Understanding Families after Traumatic Brain Injury: Family processes and structures over the long-term

Michelle McIntyre

MEd

School of Human Services and Social Work

Menzies Health Institute Queensland

Griffith University

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Statement of Originality

I declare that this work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed)_____________________________

Michelle McIntyre

October 22, 2015
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Publications Arising From or Related to This Thesis

Abstract

This study explored the family response to adult traumatic brain injury (TBI), specifically investigating the long-term experience of TBI from the perspective of families. Families of people with TBI are a vital resource for the injured person and society. Yet paradoxically, rather than being assisted to fulfil this important role, inadequate family supports mean family members often become reliant on health, housing and social services themselves.

Despite the abundance of research indicating the profound ongoing impact of TBI on families, services still fail to meet the needs of families. No qualitative studies have explored the long-term experiences of the family system after TBI. The processes families engage in to manage TBI over the long-term are poorly understood, and the family perspective underrepresented. Understanding the long-term experiences of TBI from the family perspectives are crucial for determining how to better assist families, through appropriate supports at optimal times in ways that build on family strengths and resources. It is this knowledge, to be gained from the experiences of families, which is required to guide the development of effective and timely supports, and move from crisis management to crisis prevention.

When seeking to understand the perspectives of participants, and when the topic under investigation is poorly understood, qualitative research methods are desirable. This qualitative study was underpinned by the theory and methods of constructivist grounded theory, which was seen as the most appropriate method for developing a theory about the long-term family experience of TBI. The study aimed to answer the questions:

1) What is the long-term experience of families following TBI? and;

2) How did families respond to TBI, and what processes did they engage in to manage over time?
From a sample of participants who engaged in a previous study conducted between 2001 and 2003 (Study 1), six families were recruited to participate in the current study (Study 2). Families participated in in-depth family interviews. Analysis of the interview data revealed that families had engaged in two core processes in order to manage TBI, namely the process of reconnecting and reinventing; and the process of making the unbearable bearable. Three clusters of families were identified, defined by the way in which they handled these processes and sub-processes over time.

In addition to identifying these processes, four other important conclusions were drawn. First, results showed that early family responses were maintained over time, underscoring the need for effective early intervention. Second, recovery and family adaptation was ongoing, indicating the importance of continued support. Third, families can be strengthened or weakened by the experience of TBI depending on internal and external factors, and fourth, the response of individual family members has implications for all family members and for the family unit as a whole.

Although limited by small numbers, the longitudinal family systems perspective of this study has brought new insights and important implications for rehabilitation. In particular, the findings confirm the critical role of the family in rehabilitation due to its reciprocal relationship with injured individuals and the extent to which a key family member takes on a primary case management role. The ability of the family to thrive following TBI is associated with the extent to which the individuals can maximise their outcomes. However, this ability to thrive depends on the presence of clear communication, shared views about the injury and an ability to manage the difficult contracting, recalibrating and reinventing processes that were identified in this study. Rehabilitation professionals need to be able to identify families at risk, support key family members to take on the role of informal case
manager, assist all family members with the processes of adaptation and recognise when to intervene or not.
# Table of Contents

Statement of Originality................................................................................................. ii  
Acknowledgements........................................................................................................ iii  
Publications arising from or related to this thesis.......................................................... iv  
Abstract........................................................................................................................... v  
Table of Contents............................................................................................................. viii  
List of Appendices........................................................................................................... xiii  
List of Tables.................................................................................................................... xiv  
List of Figures................................................................................................................... xiv  

Chapter 1: Background to Families and Traumatic Brain Injury............................... 1  

Traumatic Brain Injury................................................................................................. 1  

Injury severity and classification.................................................................................... 3  

Sequelae of TBI.............................................................................................................. 5  

Families and Traumatic Brain Injury............................................................................ 5  

The role of the family after TBI.................................................................................... 7  

Rehabilitation and home care....................................................................................... 7  

Accommodation and financial support........................................................................ 8  

Social support and community re-integration............................................................ 9  

The impact of TBI on the family.................................................................................. 9  

Burden studies............................................................................................................. 11  

Comparative family member impact studies............................................................ 12  

Family system studies............................................................................................... 13
The long-term impact of TBI ................................................................. 17
Qualitative research ................................................................. 18
Positive experiences after TBI .................................................. 19
Conclusion .................................................................................. 21
Chapter 2: Family Theory and Research ..................................... 22
Defining Family ........................................................................ 22
The Development of Family Theory .......................................... 24
Family Systems Theory ............................................................. 26
Family Stress Theory ................................................................. 28
Family Resilience .................................................................... 31
Conclusion .................................................................................. 33
The Current Study ..................................................................... 34
Research problem .................................................................... 34
Aim .......................................................................................... 35
Research questions .................................................................. 35
Chapter 3: Method and Procedures .......................................... 36
Theoretical Approach: Constructivist Grounded Theory .......... 37
Grounded theory ...................................................................... 37
Constructivist grounded theory .............................................. 39
Theoretical sampling ............................................................... 41
Constant comparison .............................................................. 41
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Design and Procedures</td>
<td>42</td>
</tr>
<tr>
<td>Sample and recruitment</td>
<td>42</td>
</tr>
<tr>
<td>Data collection</td>
<td>43</td>
</tr>
<tr>
<td>Study 1 interviews</td>
<td>43</td>
</tr>
<tr>
<td>Study 2 family interviews</td>
<td>44</td>
</tr>
<tr>
<td>Memos and reflective writing</td>
<td>48</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>48</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>49</td>
</tr>
<tr>
<td>Study 1: Thematic analysis</td>
<td>49</td>
</tr>
<tr>
<td>Study 2: Family stories and coding</td>
<td>50</td>
</tr>
<tr>
<td>Trustworthiness and Authenticity</td>
<td>52</td>
</tr>
<tr>
<td>The Families</td>
<td>53</td>
</tr>
<tr>
<td>Chapter 4: Results. The Family Response to TBI</td>
<td>61</td>
</tr>
<tr>
<td>Family 1 Brendan’s Family</td>
<td>61</td>
</tr>
<tr>
<td>Family 2 Alison’s Family</td>
<td>70</td>
</tr>
<tr>
<td>Family 3 Daryl’s Family</td>
<td>78</td>
</tr>
<tr>
<td>Family 4 Neville’s Family</td>
<td>85</td>
</tr>
<tr>
<td>Family 5 Nathan’s Family</td>
<td>92</td>
</tr>
<tr>
<td>Family 6 Ronald’s Family</td>
<td>100</td>
</tr>
<tr>
<td>Conclusion</td>
<td>106</td>
</tr>
</tbody>
</table>
Chapter 5: Results. Building a Theory of the Family Response to TBI

The Process of Reconnecting and Reinventing

The Process of Making the Unbearable Bearable

Contracting

Spatial contraction

Resistance to services

Temporal contraction

Emotional contraction

Resignation

Compartmentalising

Recalibrating

Humour

Hope

Determination

Positive focus

Conclusion

Chapter 6: Discussion and Implications

Review of findings

Family responses are maintained over time

Recovery and family adaptation is ongoing

Families can be strengthened or weakened by TBI
Appendices

Appendix A  Consent to Contact ................................................................. 194

Appendix B  Participant Information and Consent ....................................... 196

Appendix C  Assessment of Capacity to Consent ......................................... 201

Appendix D  Revocation of Consent ............................................................ 202

Appendix E  Family Interview Protocol Version 1 ......................................... 204

Appendix F  Family Interview Protocol Version 5 ......................................... 206

Appendix G  Risk Minimisation Strategy ....................................................... 208

Appendix H  Themes Study 1 ...................................................................... 209

Appendix I  Family Experience Interview Table ........................................... 211

Appendix J  Family Interview Reflection Sheet ............................................ 214

Appendix K  Family Interview Reflection Memo ........................................... 215

Appendix L  Transcript Coding: Initial Coding .............................................. 218

Appendix M  Case Analysis Memo ............................................................... 219

Appendix N  Comparative Analysis Memo ................................................... 221

Appendix O  Focussed Codes ..................................................................... 223

Appendix P  Procedural Memo ................................................................. 224
List of Tables

Table 1. Classifications of TBI Severity .........................................................4
Table 2. Interview Schedule ........................................................................44
Table 3. Inured Person Details ....................................................................59
Table 4. Family Details ...............................................................................60
Table 5. The Process of Reconnecting and Reinventing ..............................147
Table 6. The Process of Making the Unbearable Bearable ...........................148
Table 7. A Model of the Family Response and Implications .......................162

List of Figures

Figure 1. Incident Cases of TBI by Age and Gender Australia, 2008 .............2
Figure 2. Mechanism of Injury of TBI in Australia, 2006-2007 ....................3
Chapter 1: Introduction to Families and Traumatic Brain Injury

Traumatic brain injury (TBI) does not just happen to individuals, it happens to whole families. The impacts are sudden and permanent, and they affect all family members. Families are a vital source of support for people with TBI, but the lack of appropriate and effective assistance can lead to undue hardship and negative outcomes for families. Any family can be affected by TBI. TBI is relatively common in Australia, being ten times more prevalent than spinal cord injury (Khan, Baguley, & Cameron, 2003). The Australian Institute of Health and Welfare has reported a rate of 107 TBIs per 100,000 population in Australia (AIHW, 2007), with a total cost estimated to be $8.6 billion for financial and burden of disease costs (Access Economics, 2009). As more people survive their injuries the costs of care, loss of productivity, and social consequences increase (Foster et al., 2012).

To manage this enormous public health cost, the health system relies heavily on the informal support of families to assist people with TBI over their life-time. However, the pressures created by TBI mean families often experience emotional distress, and relationship breakdown, creating further demands on services. There is a reciprocal relationship between family functioning and the injured person’s outcome, with each affecting the other, underscoring the need for supports targeting the entire family system, not just individuals (Maitz & Sachs, 1995; Schönberger, Ponsford, Olver, & Ponsford, 2010). The provision of timely supports that build family capacity to adapt to TBI, and assist families to fulfil their supportive role is crucial.

Traumatic Brain Injury

TBI is also known as a closed head injury, and has been defined as “an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma” (Kay & Lezak, 1990). TBI is an acquired brain
injury (ABI) which means it is sustained after birth, and is distinct from other incidences of ABI in that it is not the result of illness such as stroke, tumours or other neurological disorders, but rather due to sudden external force. In Australia, TBI is experienced most frequently by young males between the ages of 15-24 (Figure 1). The most common cause of TBI in Australia is motor vehicle accidents, followed by falls, strikes or collisions with objects, and water related accidents (Figure 2) (Access Economics, 2009). The high incidence of TBI in young males, and mostly related to motor vehicle accidents, is reflective of world trends. TBI changes lives instantly and permanently, usually resulting in the need for some form of formal and/or informal support for the rest of the injured person’s life.

Figure 1. Incident cases of TBI by age and gender Australia, 2008 (Source: Access economics, 2009).
Injury severity and classification.

