2012), the spaces were 'alien' to children (and indeed patients in Moore et al., 2013), who felt *not-at-home* and ill at ease. Hospital was scary for the sudden uncertainty it introduced into children's lives.

The experienced uncertainty of parental injury, and feeling of *not-at-homeness*, also impacted upon how children felt within the home. Moore et al. (2013) describe how an individual's experience of uncertainty around their illness can

leave them 'drifting' whereby they are 'cast out' of their familiar world, experiencing *"chaos, drifting in a 'meaningless' space"* (p. 154). Illness can leave a person feeling alienated from their normal day-to-day world, experiencing an *"existential outsideness: a sense of not belonging"* (p. 154), feeling not-at-home in the world. Children in the current study similarly provided accounts that spoke of the sense of introduced 'chaos' into their day-to-day existence.

Changes to the *known* parent, who was previously familiar and predictable, altered the 'warmth' of atmosphere of life at home for children. Children in the current study described change to their injured parent's behaviour as being scary, confusing and frustrating. Issues with parental mood, especially anger management, created feelings of tension in the home and left children feeling sad. Similar issues were reported in other studies exploring children's experience of parental ABI, which also seem to speak to change in the *felt space* of home:

> Some described feeling uncomfortable at home and said they would not bring friends home or host parties. A boy aged 15 explained how he did not think of this [sic] injured father when with friends, but every time he came home he felt a lump in his stomach before opening the front door, because he did not know what mood his father would be in. (Kieffer-Kristensen & Johansen, 2013, p. 1566)

The experiences sit in contrast to the notion of *at-homeness*, which emphasises *"a comforting feel of home, where one can relax and enjoy a positive atmosphere"* (Moore et al., 2013, p. 155; Seamon, 2015). The extract from Kieffer-Kristensen and Johansen (2013) illustrates the sense *un*ease where children appeared restricted in the space experience of home, and for this boy, a sense of dread for what atmosphere may await at home. As Seamon (2015) notes, *"to be 'ill at ease' connotes sickness"*, and this boy's experience serves as an example of how space *is felt* as part of oneself ('a lump in the stomach'), as an embodied experience, which can impact feelings and direct behaviour.

Children's experiences of parental ABI appear similar to those seen in studies exploring parental cancer and mental health issues, which also provide examples of experience that are indicative of sense of *felt* unease within life at home. For example, Helseth and Ulfsæt (2003) describe how parental cancer was seen to affect *"the emotional climate in the family, bringing insecurity and worries into daily*

*life"* (p.358). Similarly, children experiencing parental mental illness describe the change in atmosphere at home, when *"family life became uncertain"* (Ahlström et al., 2011, p. 564) and unpredictable (Trondsen, 2012).

Children in the current study provided accounts that spoke of the 'worries brought into daily life' after parental TBI. van Manen (2002) discusses the idea that the call to care for another is expressed as worry. Rather than a sense of duty or obligation, worrying is regarded to be *"the spiritual glue that keeps the mother or father affixed to the life of their child"* (p. 264). Children's accounts within the current study suggest that the experience of caring-as-worrying extends to children within the home. Children's narratives highlighted worries relating to their injured parent's symptoms and behaviour, about the risk of further injuries, and about loss. Through their accounts, it could be seen that children were actively engaged in efforts to monitor and support their parents. For example, children tried to take care of their injured parent by offering food, lying with them to help them sleep, and adapting their play to try and protect them from further injuries.

In their research exploring children's constructions of 'home', Kyrönlampi-Kylmänen and Määttä (2012) similarly suggest care for parental wellbeing is a source of worry for children. Kyrönlampi-Kylmänen and Määttä reported the young children in their study viewed home as a place of their own; a place of joy and togetherness; a place for play; and also a place *filled with worries*. Children expressed their worries for their parent's tiredness and frustrations at how much their parents worked at home. The authors described the ways in which children sought to actively "*organise the home*" to support their parents, reduce their tiredness and maintain a level of closeness with them (p.79). Just as seen in the current study, their finding contests the assumption of childhood as 'carefree' and demonstrates children's agency as active participants within their lives (Christensen & James, 2008). It is important to recognise that life at home is not necessarily devoid of worries for children. For those living in the context of parental illness or injury (including participants within the current study) worries included issues relating to mortality and loss (through hospitalisation, death, or separation) (e.g. Finch & Gibson, 2009; Harris & Stuart, 2006; Trondsen, 2012; Zahlis, 2001).

**The Interpersonal Space of Home**

For children in the current study, the significance of home as a 'special space experience' relates to the idea that it is *shared space*, as a family.

> […] home is the centre point of world experiences and highlights human qualities, emotional bonds and the personal relationships within the home.  (Carroll et al., 2009, p. 541)

Home is a relational space.  It is a place defined by 'interpersonal interactions' (Johnson & Bibbo, 2014), which contribute to a sense of freedom to *be what we are* and an understanding of ourselves *in relation* to others with whom we share the space (van Manen, 1990).  For children living in the context of parental TBI, the *shared, interpersonal* space of home was impacted by injury.  Children experienced change to their known ways of being, individually and as a family.

Children in the current study experienced an altered sense of ease *in relation* to their injured parent.  As earlier stated (p.76), the lived relation between parent and child is special and deeply personal, offering the child *"a fundamental sense of support and security"* (van Manen, 1990, p. 106)*.*  Children described how their parent (previously *known* through this personally significant relation) changed after injury and appeared to *be "strange"* to them; acting, behaving and interacting in ways that were unusual to them.  They experienced a sense of discomfort as the taken-for-granted ways of *being together* altered after injury.

Changes in parent-child relationships after parental injury have been reported across studies looking at parental ABI (Butera-Prinzi & Perlesz, 2004; Harris & Stuart, 2006; Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2011), as well as those looking at early-onset parental dementia (J. Allen & Oyebode, 2009; Svanberg, Stott, & Spector, 2010).  Such studies describe the ambiguous nature of the losses (Boss, 1999) children experienced within changed relationships after parental brain injury or disease.  In Svanberg et al. (2010), children spoke of the need to develop a new relationship with their parent, experiencing a loss of the person they had known before dementia; *"they're not, being, themselves… they're not…the same person"* (p. 743).  Further, J. Allen and Oyebode (2009) observed that most participants in their study felt they had lost their 'real father', suffering not

only a loss of the previous relationship, but also for experiences they had anticipated for their future selves, impacting upon who they felt they could *be* in the future.

For children in the current study, home as a relational space was impacted by parental injury.  Changes to family life at home came about suddenly ("*it was almost like a switch had been flicked*"), creating *"chaos"*, as roles, routines and expectations suddenly shifted.  This shift included a change to who was physically present within the home, with some children experiencing the extended absence of the injured parent from life at home with family or experiencing change to who worked out of the home.  Managing the demands of the injured family member was recognised to place additional burden on the non-injured parent, who children described as stressed and less available to offer them emotional support.  Children described missing their parents, and feeling like they had no one to talk to.  The sense of home as a place of togetherness and connectivity was altered after parental TBI.

Children living in other contexts of parental illness or impairment have been reported to experience similar disruption to family connectivity in the wake of parental ill health.  Ahlström et al. (2011), for example, describe how parental depression alters the usual reciprocal roles of support within the home, resulting in "*fewer opportunities for togetherness in family life*" (p.565).  Similarly, in their study exploring experiences of parental cancer, Stiffler et al. (2008) emphasise how daughters' *"mourned the loss of their mothers as they had known them"* when their treatment made them less available and left *"a hole where mom used to be"* (p. 936):

> They felt profound loss related to not being able to rely on their mothers, loss of their mothers' companionship, and loss of their mothers' involvement in their everyday activities.  *"I think I just needed attention from my mom.  Others can give you as much attention, but it's not the same.  When you are 14 years old, they can give you attention but they don't understand the kind of attention that you need."* (Stiffler et al., 2008, p. 936)

The extract resonates with the description Holly shared in the current study of how she just missed her parents, and missed having her mum (the non-injured

parent) available as the person she *wanted* to be with and talk to about what they were going through, as having other people available was just not the same. The experiences speak to an altered way-of-being-in-the-world that was apparent across studies, which emphasised how a change in the normal balance of relationships within the home could reduce the emotional availability of both the ill and well parent. Children are less able to rely on their parent(s) in ways they were used to, feeling loss of connection to those who normally offer them a 'fundamental sense of support and security' (van Manen, 1990). These findings resonate with the sense of 'absent presence' described in research looking at parental experiences after ABI (Kitzmüller et al., 2012), where parents report feeling both physically and emotionally absent from their children after injury (Edwards et al., 2014).

The relational space of home was also impacted upon by the mood of people within the space. As indicated above, issues with anger management contributed to a negative atmosphere at home (see p.95), appearing to add to children's feelings of sadness, confusion and frustration.