TBI severity ranges from mild to severe, with severity classified through a variety of measures. 75% of all TBI’s are classified as mild, and can involve loss of consciousness from 0-30 minutes, with symptoms usually temporary and typically resolved within three months. Moderate to severe TBI involves longer periods of loss of consciousness, and can result in a range of permanent physical, cognitive, emotional and psychological sequelae. Although consensus is lacking regarding a definitive indicator of TBI severity, indices used for documenting TBI severity include: Length of Post-traumatic Amnesia (PTA; Russell, 1932); Length of Loss of Consciousness (LOC); the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974); and the Rancho Los Amigos Levels of Cognitive Functioning (LOCF; Hagen & Malkmus, 1972) Scale (see Table 1). The GCS is the most widely recognised neurological assessment of TBI severity, and is typically administered at the time of the injury. An assessment is made of the injured person’s ocular, verbal and motor responses and a score given out of 15.
A score of 13-15 is classified as a mild TBI or concussion; with 8-12 classified as moderate, and below 7 as severe. Zhang and colleagues (2001) extended the GCS scale to include very severe. The GCS was not developed specifically for use with TBI, and problems with its application in this context have been noted (Green, 2011; Zuercher, Ummelhofer, Baltussen, & Walder, 2009). The Rancho LOCF scale uses an eight point assessment scale used to determine cognitive and behavioural functioning post coma, and is often used in conjunction with GCS.

Table 1

*Classifications of TBI Severity*

<table>
<thead>
<tr>
<th>Classification</th>
<th>PTA</th>
<th>LOC</th>
<th>GCS Teasdale (1974)</th>
<th>GCS Zhang (2001)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Mild</td>
<td>&lt; 5 minutes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>5 - 60 minutes</td>
<td>0-30 min</td>
<td>13-15</td>
<td>13-15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>minutes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>1 - 24 hours</td>
<td>&gt;30 min to &lt;24 hours</td>
<td>9-12</td>
<td>9-12</td>
</tr>
<tr>
<td>Severe</td>
<td>1 - 7 days</td>
<td>&gt;24 hours</td>
<td>3-8</td>
<td>6-8</td>
</tr>
<tr>
<td>Very Severe</td>
<td>1 - 4 weeks</td>
<td></td>
<td></td>
<td>3-5</td>
</tr>
<tr>
<td>Extremely Severe</td>
<td></td>
<td></td>
<td></td>
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</table>
Sequelae of TBI.

Traumatic brain injury involves a broad range of consequences depending on injury severity and location, as well as other factors. People with TBI typically experience a range of physical, cognitive, psychological, behavioural, and social impacts. Symptoms of TBI commonly include impaired memory and judgement; difficulty with concentration, decision-making and problem-solving; and changes to personality and behaviour (Thompson, 2009). Chronic pain, usually in the form of headaches, is experienced by at least 50% of people with TBI (Lahz & Bryant, 1996). Although physical impairments can pose barriers to work and social inclusion what people report as most disabling are the personality, cognitive and behavioural changes, which can result in an altered sense of self. Problems with working memory, attention and concentration, and executive function often mean people are unable to resume pre-injury employment. Personality and behaviour changes including anger and poor impulse control typically cause conflict in existing relationships, and hinder the formation of new relationships. Friendship networks tend to diminish so social isolation is common. Although in some cases injury symptoms are easily observed, in others they are less obvious, adding to the feeling of being misunderstood by others. Ongoing challenges relating to community integration and psychological adjustment make everyday life following TBI more complex (Fuchs, Crawford, & Milders, 2003; McCabe et al., 2007). Barriers to the resumption of employment, and diminished social and financial resources create further stress and burden for people with TBI. The presence of family support is vital to managing these symptoms and side effects.

Families and Traumatic Brain Injury

Families of people with TBI are generally expected to assume responsibility for the life-long needs of the injured family member (Gan & Schuller, 2002; Kosciulek &
Lustig, 1999; Verhaeghe, Defloor, Grypdonck, 2005), often in the absence of adequate professional support (Degeneffe, 2001). Families typically provide significant emotional, social, financial and daily living support (Gan & Schuller, 2002). Indeed, health and social services rely on this on-going contribution. However, families are challenged by TBI in multiple ways, which can undermine their capacity to maintain this supportive function. TBI changes roles and relationships within the family, altering family dynamics. The ability of the family to manage these sudden changes impacts the entire family unit, and the family response has on-going reciprocal impacts on individual family members. Families often struggle to cope, leading to fractured relationships, diminished capacity for long-term family involvement, and increased pressure on health and social services. It is vital that families are supported to successfully negotiate the challenges of TBI, avoiding family crises, negative outcomes, and further demand on services.

It has been noted that although there is an abundance of research highlighting the profound effect of TBI on families, there is inadequate support available for families, particularly over the long-term (Degeneffe & Bursnall, 2015; Kolakowsky-Hayner, Miner, & Kreutzer, 2001). Services report high levels of family crisis after TBI, and a lack of effective strategies for engaging and supporting families (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007; Bowen, Yeates, & Palmer, 2010; Foster et al., 2012). However, the family perspective has not been adequately reported, particularly over the long-term. The ways in which families manage over time is poorly understood. This knowledge, held by the families who have lived the experience of TBI, is crucial to finding effective, appropriate and timely supports for other families facing this situation. A deeper understanding of the family experience of TBI is needed to inform more
effective service provision for this population, to minimise suffering and to maximise family potential for the continued support of their injured family member.

**The role of the family after TBI.**

Understandings of the meaning of “family” have broadened over time to increasingly recognize diversity and pluralism (Holstein & Gubrium, 1999). The concept of family has been further explored in Chapter 2, but refers to the inner circle of supports who mobilise to “influence recovery” (Foster et al., 2012). Families typically fulfil a multitude of functions which are beneficial to the injured person and society. When someone sustains a TBI, the family can be “the most powerful and enduring influence” on their lives (Krauss & Seltzer, 1993, p.18, cited in Frain, et al., 2007). Families offer support in multiple ways, contributing to positive outcomes for the injured person and constituting a vital resource for health and social services. These supports are explained below.

**Rehabilitation and home care.**

Families are an essential part of the rehabilitation process, and family engagement in rehabilitation has been shown to improve outcomes for the injured person (Braga, da Paz Junior, & Ylvisaker, 2005; Chua, Ng, Yap, & Bok, 2007; Sherer et al., 2007). Many families wish to care for their loved one at home and, for many people who sustain a TBI, returning to the family home is the most desirable outcome at the completion of inpatient care. The circumstances of home care encompass a variety of living arrangements depending on the stage of the family, and the family structure. These include for example, a spouse or de-facto moving back with their partner (with or without children); a younger adult moving back to their family of origin (with parents and/or siblings); or an older adult moving in with adult children. Home care has emotional and social benefits for the individual and family, and economic benefits for
the health system. Although many families choose to take on responsibility for the long-term care of their injured loved one, home care can increase pressure on families. Primary carers commonly experience social isolation, the inability to continue working, and anxiety and depression (Perlezsz, Kinsella, & Crowe, 2000). Levine (1999) underscored the importance of carers stating “family caregivers must be supported, because the health care system cannot exist without them. Exhausted caregivers may become care recipients, leading to a further, often preventable, drain in resources” (p.1559). Carers may have less time for other family members, and others may have to take on different roles and responsibilities, impacting on the entire family (Anderson, Parmenter, & Mok, 2002; Degeneffe, 2001).

**Accommodation and financial support.**

People with TBI often become financially dependent on family due to diminished financial resources after their injury. A significant shortage of affordable and appropriate housing for people with disabilities has been identified in Australia (Bleasdale, 2007), and “there is no national framework to coordinate flexible delivery of housing and support services for people with different types of disabilities” (Saugeres, 2011, p. 2). Living with family is often the only viable option for people with TBI, although this can be challenging for families, and may precipitate family crises and relationship breakdowns. Financial hardship can contribute to the challenges families encounter. TBI can have a significant impact on the financial circumstances of the entire family, not just the injured person. Homes may need extensive and costly modifications where physical impairments are present. Finances may also be diminished if the injured person was the main income earner, or if carer responsibilities inhibit participation in employment. Indeed, in Australia it has been found that households that include a person with a disability experience higher rates of poverty than non-disability
households, and hardship is more prevalent (Saunders, 2006). Depleted financial resources can mean families are unable to maintain mortgages, and have to rely on rental or social housing. The Australian Housing and Urban Research Institute reported that home ownership was less likely to be found in households where a disability was present and, instead, these households were more likely to rely on social housing than households where there was no disability (Beer, 2008).

**Social support and community re-integration.**

Social support has been identified as a significant contributor to wellbeing for people following TBI, and families are usually the most significant provider of this support (Sady et al., 2010). Research has long indicated an increasing reliance on family, rather than friends, for social support over time (Kozloff, 1987; Oddy, Coughlan, Tyerman, & Jenkins, 1985). However, family members can face social isolation themselves due to factors such as reduced leisure activities resulting from carer responsibilities; disinclination to socialise because of access difficulties, or fear of unpredictable behaviours in the injured person; and a tendency for extended family and friend networks to diminish (Ergh, Hanks, Rapport, & Coleman, 2003). Families have also been shown to improve community re-integration for people with TBI. Community reintegration has been defined as “the opportunity to have a place to live, maintain a social network and be engaged in productive activity” (Lefebvre, Cloutier, & Levert, 2008), which is beneficial to the injured person, the family, and the community (Chelboun & Hux, 2011; Flanagan, 1998; W instanley, Simpson, Tate, & Myles, 2006).

**The impact of TBI on the family.**

As shown above, people with TBI rely on their families for support, and the health system needs families to provide this support. However, the changes and challenges experienced by the entire family after TBI can undermine the ability of
families to function. TBI presents a sudden disruption in life continuity and family dynamics, which profoundly impacts on the ability of the family to adjust (Cavallo & Kay, 2011). Changes in relationships, stresses associated with personality and behaviour changes in the injured person, loss of income, and diminished social networks all create stress, and contribute to altering established organisational and communication patterns within families (Larøi, 2003). Families need to adjust to these changes in order to continue functioning. However, adjustment is a complex process, presenting some unique challenges as families re-negotiate roles and routines. Unlike stroke or dementia, which primarily affect the elderly, the prevalence of TBI in young adult males means affected families are often in the early stages of their development, and less equipped to adjust (Cavallo & Kay, 2011; Moore, Stambrook, & Peters, 1993). Alternatively, the families of origin have adapted to later stages of life without dependent children and are often cast back into an early stage of development. Friction in family relationships, which often follows TBI, can result in distress and illness for family members, inhibiting relatives’ capacity to support the injured person. Indeed, research has consistently indicated that the distress resulting from TBI was as great for family members as for the injured person (Brooks, 1991; Gan & Schuller, 2002; Kosciulek & Lustig, 1998). In the face of the myriad of challenges associated with TBI, many families struggle to manage, resulting in fractured relationships and diminished capacity for long-term family involvement in rehabilitation and care (Ergh, Rapport, Coleman, & Hanks, 2002). This crisis within the family system results in increased pressure on services when families reach breaking point, despite their best intentions.

There is a significant body of research spanning the early 1970s to the present investigating the impact of TBI on families. Wade and colleagues (2002) categorized this family outcomes research into the three broad classes of (1) injury-related burden;
(2) caregiver psychological distress and (3) family functioning. Whereas the injury-related burden literature focussed on injury characteristics (such as injury severity and neurobehavioral symptoms), caregiver distress and family functioning studies acknowledge a range of internal (such as coping styles, relationships, and communication patterns) and external (such as social and financial resources and supports) non-injury related influences on outcomes. The following summarises the extant research investigating families and TBI, outlining the dominant lines of enquiry and noteworthy findings.

**Burden studies.**

The earliest research involving the family members of people with brain injury emerged in the early 1970s. Kay and Cavallo (1991) noted an individual focus in the early research, with families initially participating in research as “windows” into the injured person. In a number of studies, family members provided information on changes and deficits deemed to be beyond the capacity of the injured person to accurately understand and describe (Bond, 1976; Hopay, 1970; Oddy et al., 1985). Other research in the 70s and 80s focussed directly on family members, predominantly investigating the subjective burden and psychological distress experienced. Notable was the work generated by Brooks, Livingston, McKinlay and colleagues (the Glasgow group). These studies examined the impact of injury severity and neurobehavioral symptoms on the family, and stress and depression in carers and other family members. A number of studies concluded that the significant burden for families derived from emotional, behavioural and personality changes in the injured person, rather than cognitive or physical disabilities (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986, 1987; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978; Thomsen, 1974). Neurobehavioral symptoms such as impulsivity,
disinhibition, and anger were associated with the greatest perceived burden (McKinlay et al., 1981; Oddy et al., 1978), and the impacts were found to increase over time (Brooks et al., 1986; Brooks & McKinlay, 1983). Similarly other studies concluded that, in the long-term, character changes in the injured person were the greatest cause of stress for families, with many reporting a sense that their loved one had become a stranger (Lezak, 1978; Mauss-Clum & Ryan, 1981). Later studies reported that behavioural problems and personality change were consistently found to have had the greatest impact on caregiver and family functioning (Allen, Linn, Gutierrez, & Willer, 1994; Anderson et al., 2002; Kreutzer, Gervasio, & Camplair, 1994; Ponsford & Schönberger, 2010). Family appraisal of the neurobehavioral status of the injured person was found to be a stronger predictor of family outcome than neuropsychological test results (Serio, Kreutzer, & Gervasio, 1995).

**Comparative family member impact studies.**

A number of studies have investigated the impact of TBI according to the relationship to the injured person, and carer status. Broadly, primary caregivers (usually women) have been shown to experience greater stress than non-carer relatives, which tends not to decrease over time (Degeneffe, 2001; Douglas & Spellacy, 1996; Kreutzer, Marwitz, & Kepler, 1992; Perlesz et al., 2000). Carers often reported social isolation, and concomitant anxiety and depression (Ergh et al., 2003; Ergh et al., 2002; Mauss-Clum & Ryan, 1981). Wives of severely brain-injured soldiers reported depression and changed life patterns (Rosenbaum & Najenson, 1976). For men, who were more likely to be secondary or tertiary carers, distress was more commonly reported in terms of anger and fatigue (Perlesz et al., 2000). Marital relationships have been shown to be more negatively impacted than those of parents and children (Gervasio & Kreutzer, 1997), with marriages frequently ending in divorce (Parente, DiCesare, & Parente,
1990). Spouses report dissatisfaction with the role of carer, perhaps due to the incompatibility of this role with that of sexual partner (Bowen et al., 2009). Comparing the experiences of parents and spouses of people with a TBI, Allen et al. (1994) found parents to be more concerned for their loved one’s future, whereas spouses reported more negative emotional responses. Wives of men with TBI were more depressed than wives of men with spinal cord injuries (Rosenbaum & Najenson, 1976). The perception in adult siblings of people with TBI that the injury resulted in restrictions to family activities and reduced access to social support was found to be correlated with higher levels of sibling depression (Degeneffe & Lynch, 2006).

**Family system studies.**

In has been noted that the majority of family and TBI research, particularly the formative studies, focused on reports of individual experiences and outcomes (Cavallo & Kay, 2011). Later lines of enquiry, in contrast, were reflective of broader shifts in health and illness research from an individual to a systems perspective (Boschen et al., 2007; Cavallo & Kay, 2011; Maitz, 1991; Williams & Kay, 1991). TBI research from a family systems perspective recognised the interdependencies between family members, and how changes in one member of the system affected the entire system (Gan, Campbell, Gemeinhardt, & McFadden, 2006), underscoring the need for whole-of-family support after TBI (Degeneffe, Gagne, & Tucker, 2013; Larøi, 2003; Maitz & Sachs, 1995; Rolland, 2012). This line of research examined the ways in which TBI altered family roles, relationships, and social status (Cavallo & Kay, 2011), with a focus on family functioning and family stress, coping and adaptation. The research drew on concepts and models from general family theory, which are elaborated in Chapter 2.

Studies conducted by Rosenbaum and Najenson (1976) and Mauss-Clum and Ryan (1981) investigating the experiences of wives of men with TBI were precursors to
the family system studies (Kay & Cavallo, 1991). Kay and Cavallo (1991) described Kozloff’s (1987) study using a social network analysis as the turning point in TBI research towards a systemic perspective. Much of the TBI research reflecting a family systems framework included measures of family functioning, which was defined as the ongoing capacity of the family to cope with stressors and meet the needs of the family collectively. A number of studies have assessed family functioning after TBI to determine the impact of TBI on family systems, and to predict factors likely to undermine healthy family functioning after TBI. This research was motivated by the consistent finding of increased rates of unhealthy family functioning after TBI (Anderson et al., 2002; Ergh et al., 2002; Gan & Schuller, 2002; Testa, Malec, Moessner, & Brown, 2006), even up to 25 years post-injury (Schönberger et al., 2010).

A range of factors that predict poor family functioning have been identified including behaviour changes in the injured person (Kreutzer et al., 1994; Ponsford, Olver, Ponsford, & Nelms, 2003; Schönberger et al., 2010), cognitive issues (Ergh et al., 2002; Machamer, Temkin, & Dikmen, 2002) and the injured person’s level of integration into the community (Winstanley et al., 2006). The importance of social support as a buffer for some of the negative impacts of TBI on the family system has also been highlighted (Ergh et al., 2002).

Researchers have applied general models of family stress, coping and adaptation to the context of TBI. These models have been used to predict the way families are likely to respond to a traumatic event based on intrinsic and extrinsic factors. Variables such as the life stage of the family, the nature of stressors, and family characteristics including bonding and communication patterns, flexibility, family schema, stress response, coping capabilities, and internal and external resources were shown to be associated with family adaptation. Research conducted by Kosciulek and colleagues
(Kosciulek, 1994, 1997a; Kosciulek & Pichette, 1996) over two decades ago investigated coping variables including positive appraisal, resource acquisition, family tension management, head injury demand reduction, and acquiring social support in relation to family adaptation. Positive appraisal and family tension management were found to be predictive of family adaptation. In a more recent study, Carnes and Quinn (2005) investigated family adaptation to the role of caregiver, using the Family Adjustment and Adaptation Response (FAAR) model (McCubbin & Patterson, 1983b). Variables found to influence family adaptation included social support, increased financial resources, coping skills and re-framing, and those that added to distress included emotional and behavioural changes in the injured person, and concerns regarding insurance.

In another study Kosciulek (1997b) investigated the relationship between family schema (world view about their situation) and family adaptation. The ways families viewed the injury was found to affect family adaptation, with manageability and meaningfulness found to predict family adaptation. Kosciulek (1996) used Olson’s (1993) circumplex model of marital and family systems as a framework for investigating brain injury family types. Consistent with the model, more balanced families displayed higher levels of positive communication, which facilitated greater flexibility and ability to adapt. A later study investigated the nature of the variation across three different family types (balanced, mid-range and extreme) (Kosciulek & Lustig, 1999). Results indicated that differentiation was most significant in the factors of affective and cognitive functioning of the family members with brain injury, family adaptation, and primary caregiver age. Also focusing on family types, Moore and colleagues (1993) investigated the impact of TBI on the family from a family development perspective. Underpinned by the family life cycle model (Carter &
McGoldrick, 1989) the study highlighted the unique challenges faced by younger developing families when the husband sustained a TBI, particularly when there were financial pressures. Curtiss and associates (2000) also used the Circumplex model (Olson, 1993) in a study of family adaptation in the acute stage post-injury, with results again being consistent with the model in that significant changes in coping styles and family structure were found post-injury, and pre-existing family structure impacted outcomes (Cavallo & Kay, 2011).

The resiliency model of family stress adjustment and adaptation (McCubbin, Thompson, & McCubbin, 1991) underpinned Kosciulek and Lustig’s (1998) assessment of the relationship between TBI-related family stress and family adaptation. The resiliency model was viewed as a useful framework for understanding the family system response to brain injury related stress (Kosciulek, McCubbin, & McCubbin, 1993).

Stressors were identified as follows (Kosciulek & Lustig, 1998, p. 9):

(a) The brain injury and related hardships over time.
(b) Normative family cycle transitions such as graduations and marriages.
(c) Prior strains accumulated over time.
(d) Situational demands and contextual difficulties such as the transition to service systems.
(e) Consequences of family efforts to cope such as the handling of anger and grieving.
(f) Intra-family and social ambiguity such as the lack of understanding by friends and disruptions to the family structure.

The study concluded that persistent emotional and behavioural problems in the person with TBI were a major stressor for families and predictive of poor family functioning. The “pile-up” of stressors on families was significant. Positive family adaptation was
seen as the process of re-balancing within the family system allowing for organisation and unity, and promoting growth and development (Kosciulek & Lustig, 1998).

**The long-term impact of TBI.**

TBI research and support services typically focus on the acute and early reintegration phases of recovery, usually up to two years post-injury. The consequence of this situation is that experiences beyond the acute rehabilitation phase are poorly understood, and families are left to cope largely without professional support (Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). However, rather than remaining stable, family adaptation to TBI is subject to considerable change over time, and the early impacts do not diminish (Verhaeghe et al., 2005). Relationship strain and social isolation of the injured person and relatives have been identified as on-going problems for more than ten years post-injury (Lewin, Marshall, & Roberts, 1979; Oddy et al., 1985; Thomsen, 1984). Normative changes in the family life course such as school transitions, marriages, and deaths in the family can also exacerbate existing stresses within the family.