> [...] the space in which we find ourselves affects the way we feel; it is possible to say that we become the space we are in and the space becomes us. (Norlyk et al., 2013, p. 4)

The mood of the injured parent affected the mood of the home and how children felt themselves. Similar accounts are seen in studies looking at children's experiences of parental mental illness. For example, Ahlström, Skärsäter, and Danielson (2009) explored families ways of living with major depression and showed how the ill parent's mood impacted the feelings of everyone in the home *"when she feels bad...I feel like I have no energy to do anything either"* (p. 312). Children's accounts demonstrated how the mood of the home is 'felt':

> *"You notice it right away. It's enough to just look at her, then I saw what kind of day it would be. It was almost in the air and you could sense how it was going to be later, during the day"* (p. 312).

The space experience of home impacts how we feel, and equally is impacted by how we feel.

**Renegotiating the Special Space of Home**

Children's accounts in the current study provided examples of how their concerns and perspectives of living in the context of parental TBI changed over time, emphasising the lived space of home is not static.  As stated, the fluidity of home is 'constantly re-positioned and re-produced over time' in relation to the people within the space.  Children's narratives underscored the role they played, as active members of the family system and contributors to the shared identity of home, in renegotiating the special space experience of home.  With time, children attuned to their changed parent and new requirements of the home space, enabling a new sense of familiarity to be formed, renewing predictability within the home.

Children described how over time they had become better able to spot triggers for behaviour or situations where their parent may struggle to cope.  They described how they tuned into their parent's appearance and behaviour to spot signs that they were struggling, a finding reported elsewhere in parental ABI literature where children were described as *"highly attuned to parents' well being"* (Moreno-Lopez et al., 2011, p. 1228).  Similar descriptions are seen in studies of childhood experience of parental illness, where children are engaged in a process of monitoring their parents' physical and emotional states in order to make sense of the changed context of home, making effort to protect their parent(s) from further strain.  For example, studies looking at parental breast cancer report how children became *"watchers of their mothers"* (Zahlis, 2001, p. 1024) and *"keenly aware of their parents' moods, levels of energy, and side effects of treatment"* (Davey et al., 2011, p. 84) .  Studies looking at parental mental illness explain how children's attentiveness to their parents reduced the level of unpredictability within the home as they learnt to read the signs of illness (Ahlström et al., 2011).  In other studies, monitoring appeared to offer children reassurance as they could make sense of their parent's behaviour and put it in perspective (Garley et al., 1997; Helseth & Ulfsæt, 2003).

In being better able to predict their parent's behaviour children in the current study (and indeed others) appeared to reduce the level of uncertainty experienced within the home.  They actively made adjustments to their own ways of being in the home in order to accommodate the changed needs of their parent, supporting

them to manage the symptoms of their injury. Negotiating the home space in this way was not necessarily straightforward, with some children expressing frustration at their restrictions in being able to use the home space as they chose. However, children also reported positive aspects of the renegotiations, feeling they had experienced opportunity to find new ways of being, personally and as a family. Positive changes appeared to impact upon their sense of self, experiencing increased independence or the chance to contribute to family life in different ways. Children also described positive outcomes of their injured parent being home more since their TBI, which influenced their sense of connection *in relation* to them.

Children's accounts demonstrated that adjustment to life after parental TBI involved change to the felt and interpersonal space of home. Their descriptions emphasise the importance of looking at the wider context of a person's life, to consider how the special space experience of home may influence a person's recovery after injury.

## Implications for Rehabilitation

The study findings highlight the need to acknowledge children as family members impacted by parental TBI. Children need to be recognised for their reciprocal position within the family system (Rolland, 1999), being not only impacted by the injury, but also influencing the impact of the injury on the family. The need to acknowledge and recognise children within such contexts includes clinicians working directly with families, as well as those directing policy and research in the area of rehabilitation.

### Acknowledging Children as Active Participants

The current study suggests clinicians need to be aware of children living within the context of parental TBI, recognising their position within the home as active members of the family system (Rolland, 1999), vulnerable to the impact of parental TBI. Health practitioners working with families after TBI are uniquely positioned to identify children who may be struggling to cope with the changes they are experiencing as a result of parental injury. Children's accounts demonstrated how the wellbeing of family members within the shared,

interpersonal space of home are intimately connected, reliant on each other for support. Therefore, when working with the injured person, clinicians need to consider their client's wellbeing *in relation* to their family members, addressing the impact of injury on the usual roles, routines and rhythms of family life that existed prior to injury. TBI disrupts ways of being as a family, therefore health professionals have a role to play in supporting families to reconnect after injury as they find new ways of being together.

A starting point to this process would be for health services to identify which of their clients are performing parenting roles and consider what support parents need to cope with the demands of parenting after TBI. As part of this process clinicians would be well placed to explore what support children may need to cope with the changes resulting from parental injury, as well as how they may be better supported in their *contributions* to family recovery. Acknowledging the various ways in which children seek to support their parents and mediate the stressors in family life reveals ways in which the rehabilitation process as a whole could be bolstered. Similar recommendations have been made within studies exploring parental experiences after TBI, which emphasise how rehabilitation practice has the potential to harness support for the patient by looking at the roles family members, including children, play within the patient's life (e.g. Edwards et al., 2014).

Children's accounts demonstrated one area of change that they struggled with most after parental injury related to their parent's personality changes and issues with anger management. Only two families in the current study had received access to professional support for their children after parental TBI, and in both cases there was a sense that these services had been disappointing, having failed to deliver what was meaningful to the child. Children highlighted that having professionals who would *listen* to them rather than simply try to tell them what to do was important, indicating the importance of engagement within the therapeutic relationship (Darragh, Sample, & Krieger, 2001). Their accounts underscored that it is the experience of parental injury *as lived* that matters most. They wanted information that could be tailored to their specific needs, *working with them* to find practical solutions as to how *they could act* in response to their parent's changes, rather than offering generic information about TBI or focusing on the needs of the

injured parent. Children's accounts emphasised that talking to people about their experiences is not straightforward, whether it be friends or professionals, highlighting the process relies on trust, a level of understanding and having people who are prepared to listen. Some children suggested that they felt it may have been helpful to have had the opportunity to talk with other children going through similar experiences, rather than professionals.

The need for greater acknowledgement of children within the home after parental TBI extends beyond the role of the clinician and includes those who direct the design of research and policy. Research and policy needs to recognise children as active members of society, who not only deserve to be the subject of research, but can also actively *contribute* their understandings as participants. The current study has demonstrated that *hearing from children* can offer new insights into experience, not only of personal experiences of parental TBI, but ideas that relate to the family experience as a whole. The findings have shown that children, given opportunity to talk directly about their lived experiences, can demonstrate their competencies as active participants within research.

Adults who are positioned within the lives of children, through choice or circumstance, not only have a role to protect them, but also to acknowledge their rights and support needs. Children are impacted by decision-making that concerns the adults in their lives, and should be given opportunity to have input into decisions that affect their lives (Lansdown, 2001; Ministry of Social Development, 2002). Developing adult rehabilitation policy (including guidelines for clinical practice) that recognises the position of children within the context of parental TBI would allow their needs to considered alongside those of the whole family system. The findings of this study suggest the need for an increased focus on the reciprocal role of family functioning on health and wellbeing, recognising children as members of the rehabilitation team, who will be facing unique experiences of coping and adjustment following parental TBI.

**Considering the Special Space Experience of Home**

The study findings draw attention to *recovery spaces* after parental TBI and the need for greater consideration of the *special space experience of home* in the context of rehabilitation. Conceptualisations of home in rehabilitation focus on it

103

being *"a material, physical space"*, neglecting it as a place of personal significance and meaning (Meijering et al., 2016, p. 35).  In the context of rehabilitation, home is a place of assessment, measured as a functional space in terms of the potential need for physical adaptations to support independent living after injury (Meijering et al., 2016).  The home is also a place of rehabilitation, a site of community-based healthcare practice for the clinician that holds different meanings to work within the hospital (Heath et al., 2012).  Yet, for the injured parent and their family, the home is a private, trusted space that forms part of their identities and encompasses personal relationships; a special space experience that affects how they feel and who they are able to be.

Children's accounts demonstrated the need to remain mindful that although the home may (temporarily) become the place of rehabilitation work, it remains the space of home.  It is a private space, normally reserved for people with whom inhabitants invite into the home on an interpersonal level.  Therefore, there is a need to respect the *specialness* of the space, acknowledging all who live there and aspects of significance that are important to the family/whānau.  In acknowledging the disruption that parental TBI can cause to the experienced space of home, there is scope for rehabilitation work to consider how functional adaptations to the home may add to these experiences of discomfort within the home, changing how it feels to be at home.  Clinicians may have a role to play in supporting families in their process of renegotiating the home space.