The ongoing social, cognitive, behavioural and emotional sequelae of the TBI may become more apparent to families over time (Moore et al., 1993; Verhaeghe et al., 2005). For instance, early research conducted by Brooks et al. (1986) determined that family stress resulting from personality and behavioural issues in the injured person were greater at five years post-injury than they were three, six, and twelve months post-injury, and that families continued to experience burden after seven years post-injury (Brooks et al., 1987). A review of stress and coping in families after TBI found significant on-going stresses in families, and called for professional intervention for families up to ten to fifteen years post-injury, concluding that “every attempt should be made to develop models of long-term support and care that alleviate sources of burden”
(Verhaeghe et al., 2005). For families affected by TBI, adaptation is a life-long process, clearly requiring long-term follow up services to support them to “cope with the problems that evolve over time” (Lefebvre et al., 2008, p. 542). Although it is clear that families face life-long challenges, research has tended to emphasise the early recovery and reintegration stages (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005). The ways in which families manage the impacts of TBI over the long-term is poorly understood. This research gap means that family experience and knowledge remains untapped, and families’ long-term needs are often unmet.

**Qualitative research.**

The majority of TBI family studies are quantitative, with relatively few qualitative explorations of the experience of TBI. When qualitative studies have been conducted the focus has largely been on individual family member experiences such as caregivers (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010), parents (Roscigno & Swanson, 2011), spouses (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011), and other relatives (Jumisko et al., 2007; Lefebvre & Levert, 2012). Some qualitative studies have explored specific issues such as the experience of trauma in families after TBI (Perlesz, 1999), the impact of challenging behaviour for relatives (Braine, 2011), the effect of irritability on family relationships (Hammond, Davis, Cook, Philbrick, & Hirsch, 2012), partner intimacy (Gill, Sander, Robins, Mazzei, & Struchen, 2011), family experiences of the care continuum (Keenan & Joseph, 2010; Lefebvre et al., 2005), the transition to home (Nalder, Fleming, Cornwell, & Foster, 2012; Robson, Ziviani, & Spina, 2005), and social networks (Chelboun & Hux, 2011; Lefebvre et al., 2008). The work conducted by Lefebvre and colleagues investigating family experiences of the care continuum (Lefebvre et al., 2005), and perceptions of long-term social integration (Lefebvre et al., 2008) are rare examples of qualitative research that
examines the long-term experience of TBI. This work highlights the importance of the inclusion of entire families in ongoing care processes, and the need for qualitative accounts of care experiences (Lefebvre et al., 2008).

Qualitative studies explicitly investigating the family system following TBI are rare. In one study that investigated the impact of TBI on the family system from the perspective of adult siblings (Degeneffe et al., 2013), siblings reported both positive and negative impacts on their families. Klonoff and colleagues (2008) drew on family interviews to describe the experiences of families in different phases after TBI, from acute, to rehabilitation, to home. Another study used semi-structured family focus groups to investigate families’ perceptions of their needs and service gaps (Leith, Phillips, & Sample, 2004). There was consensus on the need for early, continuous, comprehensive service delivery; information/education; formal/informal advocacy; empowerment of persons with TBI/families; and human connectedness/social belonging. However, this study focused on participants who were less than five years post-injury. No qualitative studies have explored the long-term experiences of the family system after TBI. Understanding the long-term experiences of TBI from the family perspective is crucial for determining how to better assist families, through appropriate supports at optimal times in ways that build on family strengths and resources.

**Positive experiences after TBI.**

For some time now, a small number of researchers have noted an emphasis in TBI family research on negatives such as burden and distress (Adams, 1996; Kosciulek, 1994; Perlesz, Kinsella, & Crowe, 1999; Ridley, 1989). Although crisis is understandable and common following TBI, families also exhibit strengths and may encounter positive outcomes and experiences that have been largely overlooked in the
current literature (Kendall & Terry, 2008; Machamer et al., 2002). Consequently, little is known about “positive emotions, resilience, or instances when depression does not occur” (Bowen et al., 2010, p. 285). Kosciulek and Lustig’s (1998) application of the resiliency model to TBI is one of the rare instances where positive processes have been investigated in relation to families and TBI. There have been some reports of positive experiences for families after TBI (Dell Orto & Power, 2000; Machamer et al., 2002; Rees, 2011). For instance, in a study investigating significant-other burden, 60% reported their overall experience as being more positive than negative, and 93% were reportedly happy to be able to care for their loved one (Machamer et al., 2002). Similarly, an early study conducted by Knight, Devereux and Godfrey (1998), revealed that many of the negative reports from primary caregivers were balanced by comments expressing resolve in the face of adversity, improvements in spousal relationships, and descriptions of caregiving as being uplifting. A recent study of adult siblings of people with brain injury found negative and positive impacts, with aspects of caring about their injured sibling, and the process of making sense of the experience resulting in a positive appraisal of their circumstances (Degeneffe & Olney, 2010). However these examples are the exception and positive findings have usually emerged incidentally from research focused on other facets of TBI, typically emphasising family burden and dysfunction. It has long been noted that the tendency to focus on deficits and difficulties following TBI means that positive processes in which families engage to cope over time have been largely ignored (Ridley, 1989). Existing research has provided invaluable insights into the challenges facing people with TBI and their families. However, the emphasis on family crisis and dysfunction means that understandings of healthy family adaptation remain elusive (Rolland, 2012), and knowledge of the family experience of TBI incomplete.
Conclusion

Families typically play a major role in the rehabilitation and life-long care of people with TBI, as well as providing housing, and assisting in community reintegration. Family support is particularly important over the long-term when support services and external social networks for the injured person tend to decrease. Healthy family functioning after TBI is crucial for the wellbeing of the entire family, and health and social services depend on the families’ capacity for life-long support. However the myriad of impacts associated with TBI put strain on families, and change family dynamics in complex ways. The result can be unhealthy family functioning, poor outcomes for all family members, and family crises, which ultimately diminish the capacity of the family to support the injured person.

Despite the abundance of research indicating the profound ongoing impact of TBI on families, services still fail to meet the needs of families (Frain et al., 2007; Larøi, 2003). Services tend to focus on the injured person, and even when family members are considered, this tends to be in the form of education or individual support (Boschen et al., 2007). Interventions that acknowledge and support the family as a system are rare (Larøi, 2003) (see Charles, Butera-Prinzi, & Perlesz, 2007; and Klonoff, Koberstein, Talley, & Dawson, 2008 for examples). In the context of the current client-centred approach to health care delivery in Australia, more than ever, the experiences and perspective of service users must be incorporated into the development and delivery of rehabilitation services (Hammell, 2007). Further, most family research is short-term, and quantitative, with relatively little research based on knowledge drawn from families’ lived experiences. As a result, little is known about how families experience changes in family dynamics, the processes families engage in to manage TBI, and what strengths and capacities emerge to assist families over the long-term.
Chapter 2: Family Theory and Research

The purpose of this chapter is to elaborate the concepts relating to family theory and research introduced in Chapter 1. It is not intended to be an exhaustive review of sociological family theory, but rather to provide an historical context to the family dynamics and family intervention literature discussed.

Defining Family

The meaning of “family” in contemporary Western society is contested, and ideas about what constitutes a “normal” family are not easily defined (Holstein & Gubrium, 1999; Walsh, 2011). Family life and conceptualisations of family have evolved over time. Walsh (2011) noted the “diversity and complexity” of contemporary families, and underscored the need for current definitions to be “expanded to encompass a broad spectrum and fluid reshaping of relational and household patterns” (p.3). Families can be made up of varying structures (including family of origin; marital; cohabitative; and blended), and members (including parents, siblings, children, spouse, or significant others). In a framework originally developed by Koerner and Fitzpatrick (2004), and advanced by (Weigel, 2008) definitions of family have been categorised to reflect the three broad perspectives of structural; functional and transactional definitions. Structural definitions refer to the presence or absence of family members, such as Stephens (1963) definition of family as:

- a social arrangement based on marriage and the marriage contract, including recognition of the rights and duties of parenthood, common residence for husband, wife and children, and reciprocal economic obligations between husband and wife (p.4).

Functional definitions allude to the psychosocial tasks and roles enacted within families primarily to fulfil societal functions such as raising and socialising children.
Transactional definitions are based more on the relational aspect of family life and describe the family in terms of identity, shared history and emotion (Koerner & Fitzpatrick, 2004). Donalek (2009) suggested that any meaningful definition of family should reflect what family does rather than being based on structural parameters. She drew on ideas raised by Stuart (1992) and Daly (2003) to define family as:

…a self-defined social unit whose members may be biologically or legally related and live together and who have a shared reality and ongoing formation of meaning as part of that communal character; commitment to the security and socialisation of members; boundaries that maintain identity and privacy; activities that create shared memories; labour that may provide collective support; and finally, action towards the goal of sustainability (Donalek, 2009, p. 22)

This definition suggests a dynamic view of the family and points to a constructivist notion of the family as a unit of co-creation and meaning-making, also underscoring the affective and supportive aspect of family function. Weigel (2008) pointed out that some scholars have contested the notion that family can be formally defined, countering that family is a socially constructed and fluid concept (Holstein & Gubrium, 1999), and is most appropriately defined in terms of the meaning, language and lived experience of laypersons (Bernardes, 1999). Weigel’s (2008) investigation of lay conceptions of family indicated a more diverse and complex definition of family than reflected in scholarly definitions, with affective features such as love, support, respect, acceptance and caring viewed as being central to the concept. Similarly, Daly (2003) distinguished between family theory created by scholars and the implicit theories generated through the lived family experience.
The Development of Family Theory

Doherty and colleagues (1993) noted that family theory is “simultaneously about social science theory; methodology; application in the realms of education, clinical practice and public policy; and the social and moral dilemmas of our time” (p.3). There is no one theory of the family, but rather “a multiplicity of theories that have informed our understanding of the function of family as shaped by culture, class, and historical context” (Dore, 2008, p. 431). Dore (2008) traced the evolution of family theory, noting its emergence around the turn of the 20th century in response to the changing role of the family at this time. The work of social philosophers such as Auguste Comte (1853) and Emil Durkheim (1902/1960), who examined the roles played by families and the interdependencies between families and society, informed what became known as structural-functionalist theory. A structural functionalist view of society posits that societal structures such as the family and the state, must work together in order to function as a whole (Dore, 2008). Later, American theorists such as George Murdock (1949) and Talcott Parsons (1955) refined structural-functionalist theory as it applied to the family, and advocated the nuclear family structure of two parents and children as the most desirable and beneficial for society. The family was seen as a social institution which was needed to perform particular functions for society. Families who failed in this role were classed as dysfunctional. Family function was for procreation and meeting the needs of the adults, with females meeting expressive needs, and males economic (Dore, 2008).

From the late 1950s to early 1960s, structural-functional theory declined in popularity, with critics arguing that it perpetuated an inherently unequal patriarchal system, and failed to “explain the existence of poverty, social change and social injustice” (Dore, 2008, p.433). An alternative view of the family was put forward by
social exchange theorists such as Blau (1964) who posited an individualised concept of human behaviour predicated on the principle of mutual benefit. Social interaction was seen to be governed by the exchange of rewards and costs, so families functioned on the basis of mutual advantage. Like structural-functional theory, social exchange theory was similarly attacked for its rigid and reductionist view of human interaction, and inadequate acknowledgement of the implications of power and inequality (Dore, 2008).