The space of home as a *shared space* needs to be considered within rehabilitation interventions that are directed toward life at home.  Children's accounts highlighted how *recovery calls for its own space experience*, which is not necessarily matched with children's lifeworlds and the space experience of home.  For the clinician working with the family it may be helpful to consider the tensions regarding the needs of different family/whānau members within the space in order to highlight potential barriers to recovery plans and work out solutions that are meaningful to the family as a whole.  For example, acknowledging the tensions that exist between the injured parent's need for the space of home to provide opportunity for rest (as a quiet and peaceful space) and the child's need for the space of home to provide opportunity to feel free to explore their world through play (as an active space).  Work with families may be centred around establishing

104

new rhythms for family life, exploring times best suited to rest and times best suited to free play, offering further support with the process of renegotiation of the home space.  In order to do this, it becomes necessary to explore the individual and shared meanings of the home space with both injured and non-injured parents, and their children.

Clinicians supporting individuals and their families after TBI need to acknowledge the unique and fluid nature of home as a lived space.  Home is 'constantly re-positioned and re-produced over time', yet TBI introduces sudden, uninvited change into the shared space of home that takes time and effort to attune and adjust to as a family.  Children's accounts emphasised how their concerns and perspectives changed over time.  Clinicians are only ever able to get a snapshot of the lived experience of family/whānau life at home and therefore when working with families need to equip them with resources that recognise needs will change over time.  Supporting families to re-produce a sense of home after brain injury is a 'highly individualised practice' (Meijering et al., 2016), which relies on taking the full context of the injured person's lifeworld into account to understand the meaning of home.

Exploring the meaning of home to the individual may be a useful strategy to look at goal setting, finding ideas of importance to the individual for their recovery.  Children's accounts described the experienced uncertainty of life after parental TBI and the changes they faced as roles within the home shifted and routines were altered.  Individuals with TBI experience similar challenges coping with the uncertainty of life after TBI and dealing with their changed sense of self (Levack et al., 2010).  Working with the family/whānau to explore aspects of their home, and ways of being as a family, that are important to them may be beneficial to engaging the injured parent in goal setting.

## Study Strengths and Limitations

The chapter has discussed the current study's contribution to existing understanding of children's experiences of living in the context of parental TBI.  In reviewing the current study's findings, the strengths and potential limitations need to be acknowledged.

The findings of this research add to a relatively small literature base looking at the impact of parental ABI on children. The research took a purposeful stance of focusing on the lifeworlds of children living in the context of parental TBI and particularly targeted the experience of younger children, as a group often excluded from research (Carter, 2009). By researching a relatively under-explored subgroup of the population, the study adds to what is essentially a limited evidence base of qualitative studies that have aimed to explore the topic by directly asking children about their experiences.

It is acknowledged that the purposeful approach of speaking directly to children, as opposed to families, about their experiences raises some potential limitations. Talking with family and whānau may have provided useful information about children's experiences in relation to their family members. The study acknowledges that children are part of the collective group of family/whānau and therefore there may have been some advantage to considering the family as a functioning system. Also, speaking with family/whānau as a group may have given children the 'permission' to discuss topics that they may well have kept protected from me as the researcher, or outsider to private family life (Morrow, 2005). Yet, when studies group 'family' as one, there is also the risk that important differences in response of the different group members are missed (Alderson & Morrow, 2011). It can also be suggested that positioning children within research as part of families, rather than independent participants, serves to maintain their positioned vulnerability and lack of power and control within society (Lansdown, 1994). The current study provided an opportunity for children to realise their right to be heard on issues affecting their lives (UN General Assembly, 1989). By giving children a voice, the study acknowledged their status as part of a unique social group, whose perspectives or values may not necessarily be 'harmonious' with the values of the home or its adults (Hood et al., 1996).

The study appears to be the first research exploring children's experiences of living within the context of parental TBI in NZ. Yet, some sampling limitations, especially relevant to the NZ context, need to be recognised. The study refers to a relatively small number of children (n=7), with most children identifying as NZ European, living in urban settings within two parent households, where it was the father who experienced a TBI. While the findings did reflect some level of diversity

106

in the sample in that one child identified as European/Māori, two families lived in more rural settings and one child had experienced an injured mother (without the presence of a non-injured parent in the home), their accounts did not offer specific perspectives in relation to these aspects of ethnicity or living status. The current study did not seek to explicitly make comparisons between the experiences across different subgroups (such as, by ethnicity or by geographical location). Future work could explore any similarities or differences between such subgroups. Where greater diversity was achieved in terms of timeframe post injury, children's accounts offered useful insights into their experiences of parental TBI over different time periods. Recruiting a more diverse sample of participants to the study could have added richness to the findings, especially if speaking to children whose home lives were more complex prior to injury (due to issues associated with living with social disadvantage or poverty for example). Recruitment to the study, as anticipated, was challenging due to the nature of this group of people being 'unseen' in rehabilitation. There are no specific services set up to support the needs of children living in the context of parental TBI within NZ. Adult rehabilitation services were encouraging of the work, but rarely had specific data recorded as to which of their clients were parents or if there were children living within the home.

Issues of power and control were acknowledged in the study design and effort was made to engage with participants and respect their choices throughout the research. However, inherent issues of power and control remain with any research between adults and children, and thus serve as potential limitations of the study. The data gathered within the study interviews were shaped by the encounter between adult researcher and child participant, informed by engagement between the researcher and families of the participant (Ellis, 2006). The initial meeting that took place with the family as a whole prior to the research interview was useful in beginning the process of establishing trust and rapport with children as well as their parents. It proved useful as a way for children to see they had 'permission' from their parents to talk about private family issues. Children appeared concerned they may upset their parents in talking about some of the challenging aspects of their parent's injury and it needs to be acknowledged that the initial meeting may not have been sufficient in enabling children to feel

completely free in speaking with me as the researcher. Allowing time to complete more than one interview with children may have supported the process of establishing trust and rapport.

Children were recognised to be a distinct social group, active in the construction of their social worlds (Irwin & Johnson, 2005). As the adult researcher my position as outsider to this social world presents a potential limitation to the study. The creation of shared meanings within the research interview relies on shared understandings of language. Children demonstrated that their use of language was not always congruent with my use of vocabulary. Examples included how Rose selected the word *"unparticular"* to capture the experience of her dad failing to recognise who she was in relation to her siblings and how Madderson described her dad as *"really woundy"*, elaborating how he felt *"really funny and crooked"*. Effort was made to avoid assumption of understanding, seeking clarification and explanation of the meaning of the phrases children selected. The limitation of this approach is that it had the potential to undermine children's sense of understanding their own experience, meaning they were perhaps not able to narrate as freely as they would like. Returning to participants for subsequent interviews or member checking may have supported this process of establishing shared understandings between child participant and adult researcher. Children understood they had control of what they chose to share in discussions and follow-up interviews may have also given them the chance to revisit ideas from previous discussion in order to clarify ideas or add further detail. Alternatively, it would have provided opportunity for me as the researcher to seek further clarification on the basis on early interpretations of data. This may have been particularly helpful for those participants who required more directed (rather than open) questions, where there was potential for greater risk of acquiescence or (unintended) misdirection.

Using the existential dimensions of children's lifeworlds to guide analysis and interpretation (van Manen, 1990) offered unique insights into children's experiences of living in the context of parental TBI. The existential dimensions offered the lens through which to examine children's accounts, creating opportunity to reflect on aspects of everyday experiences, as lived. Focusing the interpretation in such a way made it possible to reflect upon aspects of experience

that would ordinarily be overlooked and ensured that the perspective of the child was kept central to the process. The approach made a particular way of understanding children's experiences possible, but also potentially constrained others. The study findings cannot offer a complete understanding of children's experiences. Rather, they offer insights to aid a richer understanding of children's experiences, acting as a new starting point for further questions and interpretative conversations.

## Directions for Future Research

The current study's findings support and extend existing knowledge relating to children's experiences after parental TBI, drawing attention to the reciprocal impact of injury on lives within the home. As well as raising some important implications for rehabilitation practice, research and policy, the study also highlights several areas that warrant further investigation.

The current study, as discussed, adds to knowledge regarding the experiences of younger children living in the context of parental TBI. It would be useful to conduct similar research within NZ exploring the experience of older, adolescent children to consider the similarities and differences in the types of narratives shared between the two groups. Literature exploring children's experiences of parental illness suggests younger and older children may face different challenges relating to their position within the home. Younger children's lives are more centred around the home, meaning they are more heavily reliant on their parents for access to their wider social worlds (Mordoch & Hall, 2008). Older children, on the other hand, are at a stage of life where they are facing increasing pulls away from the home space, resulting in conflicted feelings of wanting to be both present and away (e.g. Forrest, Plumb, Ziebland, & Stein, 2009; Meadus & Johnson, 2000; Stiffler et al., 2008). Furthermore, it could be useful to consider exploring the topic longitudinally, for example hearing from the participants within this study again as they transition through childhood and adolescence.