Symbolic interactionism was a sociological theory derived from pragmatism (Charmaz, 2006). The theory emerged primarily from the University of Chicago from the 1920s with the work of George Mead (1934) and Earnest Burgess, (1926, 1939), and later advanced by Herbert Blumer (1969) and other family researchers of the time. When applied to the study of families, symbolic interactionism allowed for a more flexible and nuanced understanding of family dynamics that the earlier theories (Dore, 2008), addressing the active processes through people derive meaning from their experiences. Symbolic interactionism focused on how individuals and groups interact and make meaning, and how these meanings affected behaviour. Blumer maintained that individuals reacted to their subjective interpretations of others’ actions, rather than the actions themselves, and that these interpretations are mediated by agreed upon symbols.

Dore (2008) noted that although the early family theories added value in terms of enhancing understandings of the role and function of the family in society, they were limited in their ability to explain how families functioned over time. It was only with the development of family systems theory that more comprehensive understandings of the “cognitive, social, and emotional functioning of individuals in society” (Dore, 2008, p.435) began to emerge. Family systems theory considered the entire family unit rather than individuals or dyads, such as parent and child. There was a focus on factors such
as family structure, family dynamics, roles and relationships, power relations, boundaries and communication patterns (Rothbaum, Rosen, Ujiie, & Uchida, 2002), all of which were seen to influence the way in which families adapted to change. In the health and rehabilitation context, family systems theory signified a theoretical framework that was supportive of family-centred approaches to clinical practice (Dore, 2008). The development of family systems theory is discussed below.

**Family Systems Theory**

Shifts in the Western conceptualisation of human behaviour from individualistic to systemic ways of thinking around the 1940s and 1950s influenced the direction of family research towards a new theory of the family as a system. Although the concept of systems had long been considered in terms of the natural and built environments, it was not until this time that human behaviour was considered from a systems perspective (Kerr & Bowen, 1988). Conceptualising the family as a system is a useful framework for understanding the reciprocal dynamics and interdependencies of family members, where “healthy family functioning is dependent on the functioning of each individual within that family system” (Gan et al., 2006).

The origins of Family Systems Theory can be traced to the General Systems Theory of Austrian biologist Ludwig von Bertalanffy (1950). Central to systems theory was the idea that the total is greater than the sum of its individual parts, and as such the whole system needed to be considered. von Bertalanffy’s ideas relating to system complexity gained popularity in the 1950s resulting in the establishment of the multidisciplinary Society for the Advancement of General Systems Theory at Stanford University. Cross-disciplinary collaborations between von Bertalanffy and people such as social psychologists Kurt Lewin, and anthropologists Margaret Mead and Gregory
Bateson (1972) advanced systems theory to the point that it was increasingly being used to explain complex human process and family functioning (Dore, 2008).

Significantly, Gregory Bateson was involved with a group of researchers investigating Schizophrenia at the Palo Alto Veterans Administration Hospital, thereby bringing these new understandings of systems theory to the study of mental illness. Often referred to as the Palo Alto group, these researchers looked at the communication between mothers and their children as a causative factor for schizophrenia. Although the findings are no longer regarded as credible, this was the first time individual pathology and functioning was considered in terms of the family context. Founded by Don Jackson (1959), the Mental Research Institute was an offshoot of the Palo Alto group, and involved the work of people such as Jungian Psychologist Paul Watzlawick (1967), and social worker Virginia Satir (1972) who helped to promote the integration of family systems theory into treatment interventions for families (Whitchurch & Constantine, 1993). Psychiatrist Murray Bowen (1978), who was responsible for pioneering work in the field of family therapy, was also involved with the Mental Research Institute. The work of these researchers brought about a shift towards a systemic view of health and illness and focused psychotherapy and public health interventions on the family rather than the individual (Bamm & Rosenbaum, 2008; Doherty, 1991). Individual behaviours and emotional states were no longer seen as stemming solely from intrapsychic forces, but rather as being influenced by and having influence on external factors such as family patterns and relationships.

As described by Whitchurch and Constantine (1993), the research of Hess and Handel (1959) into family marital and family interaction was the “interface” between symbolic interactionism and family systems research; and the first example of systematic empirical research into the family system. Early family systems research
considered family relationship patterns, interactions and processes, and introduced the concepts of boundaries, and family separateness-connectedness (Whitchurch & Constantine, 1993). Although the early marital and family studies were qualitative, in time quantitative research methodologies came to dominate this field, with models and assessment tools developed to investigate and explain marital dyads and family functioning. Lebow and Stroud (2012) catalogued a variety of variables that are considered in family systems research, including adaptability, cohesion, conflict, monitoring and expressiveness. Olson’s Circumplex model of marital and family systems (Olson, Russell, & Sprenkle, 1979), for example, examined family types in relation to family functioning after crisis. The circumplex model described the family types ranging from balanced to extreme, based on factors relating to cohesion (emotional bonding) and adaptability (the ability to change power structure, roles and relationship rules), facilitated by positive communication (Olson, 1993, 2000; Olson, Russell, & Sprenkle, 1983). Another notable model was the Beavers Systems Model (Beavers, 1977; Beavers & Hampson, 2003), which attempted to account for variation in level of competence between families (Whitchurch & Constantine, 1993).

**Family Stress Theory**

Closely associated with the development of family systems theory is family stress theory. Family stress theory has evolved through the work of many predominately U.S. researchers, with later models reflecting family systems principles. Early research (Angell, 1936; Cavan & Ranck, 1938; Komorovsky, 1940) laid the foundation for sociologist Reuben Hill’s (1949, 1958) work on family stress which is commonly credited as the start point of family stress theory (Burr & Klein, 1993). Hill’s seminal work, *Families under stress* (1949) focussed on families in crisis as a result of war, specifically looking at the impact of separations and reunions. This work formed the
basis of the ABCX model of family stress. The model explains how the three factors of a stressor event (A), the family’s perception of that stressor (B), and the family’s existing resources (C) interacted to predict the likelihood of a crisis (X) occurring. Hill’s model is underpinned by positivist assumptions, with the variables interacting linearly in a mechanistic and cause and effect manner, which has been criticised for its limited view of family complexity (Burr & Klein, 1993). Criticism notwithstanding, the importance of Hill’s contribution to family stress theory has been widely acknowledged, with the variables from the ABCX model continuing to inform later family stress theory. A significant aspect of Hill’s later work involved family development theory, which examined the evolution of family processes over the family life-cycle. Hill’s (1971) work on the family life cycle of the family was the pioneering work in this field, paving the way for later theorists. The seminal work by Carter and McGoldrick (1980) *The Family life cycle* advanced Hill’s model and proposed a multi-generational perspective on family processes (Dore, 2008). The model identified “centripetal” factors (including measures of family coping, marital adjustment, and number of years married) that held families together; whereas “centrifugal” factors (number of children, age of oldest child, amount of perceived financial strain) loosened familial bonds (Moore et al., 1993).

Family stress theory was influenced by postmodern thought, which shifted away from positivist family models (Doherty, 1999) as a result of the work of McCubbin and colleagues (McCubbin, 1979), and Boss (Boss, 1987, 2002), who added family culture to Hill’s ABCX model. Consequently, family stress theory began to reflect broader non-positivistic assumptions (Burr & Klein, 1993). Burr and colleagues (Burr, 1979; Burr & Klein, 1993) also contributed to the evolution of family stress theory by investigating stress through an ecosystem lens (Weber, 2011). Family stress was examined, and
defined as “a process that is interrelated with several other processes in the system” (Burr & Klein, 1993, p. 32), highlighting the systemic nature of the family.

McCubbin and colleagues built on Hill’s early ABCX model to develop the double ABCX model (McCubbin & Patterson, 1982; McCubbin & Patterson, 1983a, 1983b). The model diverged from Hill’s to include a consideration of the impact of post-crisis variables on family outcome, questioning why some families adapted more successfully than others. The model was significant in its inclusion of the variable of family coping. Coping was seen to involve the impact of family stressors; activities families engaged in to manage these stressors; and the ways these activities impacted general family functioning (Boss, 1987; Kosciulek, 1994).

Following the Double ABCX model, the Family Adjustment and Adaptation Response (FAAR) model (McCubbin & Thompson, 1991; Patterson, 1988) further developed this investigation into the inter-relationships between family characteristics and resources and family adaptation to crisis. The FAAR model assessed families from the perspective of stress and coping, and emphasized the four central constructs of family demands, balanced with family capabilities which interact with family meanings, leading to family adjustment or adaptation (Patterson, 2002a). McCubbin and colleagues work heralded a change in focus from the cause of the stress, and areas of family deficit, to a focus on the strengths of families. This work considered family types, and examined characteristics associated with successful adaptation to a crisis or life change. Adaptation was seen as “the outcome of family efforts to bring a new level of balance, harmony, and coherence to a family following a crisis” (Kosciulek, 1994) Factors such as family typologies and family schema were also considered with later models including the first references to the concept of family resilience (McCubbin & McCubbin, 1988; McCubbin, McCubbin, & Thompson, 1993).
Family Resilience

There is no single definition of resilience. It is usually defined as characteristics that assist families to be “resistant to disruption in the face of change and adaptive in the face of crisis situations” (McCubbin & McCubbin, 1988). Resilience has also been defined as “the human ability to adapt in the face of tragedy, trauma, adversity, hardship and ongoing significant life stressors (Newman, 2005, p. 227), and “a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). Common among definitions is the presence of adversity, and the inherent or emerging strengths and resources that overcome adversity. Although some researchers have made a distinction between the stable internal quality of resiliency and more situation-specific resilience, the terms are grammatically interchangeable.