The study findings recommend that children living in the context of parental TBI need to be acknowledged within adult rehabilitation practice, through policy consideration and clinical work. In order to support the translation of this finding

into practice it could be useful to explore clinicians' perspectives of work with the children of adult TBI patients, to highlight potential barriers or areas for intervention. Evidence from the UK suggests that staff attitudes and access to training may be important factors in predicting levels of work with children within adult ABI rehabilitation (Webster & Daisley, 2007). Oppenheim-Gluckman et al. (2009) cited similar themes in their study exploring doctors' discussions of the needs of ABI patients' children (in France). Alongside a lack of training, or familiarity with dealing with children, their findings emphasised the potential significance of models of practice. Doctors reported that person-centred care meant patients were the central focus and family were positioned in the capacity of support or caregivers.

Within New Zealand comparable tensions between person-centred and family-centred practice have emerged within clinicians' talk about involving family/whānau within rehabilitation (Levack, Seigert, Dean, & McPherson, 2009). The tensions are argued to relate to current funding structures that constrain the rehabilitation process, prioritising treatment of individuals over maximising quality of life for family. The broader political context of rehabilitation is important to recognise and one that can be informed through the development of research and policy that is closely attuned to current practice constraints. Therefore, research that seeks to engage clinicians on the topic of childhood experience of parental TBI would seem important in aiding the translation of the current study's findings into practice, creating the possibility to develop targeted interventions for work with family and whānau within rehabilitation.

The significance of lived space in children's narratives highlights several questions that could be addressed within future research.

Firstly, their accounts raise questions regarding the experience of feeling at-home within recovery spaces away from home. This has implication for children themselves, but also the injured person and other members of the family. Hospitals and rehabilitation centres were experienced as scary spaces. The sense of unease or *not-at-homeness* relates to more than the physical properties of the place, but also the experienced atmosphere or mood. The finding offers direction for future research exploring the design of clinical environments to consider how

they can account for *a sense of home* within the space and how this can be maintained as it is *lived* in the everyday.  Designing spaces that can offer a sense of *at-homeness* to children need to consider how they may feel welcomed within the space, as well as how they may be able to offer them a sense of freedom and control, a sense of belonging and a sense of security (Heath, Greenfield, & Redwood, 2015; Johnson & Bibbo, 2014; Moore et al., 2013; Seamon, 2015).

Secondly, it raises questions as to how people may be supported to re-produce a sense of home, within the home, after TBI.  It emphasises the need for explicit consideration of the conceptualisations of home within rehabilitation practice as more than a place of residence, using research to explore the meanings of home in the context of TBI for injured people and their families, as well as clinicians working with them.  It highlights that there may be scope to develop interventions to support families in (re)negotiating the shared space of home after injury, working to restore harmony by finding new rhythms and ways of being together.

Finally, it suggests the need to consider children's perspectives of the meaning of home more broadly.  The study has offered insight into the experience of home after parental TBI, offering suggestions of how the special space experience of home is impacted by parental injury.  Studies exploring the meaning of home as a lived space experience focus predominately on the perspectives of adults (e.g. Moore et al., 2013; Norlyk et al., 2013; Seamon, 2015) and it would be useful to have more research available offering insight into the meaning of home for children.

## Conclusions

The study draws attention to the impact parental TBI has on children in the home, and also their efforts to influence and moderate the impact of injury on their parents.  Children's accounts of living in the context of parental TBI related to an altered sense of being *at home*; experiencing changes to family cohesion and rhythms and taking an active role in tuning in and adjusting to the new ways of being as a family.  Their experiences highlighted how the special space experience of home, shared as family, can be impacted by parental injury.  Children are actively engaged in interdependent, reciprocal relationships within the family

system and the current study emphasises the need to acknowledge the position of children living in the context of parental TBI.  Taking a whole family approach to rehabilitation, which includes taking notice of children, has the potential to offer support to the family as a whole, potentially also enhancing recovery for the individual with TBI.

The study heard directly from children about their experiences of living in the context of parental TBI, giving voice to a group of people often overlooked within adult rehabilitation.  The study underscores children's competencies as narrators of their experiences and emphasises the enriched understandings that can be gained from attending to the existential dimensions of their lifeworlds.

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# Appendix B: Study Leaflet

Are you a **child** (or the parent/guardian of a child):

☑ whose mum or dad has had a brain injury (TBI, in the last 5 years)?

☑ who is between 7-11 years old?

☑ who lives in Auckland or Waikato Region?

If you are interested in finding out more about the study, please contact us.

**We would love to hear from you**

**Alexis Channon**
Phone: 09 921 9179 or Email: achannon@aut.ac.nz

Nicola Kayes
09 921 9999 ext 7309
nkayes@aut.ac.nz

Tineke Water
09 921 9999 ext 7335
twater@aut.ac.nz

CENTRE FOR
**PERSON CENTRED RESEARCH**
HEALTH AND REHABILITATION RESEARCH INSTITUTE

CENTRE FOR
**CHILD HEALTH RESEARCH**
NATIONAL INSTITUTE FOR PUBLIC HEALTH
& MENTAL HEALTH RESEARCH

**AUT**
AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

## Hearing from children

# When mum or dad has a brain injury

CENTRE FOR
**PERSON CENTRED RESEARCH**
HEALTH AND REHABILITATION RESEARCH INSTITUTE

CENTRE FOR
**CHILD HEALTH RESEARCH**
NATIONAL INSTITUTE FOR PUBLIC HEALTH
& MENTAL HEALTH RESEARCH

---

We are doing a research study to find out what it is like for children when their mum or dad has a traumatic brain injury (TBI).

We are looking for children, aged 7-11 years old, who are happy to talk to us about their ideas, understandings and experiences.

### What is this study about?

In this study, we are interested in learning what it is like for children when their parent has a traumatic brain injury (TBI).

We recognise the impact of TBI often extends beyond the injured person and can affect the whole family. We believe children often seek to gain meaning and understanding in their own terms, according to their age and stage, and who they are as people.

We would like to invite children to share their stories of their experiences, from their point of view, in order to help us understand what it is like for them when their mum or dad has a TBI.

### What happens in the study?

If your family/whānau choose to take part, one of the researchers (Alexis) will meet with you and your child/children to talk about the study. She will arrange a time to complete the interview.

During the interview, Alexis will talk with your child/children and do some art or writing activities. She will ask some questions about what it is like when a parent has a TBI.

The interview will last 45-60 minutes. Parents are welcome to stay with their children during the interview.

The interviews will be audio-recorded so we can be sure we do not miss any important details.

### How will this study help?

The study aims to increase understanding of children's experiences of parental brain injury.

We hope to be able to use this information to try and improve healthcare and support for other families who experience TBI in the future.

# Appendix C: Study Advert

# Appendix D: Recruitment Proposal

**Hearing from children: When mum or dad has a brain injury**
**Proposal to recruit via TBI Experiences Study**

Researchers:  Alexis Channon (master's student)
Dr Nicola Kayes (primary supervisor)
Tineke Water (secondary supervisor)

*Study design*

The study aims to explore children's experiences of parental traumatic brain injury (TBI).  We are seeking a small, purposeful sample of children to take part in research interviews to talk about their experiences.

To be eligible to participate in the study, children need to:
- be aged between 7-11 years
- have a parent who has had a TBI within the last 1-5 years
- be willing, and able, to communicate with a researcher, verbally in English in a research interview
- live in Auckland or Waikato region.

The study draws on participatory ways of working with children in research. Interviews are tailored to the individual needs of the child, drawing on a toolbox of techniques responsive to the child's age, stage and interests.

The study has ethical approval from AUTEC (ref: 14/109).  The potential to recruit participants through the TBI Experiences (TBI-E) Study sample was considered within this application.  The application stated that recruitment via this source would not progress until all details had been agreed by study PIs (McPherson and Theadom) and approval provided by AUTEC.

*Rationale for recruitment via TBI-E*

A breadth of recruitment approaches has been considered within the study.  The potential to explore recruitment through TBI-E has been motivated by two factors.

Firstly, as a researcher on TBI-E, I appreciate that the wider context, and impact, of TBI has been central to a number of participants' accounts within the study.  Many participants have spoken about the impact of their injury on their family, which they describe as being under-supported within the recovery journey.  For this reason, participants have expressed interest in their children being able to take part in TBI-E to share their experiences.  In the majority of cases this could be accommodated as children were over 16 years, however for both methodological and ethical reasons this could not be extended to include younger children.  One of the families in TBI-E specifically asked whether the team would be interested in hearing from their younger children about the impact of the experience from their perspective and said they would be happy for us to follow up with them in the future if such a study did come up.

Secondly, during consultation with the Kawa Whakaruruhau Komiti the importance of building upon existing connections within the community was emphasised. The committee suggested that we not only look to connections we have formed with community support agencies and rehabilitation providers, but also explore the possibility of drawing on existing connections and relationships made with families through research activity.

*The proposed recruitment strategy*

As parenting was not a focus of inquiry within the TBI-E study, it will be necessary to contact potential participants to determine eligibility and their interest in participating.

While there are potential benefits involved in recruiting participants through the TBI-E study, there are also potential risks that need to be considered. A number of ethical and methodological issues have been considered in drawing up the following proposed process for recruitment (see Appendix A).

The proposed process:

1. Alexis to screen transcripts for potentially eligible families
   *Complete: I have identified 6 participants who made reference to younger children within their transcripts at one or more interview time-points; they are:* ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮
2. Alexis to phone participants to introduce study, explaining her role on TBI-E and this study (see appendix B for phone script).
3. If families are keen to hear more about the research, Alexis to follow-up by sending a letter (or email) and participant information sheets (see appendices C).
4. Families will be given time to consider whether they would like to take part and opportunity to ask further questions about the study.
5. If choosing to participate in the research, an initial meeting with the family will be set up by Alexis to go over consent and assent procedures. This session will also be used to gather demographic data and contextual information to inform the interview structure.
6. If families choose to participate (via parental consent and child assent), an interview will be conducted with the child or children. Parental consent will be sought to share the data collected through the interview with the TBI-E study team for the purposes of secondary analysis (but this will not be a requirement of their participation).

*Appendix A: Ethical and methodological considerations*

| Possible risk | Outline of issue | Proposed strategy |
|---|---|---|
| Possible conflict of interest | We are mindful of the potential conflicts of interest associated with recruitment via the TBI-E Study. Alexis has a dual role as researcher within the TBI-E Study and as a master's student in the current research. Alexis is also line-managed by Kath McPherson who is the lead investigator for the TBI-E Study. Furthermore, Nicola Kayes has a dual role as an investigator in the TBI- E study and as Alexis' master's supervisor. | • We are mindful of trying to minimise the number of researchers that potential participants need to connect with for the purpose of participation in the study. Being positioned in the dual capacity of researcher on both TBI-E and the master's project, Alexis is ideally placed to respond to participant queries about either study.<br>• Alexis will adopt a transparent approach when communicating with families about the research. She will be open about her role on both studies and ensure the family is clear that participating in either study bears no impact on their future involvement in this, or other, research.<br>• In order to provide the clearest communication, that is both personal and sensitive to participant needs, it was felt that phoning the participants would be preferable to writing to them as a first point of contact. Therefore, a telephone script has been prepared to guide the conversation with families (see Appendix B).<br>• Independent members of the two teams (Tineke Water and Alice Theadom) will provide review of the proposed recruitment approaches. In addition, independent ethical approval will be sought. |
| Avoiding coercion | One potential risk associated with conflict of interests is that of coercion. We are mindful of the potential coercive influences that participants may experience in already being members of an existing research study. | • As detailed above, Alexis will maintain transparent, open communication with potential participants.<br>• While Alexis has knowledge of participant data within TBI-E, she has not personally conducted interviews with all participants in the study. So, although the participants are connected with the study in broad terms they do not necessarily have an existing relationship with Alexis herself.<br>• Taking existing relationships into account. Alexis will make initial contact with potential participants if she has not previously conducted a research interview with the family. Another member of the TBI-E study team will make contact with families Alexis has not previously interviewed. This team member will be someone who has not interviewed the family previously. |

| Possible risk | Outline of issue | Proposed strategy |
|---|---|---|
| Respect for rights of privacy and confidentiality | TBI-E participants shared their data (including contact information) with the TBI-E study team who have a duty to ensure that it is protected. | • Only those members of the study team who are also members of the TBI-E study team will have direct access to data from the TBI-E study.  The information is stored with restricted access on the AUT server. <br> • There is potential for data collected from the children's interview to be added to TBI-E data for the purposes of secondary analysis.  Any participants recruited via the TBI-E study will be asked for their consent for data collected through the child's interview to be used for this purpose; they will be asked whether they consent to the following statement: *I am happy for data from my child's interview to be re-analysed as part of the TBI Experiences Study.* <br> How they respond to this question will have no impact on their ability to take part in the current study should they choose to. <br> • No information given by study participants will be shared with third parties. |
| Limiting the impact on potential TBI-E follow up work | Participants within the TBI-E study were made aware that the study team were keen to continue following the study sample longitudinally if possible.  Retaining within this sample is important and additional recruitment from this sample should not jeopardise this. | • Effort has been made to ensure that the research process minimises any potential burden on participants. <br> • All communication with potential participants will be conducted in a manner that is sensitive of their recovery story and the data they have shared to date within TBI-E. <br> • Alexis will be mindful of information shared through TBI-E when meeting with families to protect the confidentiality of data shared in prior sessions. <br> • Alexis will adopt a transparent approach when communicating with families about the research.  Alexis will be open about her role on both studies and ensure that the family is clear that participating in either study bears no impact on their future involvement in this, or any other, research. Recognition will be made to the fact that the master's topic aligns with findings from TBI-E, i.e. the impact of TBI on families. |

*Phone script to be used as a guide for conversation as opposed to a verbatim script.*

- Hi my name is Alexis and I am a researcher on the TBI Experiences Study.
- I am based in Auckland and have been involved in analysing the data from the study.  We are finishing this phase of the research, but really keen to follow up with people over the longer term.  We are hoping to have some funding to support this and hopefully we may be able to contact you in the near future about this work.
- I am phoning you today about a related research project, which is separate to the TBI Experiences Study, which I am completing for my master's qualification.
- In this study, we are hoping to hear from children about their experiences after a parent has a brain injury.  We are keen to talk with them about how the experience has been from their perspective, and what things have been helpful for them along the way.
- I am aware from your accounts of recovery in the TBI Experiences Study that *[personalised notes – e.g. number of children]* and wanted to find out whether you would be interested in receiving more information about this research to share with *[your partner and]* your children.
- If I send you some information today, you can then take your time to consider whether your family would like to be involved.   It's important to say that choosing whether to take part in this research is not connected with having taken part in the TBI Experiences Study in the past or continuing to be involved in the study in the future – it is a separate piece of work.

# *Hearing from children*

## When mum or dad has a brain injury

Dear [insert name],

Thank you for taking the time to talk with me today about our research project, which is aiming to explore children's experiences of parental brain injury.

In this study, we are interested in learning what it is like for children when their parent has a traumatic brain injury (TBI). We recognise the impact of TBI often extends beyond the injured person and can affect the whole family. We believe children often seek to gain meaning and understanding in their own terms, according to their age and stage, and who they are as people.

We would like to invite children to share their stories of their experiences, from their point of view, in order to help us understand what it is like for them when their mum or dad has a TBI. We are keen to talk with children, aged between 7 and 11 years, who are happy to tell us about their ideas, understandings and experiences.

I have enclosed a copy of the study information sheets for you to read for more details about the study and what would be involved if [insert child name] wanted to take part. There are two copies of the information sheet - a parent version and a child version.

Please take your time to consider whether you would like to be involved in the study. Deciding whether to take part in this research has no impact of any research you may already be involved in or plan to be involved in the future.

I will aim to re-contact you in a week's time. In the meantime, if you have any questions about the study, please do not hesitate to get in touch.

Yours sincerely,


Alexis Channon

Centre for Person Centred Research, AUT University

# Appendix E: Participant Information Sheet for Parents



## Hearing from children
## When mum or dad has a brain injury

### Participant Information Sheet

### Invitation

Tēnā koe, talofa lava and hello. We are a team of researchers at AUT University conducting a research study into children's experiences of parental brain injury.

| Researcher: | Project Supervisors: | |
|---|---|---|
|  |  |  |
| **Alexis Channon** (09) 921 9179 achannon@aut.ac.nz | **Dr Nicola Kayes** (09) 921 9999 ext 7309 nkayes@aut.ac.nz | **Dr Tineke Water** (09) 921 9999 ext 7335 twater@aut.ac.nz |

Alexis is completing this research as part of her post-graduate qualification towards a Master's of Health Science (Rehabilitation).

We are inviting your child to take part in this study. This information sheet explains the study aims and what is involved in taking part. We appreciate your time reading this material. Please consider:

- The decision to take part in the study is entirely voluntary (you and your child's choice).

- Your child can withdraw from the study (or you can withdraw your child from the study) at any time, without having to give a reason.

- Please feel free to contact the research team if you have any questions about the study.

### What is this study about?

In this study, we are interested in learning what it is like for children when their parent has a traumatic brain injury (TBI).