Early resilience research focused primarily on individual resilience and was typically associated with childhood trauma (Coyle et al., 2009; Patterson, 2002b). More recently, resilience has increasingly been conceptualised at the family system level, which recognises the role of the family unit in buffering stress and responding to challenges. This interest in family resilience emerged as a result of changing foci within the two distinct, but related, fields of family studies and psychology, to more positive outcomes and experiences (Patterson, 2002a). This change is evidenced in the moves to strengths-based rather than deficit-based models of family dynamics (Patterson, 2002a), and positive psychology (Seligman & Csikszentmihalyi, 2000). It is reflective of Antonovsky’s notion of salutogenesis (Antonovsky, 1987, 1998), which emphasizes wellness over pathology and asks the question, “what underlies the movement towards health?” (Antonovsky, 1998, p. 7).
McCubbin and colleagues’ development of the Resiliency Model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1992) was the first time resilience had been considered in the context of family adaptation. Resilience was seen as the “family system properties, strengths, and capabilities [that] are needed, called upon, or created to manage a major transition and change calling for family reorganization and adaptation” (McCubbin & McCubbin, 1988, p. 248). The primary focus of this model was family change and adaptation over time, and it attempted to explain why some families recover while others may deteriorate under the same circumstances (McCubbin, Thompson, & McCubbin, 1996). Central to the model was the notion that family stress can be predictive of family adaptation, with stress referring to the accumulated demands endured by the family system following a major crisis (McCubbin et al., 1996). Factors such as the type of family (regenerative, resilient, rhythmic), family resources, the level of vulnerability, coping and problem-solving capacity, and the family’s appraisal of the event were seen to be predictive of the level of adaptation to stressors (Hawley, 2000). The family schema, or world view, was also seen to impact on resilience. Families who perceived life events as comprehensible, manageable, and meaningful, were seen to possess a sense of coherence (Antonovsky, 1998) which was associated with positive adaptation. Resilience was conceptualized as a regaining of equilibrium, or a return to pre-trauma functioning. The work of McCubbin and colleagues laid the foundation for later family resilience models which emerged in the family stress literature from around the late 1980s (e.g. Rutter, 1987; Stinnett & DeFrain, 1985). Walsh (2003, 2012) extended notions of family resilience to encompass those qualities that arise to combat adversity, moving from resilience as a process of managing adversity to one of transcending adversity. The key processes of family resilience described by Walsh included belief systems (the families’ appraisal of
the event, including meaning-making, positive outlook, and transcendence or spirituality); organizational patterns (including flexibility, connectedness/cohesion; social and economic resources); and communication/problem-solving (including clarity, emotional expression and collaborative problem-solving) (Walsh, 2012). Rolland (2012) posited that for families to successfully adapt to sudden onset changes they must be highly adaptable, cohesive, adept at problem-solving, and capable of re-allocating family roles. In Walsh’s model family resilience is seen not as a fixed set of qualities, but as an emergent process over time, which is affected by biopsychosocial and developmental influences, and unique to each family (Hawley, 2000; Walsh, 2012).

Conclusion

Although family systems theory is well established, particularly within the field of mental health, its application within the TBI context is limited. Moreover, existing research has not translated into effective family interventions (Foster et al., 2012; Frain et al., 2007). There is lack of evidence to indicate the optimal timing and nature of family interventions, which hinders quality service provision (Boschen et al., 2007; Bowen et al., 2010; Foster et al., 2012). Schönberger and colleagues (2010) noted a propensity in the family functioning literature for cross-sectional research designs, which means the long-term development of family functioning over time is poorly understood, contributing to the lack of translation from research to practice. Others have questioned the utility of standardised measures of family functioning, which have usually been developed for psychiatric populations, in addressing the unique aspects of TBI (Serio et al., 1995; Thompson, 2009). It has been noted that the family adjustment problems associated with TBI are unique, particularly in relation to the cognitive, emotional, personality and neurobehavioral changes often present in the injured person, which significantly disrupt the families’ sense of continuity between past and present
Therefore, general models and measures may not accurately reflect the experience of families after TBI (Florian et al., 1989; Thompson, 2009). Indeed, a review of instruments used to assess caregiver and family functioning after TBI highlighted a range of conceptual and methodological issues in these studies (Thompson, 2009). The author noted a lack of conceptual clarity within the field of family functioning and TBI, resulting in inconsistent use of terminology, and the use of more than fifty different instruments, making comparison across studies impossible.

Moreover, the failure of TBI family research to result in effective supports for families is in part due to the “myriad of potential influences on family adjustment, and the uniqueness of each family” (Maitz & Sachs, 1995, p. 1), which have not been captured in the quantitative measures of families. More in-depth qualitative analysis of the long-term family experience of TBI is needed to shed light on this experience, channelling new understandings into innovative and effective family supports, and ensuring positive outcomes for families after TBI.

**The Current Study**

**The research problem.**

Families of people with TBI are a vital resource for the injured person and society. Yet paradoxically, rather than being assisted to fulfil this important role, inadequate family supports mean family members often become reliant on health, housing and social services themselves. Despite significant research investigating the impact of TBI on families, the processes families engage in to manage TBI over the long-term are poorly understood. The emphasis in TBI family research on quantitative methods does not “take account of the unique characteristics of individual cases” (Edwards, 1998, p. 1). It is this knowledge, to be gained from the experiences of
families, which is required to guide the development of effective and timely supports, and move from crisis management to crisis prevention.

**Aim**

The aim of this study is to develop a conceptual framework for understanding the long-term family system experience of and response to TBI, from the perspective of families, thereby informing effective service delivery.

**Research questions**

Broadly: What is the long-term experience of families following TBI?

Specifically: How did families respond to TBI, and what processes did they engage in to manage over time?
Chapter 3: Method and Procedures

The current study is an investigation of the long-term experiences of TBI from the perspective of families; a topic which has not been adequately examined. When seeking to understand the perspectives of participants, and when the topic under investigation is poorly understood, qualitative research methods are desirable. Qualitative research is particularly useful for investigating the complex human system of the family. The benefits of a qualitative approach to family research have been noted as:

- Exploring family members understandings and meanings about family interactions and relationships;
- Capturing relational processes;
- Examining families within contexts;
- Giving voice to marginalised families (Ganong & Coleman, 2014, p. 452)

This potential for qualitative research to uncover the largely unheard family stories of TBI, and explore family interactions, meanings and processes in context points to the importance of a qualitative approach for the current study. Hammell and Carpenter (2004) described the utility of qualitative methods for better understanding the complexities associated with a disability such as TBI. They noted that qualitative methods are useful for “illuminating the experiences, perspectives and contexts of people’s lives” (Hammell, 2007, p. 261). These family experiences, perspectives and contexts relating to TBI, particularly over the long-term, are currently missing in the research literature, which has largely focussed on individual experiences and point-in-time assessments. Further, it has been noted that the majority of family research has relied on individual self-reports which are limited by researcher-determined parameters (Ganong & Coleman, 2014). Therefore rich data capturing the unique experiences and
voices of families has not been adequately conveyed (Leith et al., 2004). The current academic literature fails to address the malleability of the families’ emotional states over time, and fails to depict the families’ “experiential perceptions and reactions from their vantage point” (Klonoff et al., 2008, p. 110). As a result, the knowledge and skills associated with managing TBI that families gain through their experiences remains hidden. This knowledge is an important and untapped resource for services struggling to support families, and is necessary to inform the development of effective and efficient service systems and to guide policy decisions. It is only through in-depth qualitative research that families are able to convey to researchers in their words “what they think, feel and believe” (Ganong & Coleman, 2014, p. 452) about their experiences of TBI.

This qualitative study is underpinned by the theory and methods of constructivist grounded theory (CGT) (Bryant & Charmaz, 2007; Charmaz, 2006, 2012, 2014), which was seen as the most appropriate method for developing a theory about the long-term family experience of TBI.

**Theoretical Approach: Constructivist Grounded Theory**

**Grounded theory.**

Grounded theory originated in the U.S. sociological tradition, emerging from the Chicago school of research with Barney Glaser and Anselm Strauss’s innovative 1967 work, *The Discovery of grounded theory* (Glaser & Strauss, 1967). This publication described the research process they had developed during a collaborative investigation of death and dying (Glaser & Strauss 1965; 1968). The method was a reaction to the prevailing quantitative methods of the time, which they viewed as inadequate for formulating theory about complex human processes. Glaser and Strauss emphasised the development of theory grounded in qualitative data, as opposed to the deduction of “testable hypotheses from existing theories” (Charmaz, 2014), and sought to apply the
methodological rigour of quantitative research to qualitative inquiry. Grounded theory goes beyond description and attempts to analyse *processes* in order to generate a theory (Creswell, 2007), which is suited to the goal of this study to understand the long-term family experience of TBI. The open-ended nature of grounded theory means the phenomena of the family and TBI can be explored as it actually experienced by families, unencumbered by existing theories and beliefs about the experience (Creswell, 2005). Glaser and Strauss ultimately diverged in their understandings of the method, arguing for different design and philosophical underpinnings. Creswell (2005) categorises modern grounded theory into three broad traditions of emergent design (Glaser, 1992), systematic design (Strauss & Corbin, 1990, 1998), and constructivist design (Charmaz, 1990, 2000).

The literature review undertaken prior to this study revealed that existing knowledge was inadequate to fully explain the long-term family experience of TBI. A grounded theory approach was therefore appropriate as there was no existing theoretical basis for the context under investigation (Creswell, 2007; Liamputtong, 2009). A common misinterpretation of grounded theory involves the principle of theory generation uninhibited by existing literature. Although this open nature lends itself to theory formation it can be interpreted as a reason to reject theory all together. Whilst grounded theory does not start with an off-the-shelf theory, any meaningful theory “occurs in an ongoing dialogue between pre-existing theory and new insights generated as a consequence of empirical data” (Rice & Ezzy, 1999, p. 194). The intention of grounded theory is to avoid forcing theory onto the data deductively, not to avoid theory entirely (Suddaby, 2006). Research which fails to locate itself within any ongoing dialogue runs the risk of providing nothing more than superficial description. Therefore, an initial review of the family and TBI literature was undertaken which highlighted the
need for long-term qualitative data about the family experience of TBI. This review was presented in Chapter 1, and illustrated the gap in current research which guided the direction of my current study. I refrained from engaging deeply with the family theory and family adaptation literature until after the data analysis, to minimise any preconceptions.

**Constructivist grounded theory.**

A constructivist theoretical paradigm is interpretive in nature, the aim of which is to “gain understanding by interpreting subject perceptions (Lincoln, Lynham, & Guba, 2011, p. 102). Representing the voice of participants is a core principle and intention of constructivist grounded theory, and a primary goal of this study. Constructivist grounded theory best reflects the aim of this study to understand participant experiences, and is reflective of my own philosophical beliefs in terms of being “ontologically relativist and epistemologically subjectivist” (Mills, Bonner, & Francis, 2006b, p. 31). Within a constructivist paradigm, knowledge is seen to be relativist with local and specific co-constructed realities created through the interaction between researcher and participants (Guba & Lincoln, 2005). Constructivist grounded theory is discernible from other branches of grounded theory in terms of “the positioning of the researcher in relation to the participants, analysis of the data, and rendering of participants’ experiences into grounded theory” (Mills et al., 2006b). The researcher is viewed not as an objective observer, and recorder of data, but as co-constructor of the narrative. Rather than attempting to distance the researcher from the research process, the subjective nature of knowledge creation is explicitly acknowledged, wherein, “it is impossible to separate the inquirer from the inquired into. It is precisely their interaction that creates the data that will emerge from the inquiry” (Guba & Lincoln, 1989).
Moreover there exists an equal and reciprocal relationship between researcher and participants “in the co-construction of meaning and, ultimately, a theory that is grounded in the participants’ and researchers experiences” (Mills, Bonner, & Francis, 2006a, p. 9). Constructivist grounded theory “starts with the experience” and seeks to explore and understand how that experience is constructed within specific social realities (Charmaz, 2014). In this sense the researcher acknowledges his or her position as embedded within the reality of the participants’ story. This acknowledgment that research findings are not discovered, but are co-constructed by researcher and participants fosters researcher reflexivity (Charmaz, 2014, p. 13). For this reason, my data collection (described later) was based on an unstructured story telling approach that allowed families to describe their experiences in their own ways.