We recognise the impact of TBI often extends beyond the injured person and can affect the whole family. We believe children often seek to gain meaning and understanding in their own terms, according to their age and stage, and who they

Participant Information Sheet; version 2                                   4 Feb 2016

are as people.  We would like to invite children to share their stories of their experiences, from their points of view, in order to help us understand what it is like for them when their mum or dad has a TBI.

**How was I identified and why am I being invited to participate in this research?**

We want to talk to a range of children about what it is like when a parent has a TBI.

We have asked rehabilitation services and TBI support agencies to contact people who have had a TBI within the last 5 years who are parents of school-aged children.  We invite you to consider whether your child/children may be interested in taking part in this study.

We are also contacting people who have taken part in other research we have done in the Centre for Person Centred Research, such as the TBI experiences study.

To be able to participate, children need to be:
- Aged 7-11 years
- Able to communicate with a researcher
- Willing to take part in an interview with a researcher (parent/s can be present)

**What will happen in this research?**

Alexis will arrange a time to come and talk to you about the research and meet your child.  She will go over the study information and give you and your child time to ask any questions.  If your child chooses to take part, Alexis will offer your child some activities they can do to prepare for the interview if they choose.  This appointment will last about 30 minutes.

Alexis will arrange a time and place for the interview that suits you and your child. This can be in your own home or at another place if this is better for you and your child.  If you have more than one child who is interested and eligible to participate (aged 7-11 years, willing and able to take part in an interview) then we can arrange either to complete separate interviews or interview the children together as siblings.  The interview will take about 60-90 minutes.

The interview will be relaxed.  You are welcome to stay with your child through the interview if you and/or your child prefers.  We will use some arts-based techniques in the session.  Questions will focus on exploring children's understandings and experiences of having a parent with TBI.

We will ask your permission to audio-record the interview and to take photographs of any artwork completed in the session.   After the interview, Alexis will analyse this data, alongside the stories collected from other children.  With your consent, the data collected in the study will be used for publication and presentations.  The data will be anonymised and your child will be asked to choose a pseudonym (fake name) for use in reports.

If you have been contacted because you are known to us from the TBI experiences study then we would like to use the data from your child's interview to better understand the broader experience of TBI within your family/whānau unit. We will seek your permission to re-analyse your child's data with this mind. You do not have to agree to this.

### What are the discomforts and risks?

Children may become tired or uncomfortable talking with us. We recognise also that children may become upset when talking about some aspects of their experience.

### How will these discomforts and risks be alleviated?

Alexis will be sensitive to the conversation, providing support and reassurance through the interview. Children will be encouraged to talk about issues that they feel are important and equally the option of choosing not to answer questions. Children can take breaks during the interview if they (or you) wish and can also choose to stop the interview. If your child becomes upset, or Alexis is concerned about their wellbeing in any way, she will end the interview.

All participants in the study will also receive a 'support information' leaflet with contact information for adult- and child-focused support services. If we are concerned for your child and/or family/whānau we will discuss potential support options and referrals with you.

### What are the benefits?

It is possible your child may enjoy taking part in the research and talking about their experiences, but there is no guarantee they (or you) will benefit directly from being involved in this study.

The study aims to increase current understanding of children's experiences of parental brain injury. We will send your child (and you) a summary of research findings if they (or you) wish.

### How will my privacy be protected?

The interview recording and all other information that you and your child provide is confidential. However, if during the research process we learn that your child (or your family/whānau) is not safe, then we may have to notify an appropriate agency who can offer support. We will always aim to talk with you first.

No material that could personally identify you or your child will be used in any reports from this study. Your child and family will be asked to choose a pseudonym (fake name) for use in such presentations or publications.

Upon completion of the study your records will be stored for at least 10 years in a secure, locked cabinet at Auckland University of Technology. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

**What are the costs of participating in this research?**

There will not be any cost to you or your child except your time – about 1 to 2 hours.  If you need to travel to an interview we will cover any travel costs that you incur with a $20 petrol voucher.

**What opportunity do I have to consider this invitation?**

This is an invitation to take part in the study, but it is completely voluntary (yours and your child's choice).  Please take your time to read, consider and discuss this information about the study with your family/whānau.  We will give you a couple of weeks to consider this invitation, but if you need more time that is OK.  Please contact Alexis if you would like more information.

**How do I agree to participate in this research?**

You will be asked to fill out a consent form to show that you are willing for your child to take part in this study.  Your child will be asked to complete an assent form (to indicate their agreement to take part) prior to the interview.

**Will I receive feedback on the results of this research?**

If you or your child would like to receive a summary of findings you can say so on the consent form and they will be sent to you and your child at the end of the study.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext. 7309.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr Kate O'Connor, ethics@aut.ac.nz, 09 921 9999 ext 8860

**Whom do I contact for further information about this research?**

If you want more information about this research, please feel free to contact one of the researchers:

*Researcher:*

      Alexis Channon - (09) 921 9179; email achannon@aut.ac.nz.

*Project Supervisors:*

      Dr Nicola Kayes – (09) 921 9999 ext 7712; nkayes@aut.ac.nz

      Dr Tineke Water – (09) 921 9999 ext 7335; twater@aut.ac.nz

# Appendix F: Participant Information Sheet for Children

## Some other questions you may have

### What is research?

Research means finding out more about something.

### What does the brain do?

The brain is part of the body (inside the skull) that controls most things we do. It controls our body's movements, thoughts, feelings and memory.

### What's a brain injury?

When people say someone has a brain injury it means they have hit their head and hurt their brain. The brain can bruise or bleed just like other parts of the body.

So, if someone hurts their brain it can be harder to do lots of the things they would normally be able to do.

### Thank you for reading this booklet

Let us know what you think about being a part of this research project

---

## Hearing from children

**Hi, my name is Alexis**

**Hi, I'm Nic**

**Hi, I'm Tineke**

### When mum or dad has a brain injury

Hi, we are researchers at AUT University.

We are doing a research project to try and find out what it is like for children when their mum or dad has a brain injury.

We would like to invite you to be part of this research.

### Some questions you may have about taking part in this research...

#### What would I need to do?

If you choose to take part, one of the researchers (Alexis) will come to your house to talk with you and do some art or writing activities. She will ask you some questions about what it is like when your mum or dad has a brain injury.

Alexis will record the talk on a voice recorder. Later we will write down everything you said, exactly the way you said it.

Your mum or dad can stay with you for the talk if you would like. The talk will last about an hour.

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CENTRE FOR CHILD HEALTH RESEARCH
NATIONAL INSTITUTE FOR PUBLIC HEALTH & MENTAL HEALTH RESEARCH

---

### What could happen if I take part?

The good thing is that you will help us know what it's like for children when their mum or dad has a brain injury. We can then use this information to try and help other children and families in the future.

You may get tired talking to us. We can take breaks or stop at any time. You may find you don't want to talk about some things, that's OK. It's up to you what you talk about and you can choose not to answer some questions. If you get upset for any reason then we will stop and get your mum or dad, or someone else you choose, to come and help you.

### Who will know what I say?

Only the researchers will know what you said. We will ask you to choose a pretend name and then we will use that name in the study.

The information you give us is confidential (private). But, if you talk to us about something that makes us worry about your safety (or the safety of someone in your family/whānau) then we may need to talk with some other adults who can help. We will always try to talk with you about this first.

### Do I have to do this?

No, it's OK if you do not want to be part of this study. You can tell your parents or us if you don't want to do it. If you say yes, it's OK to change your mind later.

---

### What if I am not sure?

Your parents know about this study. You can ask them questions about taking part in the study. You can also ask us any questions about the study before you decide if you want to take part.

**Do you have any more questions about the study? Get in touch!**

**Alexis Channon**
09 921 9179
achannon@aut.ac.nz

**Nicola Kayes**
09 921 9999
ext 7309
nkayes@aut.ac.nz

**Tineke Water**
09 921 9999
ext 7335
twater@aut.ac.nz

### My questions for my parents or Alexis are:

# Appendix G: Consent Form

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*Hearing from children*
**When mum or dad has a brain injury**

## Parental Consent Form

> Project Supervisors:
>   Dr Nicola Kayes: (09) 921 9999 ext 7309; nkayes@aut.ac.nz
>   Dr Tineke Water: (09) 921 9999 ext 7335; twater@aut.ac.nz
> Researcher:
>   Alexis Channon: (09) 921 9179; achannon@aut.ac.nz

➢ I have read and understood the information provided about this research project in the Information Sheet dated 17 June 2014.

➢ I have had opportunity to ask questions and I am happy with the answers given.

➢ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed (written out).

➢ I understand photographs of children's artwork will be taken. I agree to these photographs being used in the findings report, publications and presentations.

➢ I understand that we (me and my child/children) may withdraw from this project at any time, without being disadvantaged in any way.

➢ If we withdraw, I understand that all relevant information including audio-recordings and transcripts, or parts thereof, will be destroyed.

➢ I agree to my child/children taking part in this research.

| | | |
|---|---|---|
| I would like to receive a summary of findings | Yes ○ | No ○ |
| I am happy to be contacted about future related studies | Yes ○ | No ○ |

*TBI Experiences Participants only: I am happy for data from my child's interview to be re-analysed as part of the TBI Experiences Study.*   *Yes* ○   *No* ○

**Child/children's Name/s**  ...............................................................................

...............................................................................

...............................................................................

**Parent/Guardian Name**  ...............................................................................

Signed  .............................................  Date  ...........................................

**Contact information**

✉ Address (postal)  ....................................................................

☏ Phone number  ....................................................................

@ Email  ....................................................................

**Researcher Name**  ...............................................................................

Signed  .............................................  Date  ...........................................

Approved by the Auckland University of Technology Ethics Committee on 17 June 2014, AUTEC Reference Number: 14/109.

# Appendix H: Assent Form

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*Hearing from children*
**When mum or dad has a brain injury**

## Child assent form – Tell us if you want to be in this research

> Project Supervisors:
>   Dr Nicola Kayes: (09) 921 9999 ext 7309; nkayes@aut.ac.nz
>   Dr Tineke Water: (09) 921 9999 ext 7335; twater@aut.ac.nz
> Researcher:
>   Alexis Channon: (09) 921 9179; achannon@aut.ac.nz

➤ I have read and understood the leaflet telling me what will happen in this study.

➤ I have been able to ask questions.  I am happy with the answers I have been told.

➤ I understand that Alexis will record our talk together so she can write down everything that we talk about.  I understand that Alexis will take photos of any artwork that I do.

➤ I understand that the things I say and the pictures of my artwork may be used by Alexis, Nicola and Tineke when they share the findings of the research.  When they do this, I want my pretend name to be:

   ………………………………………………………………………………………………………………………………………………

➤ I understand that while the information is being collected, I can stop being part of this research whenever I want and that it is perfectly OK for me to do this.

➤ I agree to take part in this research.


**Child's Name**          …………………………………………………………………………………………

Signed        ……………………………………………        Date        …………………………………………………

**Researcher Name**          …………………………………………………………………………………………

Signed        ……………………………………………        Date        …………………………………………………

Approved by the Auckland University of Technology Ethics Committee on 17 June 2014, AUTEC Reference Number: 14/109.

Child Assent Form; version 1                                              17 June 2014

# Appendix I: Ethical Approval

**A U T E C**
**S E C R E T A R I A T**

17 June 2014

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **14/109 Exploring children's experiences of parental brain injury.**

**Lay title: Hearing from children: when mum or dad has a brain injury.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 16 June 2017.

The authorizing signatures may be tabled at the meeting.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 June 2017;

- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 16 June 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
**Auckland University of Technology Ethics Committee**

Cc:        Alexis Channon achannon@aut.ac.nz

**A u c k l a n d   U n i v e r s i t y   o f   T e c h n o l o g y   E t h i c s   C o m m i t t e e**

**W A 5 0 5 F   L e v e l   5   W A   B u i l d i n g   C i t y   C a m p u s**

**P r i v a t e   B a g   9 2 0 0 6   A u c k l a n d   1 1 4 2     P h :   + 6 4 - 9 - 9 2 1 - 9 9 9 9   e x t   8 3 1 6   e m a i l   e t h i c s @ a u t . a c . n z**

138

# Appendix J: Safety Protocols

# Safety Protocols

The following protocols have been developed to ensure the safety of researchers as well as children and families within the study.

The protocols are based upon principles of empowerment, in which conversations with children and adults within the study are based upon the premise of full disclosure, informed consent and respect for confidentiality.

## Contents

### Researcher safety: Principles for the researcher

#### *Vicarious trauma*
Working on qualitative research can lead to risk of vicarious trauma through conducting and transcribing interviews, and listening to and analysing people's stories. As the researcher, you will be encouraged to debrief with a member of the research team after each interview. Regular supervision sessions will be held for more focused discussion. Be aware of potential triggers that may impact on you; develop a personal wellness plan to keep yourself well.

#### *Staying safe*
As the researcher, if at any time you encounter a situation in which you do not feel safe, do not hesitate to end the conversation or interview. Explain to the participant/s that you would like to reschedule the interview or that you will contact them at another time. For off-site interviews, follow the processes outlined within the PCR policy 'keeping ourselves safe' below.

## Keeping ourselves safe

**Procedures for PCRT researchers interviewing participants in their own home**
Agreed team procedures:

> **Always let someone know where you are going**
> - Notify a colleague of the intended visit or planned itinerary
> - leave contact details: –
> - name address and phone number of the participant you are visiting
> -  the time of the visit
> - Carry a charged cell phone preloaded with office and colleague contact numbers
> - Turn your phone on (it can be on silent to avoid disturbances)
> - Show respect to your host – dress appropriately, some places you need to remove your shoes

**Some situations will require further safety procedures**
Discuss with colleague or supervisor the assessment of risk, take action as appropriate to assessment

> **How do you make safety assessments prior to an interview?**
> - Engage in phone conversation when arranging interview and gather information to make assessments
> - Consider the physical area / location you are visiting
> - Consider the topic and likely participants
> - Consider will other people be in the house during the interview?

**Increasing risk?**

**Consider the following:**

- Arrange to check in with colleague when visit finished. Estimate finishing time; arrange a finishing scenario ("I should be back in the office by...")
- Keep keys and phone on your person
- Park your car in a way that you can make a quick exit – do not park in a drive where you can be blocked in.
- Are you going to an area where there is no cell phone coverage? (E.g. parts of Waitakeres for example) have you made allowances for this?
- Dress appropriately (do not wear excessive jewellery )
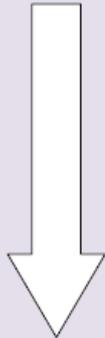
**Going to areas that are considered unsafe**

- Check the map and know where you are going before reaching the area. Make sure you have enough petrol
- Do not leave valuables on display in the car, Keep your personal documents, purse etc with you at all times
- Arrange for someone to call / text you near the scheduled end of visit to check you are okay – consider the use of code phrases
- Never sit with your back to the door and always be aware of the nearest exit
- Do not enter a house if you hear yelling screaming etc
- Consider alternative venue for interview
- Act confident and sure of yourself: ignore provocative comments or behaviours: keep your hands free: don't walk through a group of people standing together on the street
- Wear clothes and shoes that make a quick escape possible, e.g. shoes that are easily slipped back on
- Work in pairs if required

**If you are uneasy during the visit**

- **Trust your instincts:** If at any time you feel that your safety is in jeopardy terminate the visit
- If a participant or family member becomes violent or abusive respond calmly with "I" messages; keep statements matter of fact, simple and direct; keep a physical distance; don't reach out and touch the person; don't get up from the chair while the person is sitting, don't leave too abruptly
- **Immediately report any dangerous or threatening incidents to your supervisor**

## Child and family safety

The research team is aware that researching children's experiences of parental brain injury is a potentially sensitive topic. After traumatic brain injury, people can experience difficulties in regulating their mood and impairments in cognitive functioning. Furthermore partners of people with brain injury (who in this study would be defined as the non-injured parent) also report reduced mental wellbeing and elevated stress levels [1-2]. Therefore, it is anticipated that stress

within the home may be greater for families experiencing TBI.  Of the limited evidence that is available to date on children's experiences of parental brain injury, there is an indication that children receive limited information and support following a parent's injury and factors such as family violence may be introduced into the home [3].

Therefore, with this context in mind a clear set of safety protocols are set out below to guide researcher action in the case of identified risks.

### *Safeguarding Children Protocol*

The safeguarding children protocol has been developed following consultation with The Interdisciplinary Trauma Unit, as well as guidelines from Child, Youth and Family (CYF) and Child Matters.  It outlines three core components relevant to conducting research with children and families; (1) limits of confidentiality; (2) dealing with disclosure of abuse; and (3) team consultation.

1. Limits of confidentiality

Confidentiality of children and families is of utmost importance within this study, however a breach of confidentiality may be deemed necessary if:
  - There is an indication that the child, or someone else, is unsafe or at risk, from themselves or others.
  - This includes, but is not limited to, incidents of suspected child abuse or neglect.

As the researcher, you are required to work in an open and honest manner with children and families.  When explaining the study to children and parents it is important to make the limits of confidentiality clear, explaining that the information they provide is private, but if you are concerned about their safety (or the safety of others) then you may have to tell another adult to help make them safe.  Wherever possible, children and families themselves will be encouraged to share the information they have told with the appropriate agency.