Charmaz’s constructivist interpretation of grounded theory allows for flexibility in the approach. The processes described are seen as a guide for researchers, rather than a prescriptive set of rules. The processes of constructivist grounded theory lead researchers to “immerse themselves in the data in a way that embeds the narrative of the participants in the final research outcome” (Mills et al., 2006b, p. 31). Charmaz (2011) listed a number of items common to all inquiries using grounded theory tools including using an iterative process of simultaneous data collection and analysis, focusing on actions and processes, the use of constant comparative methods, the use of theoretical sampling and a focus on the development of theoretical concepts and categories instead of description or “application of current theories” (p.364). The aim of the procedures is to provide a plan for researchers to follow, and to add richness and rigour to the research. The data collection and analysis tools described by Charmaz (Charmaz, 2006, 2012, 2014) were used to guide the current study, particularly through the use of the constant comparison and theoretical sampling methods, and in the coding processes.
The application of these tools to the current study is explained below in the “Procedures” section.

**Theoretical sampling.**

In grounded theory, the method of *theoretical sampling* is used to advance the emerging theory. The sample is chosen not to increase population representativeness, which is not an aim of this study, but rather where the sample identified is that which will best assist theory formulation. Although the initial sample is based on knowledge of the context of the project, subsequent theoretical sampling takes place in response to early emergent data. The purpose of theoretical sampling is to elaborate and refine the emerging theory, which involves “starting with data, constructing tentative ideas about the data, and then examining these ideas through further empirical enquiry (Charmaz, 2014, p. 102). This process ensures that all relevant data will be included in the study. The long-term follow up design of the current study precluded theoretical sampling of additional families beyond the original sample. However, the principle of theoretical sampling was used to refine the interview protocols in response to emerging theory. This process is explained the procedures.

**Constant comparison.**

Unlike other research methods data analysis occurs simultaneously with collection, thereby allowing the researcher to change focus as data emerges. This process of *constant comparison* is the core inductive process in grounded theory data analysis, adding reliability to the findings, and further grounding theory formulation in the data. Constant comparison involves a complex system of coding and categorising data. The goal is “to discern conceptual similarities, to refine the discriminative power of categories, and to discover patterns” (Tesch, 1990, p. 96). Charmaz (2014) notes coding as the first analytical step of grounded theory, and recommends at least two
phases of coding be carried out, namely initial and focussed coding. Initial coding involves studying fragments of the data, and the use of in vivo codes can be an early strategy to ground analysis in participants’ stories. In the focussed coding phase, initial codes are tested against extensive data, comparing “data with data and data with codes” (Charmaz, 2014, p. 42). Codes can later be elaborated into extant theoretical codes, only if the emerging data indicates this is appropriate. This process is distinguishable from other qualitative research in the level of development and specificity of coding (Rice & Ezzy, 1999). Constant comparison verifies the links between data and theory and provides transparency to the analysis. The flexibility of this dynamic method aids researchers in uncovering the richest possible data, providing for robust research. Theoretical sampling and constant comparison are applied until no new examples or properties of a category emerge.

**Research Design and Procedures**

**Sample and recruitment.**

The sample was a convenience sample made up of participants associated with a research project previously undertaken within the School of Human Services Griffith University between 2001 and 2003 (Study 1), by researchers other than myself. This sample comprised a consecutive series of adults admitted to the Head Injuries Acute and Rehabilitation Unit of a large metropolitan hospital between 2000 and 2002. At that time, participants were adults who had sustained moderate to severe TBI as determined by the GCS; who were medically stable, living in the community, and able to communicate; and their families. A total of 22 people with TBI and a family member participated in the original study, and the strategy of the current study (Study 2) was to recruit a sub-sample of those families up to 13 years later. Understanding the long-term experience of families after TBI is important and under-researched, and this sample
provided a rare opportunity to obtain this long-term perspective, and to compare participant experiences over time.

All participants in Study 1 had been recipients of a post-rehabilitation brain injury service provider. This service mailed “consent to contact” letters (Appendix A) to those families deemed appropriate and contactable, outlining the nature of the project, and inviting families to participate. Twelve families were contacted. From those twelve, 6 families agreed to take part in the study, and were subsequently contacted. Families who were interested in the project were sent more detailed information about what their contribution would involve (Appendix B), and written consent was obtained from all participants. Prior to the interview, capacity to consent to research was assessed for participants with brain injury (Appendix C), and all participants were informed that they could withdraw from the research without penalty, and given revocation of consent forms (Appendix E).

Data Collection.


Interview transcripts from Study 1 provided an additional data source. This study consisted of interviews with a participant with TBI and a key family member 4 times each over an 18-month period. In the initial study, participants were first contacted at discharge from hospital. Thus, participants ranged from 9-18 months post-injury at the beginning of Study 1, to 21-29 months post at completion of Study 1. A schedule of all interviews is shown in Table 2 below. These transcripts revealed information about what the families had experienced, their concerns and hopes for the future, and how they had responded in the early post-acute phase following TBI.
### Table 2

**Interview Schedule**

<table>
<thead>
<tr>
<th>Participants</th>
<th>Study 1 2001-2003</th>
<th>Time post-injury</th>
<th>Study 2 Family interview 2014</th>
<th>Time post-injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brendan</td>
<td>06/11/01</td>
<td>26/02/02</td>
<td>10/07/02</td>
<td>30/10/02</td>
</tr>
<tr>
<td>Kate</td>
<td>27/11/01</td>
<td>26/02/02</td>
<td>10/07/02</td>
<td>15/11/02</td>
</tr>
<tr>
<td>Alison</td>
<td>15/10/02</td>
<td>11/02/03</td>
<td>16/06/03</td>
<td>17/11/03</td>
</tr>
<tr>
<td>Mary</td>
<td>15/10/02</td>
<td>11/02/10</td>
<td>16/06/03</td>
<td>17/11/03</td>
</tr>
<tr>
<td>Daryl</td>
<td>06/11/01</td>
<td>25/02/02</td>
<td>04/07/02</td>
<td>28/10/02</td>
</tr>
<tr>
<td>Sharon</td>
<td>06/11/01</td>
<td>25/02/02</td>
<td>22/07/02</td>
<td>29/10/02</td>
</tr>
<tr>
<td>Neville</td>
<td>24/10/02</td>
<td>14/02/03</td>
<td>no data collected</td>
<td></td>
</tr>
<tr>
<td>Jo</td>
<td>24/10/02</td>
<td>no data collected</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nathan</td>
<td>22/10/02</td>
<td>20/02/03</td>
<td>05/06/03</td>
<td>18/11/03</td>
</tr>
<tr>
<td>June</td>
<td>22/10/02</td>
<td>20/02/03</td>
<td>05/06/03</td>
<td>18/11/03</td>
</tr>
<tr>
<td>Ronald</td>
<td>21/10/02</td>
<td>13/03/03</td>
<td>14/07/03</td>
<td>15/01/04</td>
</tr>
<tr>
<td>Ludmi</td>
<td>21/10/02</td>
<td>-</td>
<td>19/06/03</td>
<td>17/11/03</td>
</tr>
</tbody>
</table>

**Study 2: Family interviews 2014.**

This phase of data collection involved a family interview at participants’ homes. The family interview reflected the focus of this study on family systems, and is underpinned by the theoretical principle that people construct meaning not in isolation, but through interaction with others (Leith et al., 2004; Morse & Field, 1995). The interview protocol was informed by the life history interview method (Atkinson, 2002; Martin, 2002), which provided a guide for structuring the interview protocol. The life history interview technique allows for the collection of in-depth retrospective data which “opens a window into the world of others” (Morse & Field, 1995, p. 18).
capturing the often unheard voices of families who experience TBI. In-depth or “intensive” interview techniques are recommended by Charmaz for constructivist grounded theory, for their open-ended and focussed nature, which aligns with the method (Charmaz, 2014). This approach acknowledges and draws on the value of participant perspectives in knowledge creation, assuming that the participant perspective is “meaningful, knowable, and able to be made explicit” (Patton, 2002, p. 341). The open-ended and flexible nature of the method aligns with constructivist grounded theory in that it gives power to participants to guide the direction of the discussion (Mills et al., 2006b). Constructivist grounded theory principles are also upheld insofar as questions are framed from a participant perspective rather than “an abstract body of knowledge (Martin, 2002, p. 110). Although research commonly investigates current phenomena or experiences, this study focused on the retrospective experiences of participants. The retrospective nature of the study lent itself to the life history interview method, which is effective for investigating lived experiences, and for understanding changes that have occurred over time (Marshall & Rossman, 2011). Life history interviews tend not to focus on a person’s whole life, but rather a specific aspect of their life (Lewis-Beck, Bryman, & Futing Liao). In this study, the specific focus was the long-term family experience of and response to TBI, and therefore interviews were designed to draw out this information. Through the interview a picture of the unique experience of the family emerged. Shared recollections and contested understandings within families shed light on the family experience over time.

The life history interview technique involves data collection through an in-depth interview and the arrangement of significant events into chronological order, with an emphasis on important themes as perceived by the narrator (Miller, 2000). During the family interview families were asked open-ended, semi-structured questions yielding
rich, thick data about people’s experiences, perceptions, opinions, feelings, and knowledge (Patton, 2002). The interviews were semi-structured, but participant driven, so the protocols were a guide rather than a prescriptive set of questions. It was important to have the flexibility to follow participant lead discussion. The interview protocols changed over the course of data collection in accordance with what worked best and as a consequence of theoretical sampling, as I followed emerging lines of inquiry. The original interview protocol is shown in Appendix E. The protocol included time to draw a family genogram and other diagrams, and questions were structured around specific time periods as outlined in the family history method. However, this process proved to limit the flow of the conversation, and I found that as participants told their stories the narrative jumped back and forth from the time of the injury to later time points. Rather than adhere rigidly to any structure I chose to leave the process open, ensuring that participants could determine and explain what was important for them, and wrote the stories chronologically during data analysis. As described in the data analysis section, this writing process constituted an immersion in the data which later assisted more theoretical analysis. As the interviews progressed I made continuous changes to the protocol in accordance with emerging data. Appendix F shows the final protocol.

Patton (2002) described interviews as interventions, stating “the process of being taken through a directed, reflective process affects the person being interviewed” (p.405). The interview process can have both negative and positive impacts on participants. Taking part in research has been shown to be a positive and sometimes transformational process for some participants, particularly when people feel they have knowledge to contribute and have not been listened to. Discussing the potential benefits of sharing a life story, Atkinson (1998) noted the following:
In sharing our stories, we gain a clearer perspective on personal experiences and feelings, which in turn brings greater meaning to our lives;

- We obtain greater self-knowledge, stronger self-image, and enhanced self-esteem;
- We share cherished experiences and insights with others;
- Sharing our stories can bring us joy, satisfaction, and inner peace;
- Sharing our stories is a way of purging, or releasing, certain burdens and validating personal experience, this is in fact central to the recovery process;
- Sharing our stories helps create community, and may show us that we have more in common with others than we thought;
- By sharing our stories, we can help other people see their lives more clearly or differently, and perhaps inspire them to change negative things in their lives;
- When we share our stories, others will get to know and understand us better, in ways that they had not before;
- In sharing our stories, we might gain a better sense of how we want our stories to end, or how we can give ourselves the “good” endings we want;
- By understanding our past and present, we derive a clearer perspective on our goals for the future (p.25).