Children and parents will be given information about the limits of confidentiality within the participant information sheets.  It is important to make sure children and families understand this information prior to consenting/assenting to commence the interview.

Child information sheet:
> *Only the researchers will know what you said.  We will ask you to choose a pretend name and then we will use that name in the study. The information you give us is confidential (private).  But, if you talk to us about something that makes us worry about your safety (or the safety of someone in your family/whānau) then we may need to talk with some other adults who can help.  We will always try to talk with you about this first.*

*Parent information sheet*:

> *The interview recording and all other information that you and your child provide is confidential. However, if during the research process we learn that your child (or your family/whānau) is not safe, then we may have to notify an appropriate agency who can offer support. We will always aim to talk with you first.*

1. Dealing with disclosure of abuse

While it is important children understand that it is their choice what they talk about in the interview, it is important that they are not prevented from talking about concerns they may have. If children have concerns they wish to discuss within the interview they should be given opportunity to do so. Therefore, it is important that as the researcher, you are prepared to listen to the stories the child chooses to share and to support them in that process. Guidelines for dealing with disclosures of abuse are provided within Appendix i of this protocol.

> *The CYF Factsheet (appendix i) recommends that it is best not to question children about their experience, but rather just listen and be reassuring. The best response might be "thank you for telling me about that, now I need to talk to someone so we can make sure you're safe".*

2. Consultation with the team

Any discussions that take place at the time of interview with children and families should be shared with the study supervisors and a process of consultation should take place. As the researcher, you are responsible for consulting with the research team on any issues of concern raised during the research process (before, during or after the interview) in relation to child and/or family/whanau safety, whether dealt with at the time or not. Equally, as consulting parties, the study supervisors are responsible for asking appropriate questions to determine the level of identified risk and to agree a course of action to take.

### *Supporting child wellness*

There is the potential for children to become distressed, either during or after the interview process. Talking about sensitive issues may elicit emotional reactions from children. Emotional reactions are not abnormal and should not be treated as such. It is important children are reassured that there is no right or wrong way to feel or respond during the interview or in relation to the topic.

In communicating the study information to children and families it is important that it is emphasized that there are no right or wrong ways to feel or act when talking about the topic. The researcher should explain that children are free to choose not to respond to any question. Cue cards will be made available to children so that they can indicate (non-verbally) their wish to stop the interview

the Support Information booklet, to give children and families a list of resources for further information and support in relation to mental wellbeing.

### References

[1] Marsh, N. V., Kersel, D. A., Havill, J. H., & Sleigh, J. W. (2002). Caregiver burden during the year following severe traumatic brain injury [Article]. *Journal of Clinical & Experimental Neuropsychology, 24*(4), 434-447. doi:10.1076/jcen.24.4.434.1030

[2] Moules, S., & Chandler, B. (1999). A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Injury, 13*(12), 983-993. doi:10.1080/026990599120990

[3] Butera-Prinzi, F. and A. Perlesz, *Through children's eyes: children's experience of living with a parent with an acquired brain injury.* Brain Injury, 2004. **18**(1): p. 83-101.

# maltreatment and family violence

## Factsheet:

## When children talk about abuse

When a child or young person discloses any form of abuse often it's a sensitive time in terms of, you as a carer grasping the information that has been provided. As a carer it is important you ensure your responses to the child or young person is appropriate while awaiting the process that may follow.

After receiving a disclosure it is very important to write notes about what was said. These notes can be used as evidence if abuse has been substantiated, and will also prove helpful for the caregiver if they are called as a witness in court. Where verbatim can happen, it is important this is done, avoid recording the disclosure from your perspective as the carer.

### When children talk about abuse

A child may try to find different ways to tell you that they are suffering from abuse or neglect. Talking about what has happened is really scary for children.

This means that they may:

- try to say things in a way that is tentative, vague
- use other people's names or places
- say things very quietly or simply make hints
- act out with dolls or toys, or use words that are right for their age.

It's really important to listen to what they are trying to say, be understanding and take what they say seriously. It is unusual for children or young people to make up situations of abuse.

### If a child tells you about abuse, here are some guidelines to follow

#### 1. Listen and be reassuring

It's really important to make a child feel safe in telling you. Listen to them and be reassuring of your support amongst the following things:

- Accept what they have to say and make sure you don't say anything critical.
- Let them know it's good they told you about it.
- Let them know it's not their fault.
- Let them know it's not ok for things like this to happen to kids.
- Tell them you will get help.

It's best not to question them about their experience, just listen and be reassuring. The best response might be "thank you for telling me about that, now I need to talk to someone so we can make sure you're safe".

### 2. Write it down

As soon as possible, write down what the child tells you, using the same words they say, and how you responded.

### 3. Don't question or interview the child

Make sure you don't question the child further, as this may interfere with the information they've given.

### 4. Call Child, Youth and Family or the Police.

Call Child, Youth and Family on **0508 FAMILY (0508 326 459)** or the Police as soon as possible. You can ask for whatever advice, assistance and support you need.

### 5. Keep the child safe

Make sure the child knows they are safe, and have done the right thing in telling you.

**Don't let anyone who may be involved in the abuse know the child has said anything to you.**

## What to Record

It is important to record what was said, as this will become part of the evidence. You may be called into court as a witness. You need to make full notes about it as you will not remember 12 months later what happened at the time. The Police or Social Worker will want to keep your notes on file, so make sure you ask to have a copy made for yourself.

| Facts | Names, Places, Times |
|---|---|
| Child's own words | Descriptions, behaviours actions |
| What prompted disclosure | What was going on at the time or was there a question that prompted the disclosure? |
| Observations of the child | Emotions, behaviour, actions |
| The "W" list | What, Who, When, Where |

# Appendix K: Support Information Booklet

## Panel 1 (top left)

**If you have any questions about the research, please get in touch with us**

**Alexis Channon**  09 921 9179
achannon@aut.ac.nz

**Nicola Kayes**  09 921 9999 ext 7309
nkayes@aut.ac.nz

**Tineke Water**  09 921 9999 ext 7335
twater@aut.ac.nz

**Other contacts**

If you have concerns about the study and you want to talk to someone who isn't involved, you can contact an independent health and disability advocate on:
Phone:      0800 555 050
Email:       advocacy@hdc.org.nz

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This study has received ethical approval from AUT University Ethics Committee (AUTEC) [Ref 14/109]

## Panel 2 (top right)

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**Hearing from children**

**When mum or dad has a brain injury**

**-Support Information-**

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## Panel 3 (bottom left)

**Resources and contact information**

**For general health information**

**Your GP** can offer advice and support.

**Ministry of Health Family Services Directory**
0800 211 211  www.familyservices.govt.nz/directory/

**For child & family mental health information**

**www.headspace.org.nz**
A website for young people, as well as family/whānau, with information and advice about mental health and wellness. Some useful links to relevant support services and information about referral pathways.

**www.skylight.org.nz**
A website that supports people of all ages facing a tough life situation of change, loss, trauma or grief—whatever the cause.

**For head injury information & support**

**Brain Injury Association — Headway:** 09 520 4807

**THINK! The Head Injury Network for Kiwis:**
07 839 1191
www.thinknz.org.nz/
www.facebook.com/THINKHeadInjuryAwarenessNZ

**Brainline:** www.brainline.org/

**CEMM TBI:** www.traumaticbraininjuryatoz.org/

**Other useful contacts**

**Lifeline:** 24/7 helpline 0800 543 354

## Panel 4 (bottom right)

**www.youthline.co.nz**

**Youthline: 0800 37 66 33**

Youthline
Changing lives.
0800 37 66 33
Free txt: 234
talk@youthline.co.nz

You can call the Youthline Helpline **for free 24 hours a day,** 7 days a week.
They also respond to TXT messages from 8am-midnight every day.

**www.whatsup.co.nz/**

**0800 What's up: 0800 942 8787**

0800 WHATS UP?

0800 What's Up is a **free** counselling service just for kids.  So if you need support or someone to talk to, you can give them a call for free. **Lines are open every day from 1pm-11pm.**

**www.kidsline.org.nz**

**0800 Kidsline: 0800 54 37 54**

0800 kidsline
It helps to talk.

Kidsline is a free counselling service for all kids up to 14 years old.  **You can call Kidsline for free, Monday to Friday, from 4pm-6pm.** All the counsellors at Kidsline are secondary school students.

**If you need someone to talk to, you can call…**

# Appendix L: Certificate of Appreciation



**Hearing from children**

## When mum or dad has a brain injury

### Certificate of appreciation

awarded to

_____

in recognition of your important contribution as a participant in this study.

By taking part in this research study, you have helped us to know what it is like for children when a parent has a brain injury.  We hope to use this information to try and help other children and families in the future.

Thank you so much for sharing your story with us.

Alexis Channon    Nicola Kayes        Tineke Water

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