It was hoped that participants may have experienced some of the benefits listed above as a result of sharing their stories; however in-depth interviews tend to be more intrusive and potentially involve greater participant reactivity than other approaches. It was
acknowledged that some participants may have found reliving past experiences to be emotional or distressing. Therefore a risk minimisation strategy was put in place to ensure participant safety (Appendix G). Participants were given the option of an individual interview. One mother requested individual rather than family interviews as she felt speaking in front of her son with TBI may have caused conflict. One spouse requested an individual follow-up interview after the family interview in order to disclose additional information, but otherwise, all data was collected in a family context.

Memos and reflective writing.

Researcher reflection, in the form of journal or memo writing is stressed as an important aspect of constructivist grounded theory for recording abstract thinking about the data. Memos are analytic tools which can be used to make explicit to researcher, and ultimately reader, underlying assumptions and key decisions. Charmaz recommended memo writing as a crucial step between data collection and analysis as it provides an early opportunity to analyse data and coding (Charmaz, 2014). In this study, memo writing commenced at the point of making contact with participants, and memos and reflective writing were continuously used throughout data collection and analysis. These memos served the dual purpose of assisting me to build a clear chronological story of each family’s experience, as well aiding the development of ongoing theoretical analysis. Reflections on thinking processes and important decisions about design and coding were also recorded as memos, and integrated into the analysis (Mills et al., 2006a).

Ethical Considerations.

A full ethical review was completed prior to the consent to contact process, with approval obtained through Queensland Health (HREC/13/QPAH/616) and Griffith
University Human Research Ethics Committee. Written consent was obtained from all participants, and consent forms were developed and approved by Griffith University ethics committee. Participants were given information about the purpose of the study, and were informed of their right to withdraw from the study at any time.

**Data Analysis.**

Data analysis was a complex and iterative process. In accordance with the grounded theory method, I undertook a process of concurrent data collection and analysis, with emerging data informing later interviews. There was a large volume of data from multiple time points, including four sets of interview data from Study 1 and family and individual interviews from Study 2. As analysis progressed memos, reflective writing and emerging theory were also incorporated into the constant comparative data analysis process. Although I was interested in developing theory and comparing families, it was also important that each family’s unique experience be preserved. Therefore, I developed processes and methods for analysing data within families over time and across families using tables, coding methods, and writing which served these dual purposes. A number of procedures were used to organise data and assist analysis which are described below.

**Study 1: Thematic analysis.**

Prior to the commencement of the 2014 interviews, a preliminary analysis of interview data from Study 1 was undertaken. Open coding was used on these interview transcripts to identify key themes (Appendix H), but no attempt to formulate theory was undertaken at this stage. Responses to questions were tracked on the Family Experience Interview Table providing a data base of the family experience (Appendix I). This process served the purpose of familiarising myself with the family stories as told in the 18 months following discharge, and provided a reference point against which to check
and compare families across time and with other families. The results of the early data analysis were not used to inform the interview protocols for Study 2, which were open-ended and flexible.

**Study 2: Family stories and coding.**

For Study 2, the family interviews were recorded and transcribed verbatim to ensure accuracy. In accordance with constructivist grounded theory data collection and analysis were carried out concurrently. Data analysis commenced at the completion of the first interview, and evolved throughout the data collection process. Memos were made from the first point of contact with participants. These early memos noted observations about the injured participant’s engagement in the process of organising the interview, which provided insight into family dynamics and the injured person’s independence. These observations were noted on the Interview Reflection Sheet (Appendix J). This sheet was also used to record initial observations at the completion of the interview. Within 24 hours of each interview, I listened back to the audio and made detailed Family Interview Reflection Memos (Appendix K). This process helped to enhance familiarity with each family story, which was important for later analysis. Listening to the audio also gave the added benefit of picking up the subtle information conveyed through the tone and emotion, which could be lost in the transcripts.

Charmaz (2014) recommended two coding phases: initial coding, which is open and rapid; and focussed coding, which is more theoretical, and involves deeper analysis. During initial coding, Charmaz advises researchers to “remain open to exploring whatever theoretical possibilities we can discern in the data” (Charmaz, 2014, p.116). For this study, initial coding done on interview transcripts for each family interview, which ensured the context of the family story was not lost. Appendix L shows an example of the transcript coding. This process assisted in writing up the family case
summaries, and contributed to later analysis. At the same time as the initial coding was conducted, I read the transcripts from both Study 1 and 2 for each family and extracted details such as injury details, pre- and post-injury circumstances, and constructed a timeline of events in order to write up family case summaries. These summaries provided a method to “reduce a large qualitative data set in a way that preserved the family focus of the research” (Knafl & Ayres, 1996, p. 350). This process ensured a clear an accurate picture of events, and enabled me to check consistency between the early and later data (which was consistent in all cases). This descriptive process not only ensured correctness of facts pertaining to family stories, but it also provided immersion in the data multiple times. This built a familiarity with the stories which aided my analysis and theory development. Throughout this process, a picture of the family experience emerged; the stories themselves, as well as the ways in which families responded. During this process, I wrote analytical memos about families (Appendix M), as well as noting down emerging ideas relating to the comparative analysis (Appendix N). For each family, I asked, “What is happening/happened in this family”; “how does this compare with what is happening/happened in other families?”

From this early analysis I proceeded to focussed coding, identifying the codes that looked more significant, or appeared more frequently among the initial codes (Charmaz, 2014). As this process progressed, more theoretical codes were developed. Appendix O shows the final list of focussed theoretical codes, which informed later categories and processes. The observations and ideas recorded in the memos and reflective writing guided further lines of enquiry, and eventually informed theory generation. Raw data was often used in the memos which Charmaz recommended as a strategy to preserve the participants’ voice and meaning (Charmaz, 2014).
In constructivist grounded theory, data analysis involves constant comparison between the data, the emergent theory, and memos; all of which interact with the researcher perspectives. I engaged in ongoing cycles of this process, comparing new data with early data; codes within and across families; and emerging theory with existing codes and categories, resulting in the identification of the codes, categories and processes making up the final results. Memos were also made to record reflections and procedural decisions (Appendix P) during this process.

**Trustworthiness and Authenticity**

The relativist and subjectivist nature of constructivist grounded theory implies that there is not an objective knowable reality, that “data do not provide a window on reality; rather the ‘discovered’ reality arises from the interactive process and its temporal, cultural and structural contexts” (Charmaz, 2000, p. 524). The narratives constructed by researcher and participant are therefore reflective of participants’ “truth”. Participants are considered the experts in their own lives, and it is largely assumed “that the storyteller knows the story being told and that it is a truthful and thorough representation of that story” (Atkinson, 1998, p. 59). However, there are a number of strategies within the research design which ensure that the reconstruction of participant experiences provides “plausible accounts” (Charmaz, 2014) of human processes, which can ultimately inform service delivery. In terms of the authenticity of family stories, any contested recollections were highlighted during the family interview. Constant comparison from multiple data sources including the family interviews, memos, and the data from Study 1, together with the systematic data analysis of grounded theory contributed to the trustworthiness of the study (Creswell, 2007; Patton, 2002). Member checking of the transcripts, allowed participants the opportunity to verify the accounts given (Creswell, 2007; Lincoln & Guba, 1985). The retrospective nature of this study
meant that participants had had time to reflect on their experiences; their stories having had “a chance to mature, to become fleshed with detail, and to deepen in perspective” (Morse, 2002, p. 321). This sample allowed for comparisons to be made between the current and prior data sets, strengthening the trustworthiness of the retrospective data. The importance of researcher reflexivity is stressed in CGT, with researcher reflections on his or her “research experience, decisions and interpretations” (Charmaz, 2006, p.188) assisting to bring the researcher into the research process, adding to the transparency and trustworthiness of the research. The research process of memoing about my decisions and reflections made clear my underlying assumptions. Frequent discussions with my supervisors also brought to light any biases. I came to this research with relatively little experience in family theory. This was useful in that I undertook the interviews free from preconceptions based on existing theory.

The Families

Six families agreed to participate in the project. Details of the injured person and their family appear in Table 3 and Table 4 below. The following provides some background information to the families. The names of participants have been changed.

Family 1: Brendan’s family.

I met Brendan and his parents Kate and William at their home in 2014. Brendan was 33 at Study 2 (14 years post-injury), living in a self-contained area of the family home. Brendan’s only sibling Rose lived with her partner interstate. The family reported a close relationship with Rose; however she was not available to participate in the study. Brendan was working at a local supermarket and reported good relationships with friends and his community. In November 2000, Brendan had been living with his parents when he sustained a severe TBI as the result of a car accident at 19 years of age. Brendan is legally blind as a result of the accident, with partial sight in his left eye.
Other residual impairments included clonus of the foot, and cognitive impairment. Anger and mood swings caused problems for Brendan and his family particularly in the first two years post-injury. Brendan spent 4 ½ months in acute hospital and rehabilitation wards, and continued outpatient rehabilitation for about 9 years. Brendan had organised this himself in order to continue working on his physical recovery.

Brendan and his family had worked hard at maximising Brendan’s recovery and independence, and were still looking at future improvements. Although Brendan lived with his parents, he was quite self-sufficient and independent. Brendan had maintained friendships, and at the time of Study 2 he had been planning his first overseas trip with friends. Prior to the interview I had spoken to Brendan and Kate multiple times over the telephone in setting up the meeting, and had developed a good rapport with them. Brendan was eager to tell his story and contributed significantly to the interview.

**Family 2: Alison’s family.**

I met Alison and her mother Mary in February 2014 at Alison’s unit, where she was living independently, with some assistance from her mother and an apartment warden. Alison was 33 years old at the time of the interview, 13 years post-injury. Alison has no siblings and her parents had divorced 4 years prior to the injury. Both Alison’s parents had re-married, and Alison had lived for some time with Mary and her husband John. Alison had been living independently since 2007, and was involved in volunteer work, and other community activities. Alison had also been able to complete her Degree in 2009 (8 years after the accident) which she had been undertaking when she was injured. In June 2001, Alison sustained a severe TBI as a passenger in a motor vehicle accident, driven by her then boyfriend. Alison sustained severe physical and cognitive injuries and lost her speech. Alison now communicates with gestures and voice devices. Alison was in inpatient care for 12 months, and initially needed full time
care after she returned home. Prior to the accident, Alison had been living out of home with friends. She worked part-time in a florist, and was in her third year of studying history and journalism at University. Alison had been unable to regain employment, but had done volunteer work which she found rewarding. As a result of Alison’s communication barriers, she tended to allow Mary to speak on her behalf, adding intermittently and clarifying points when required. Mary encouraged Alison to contribute, and always checked that Alison was happy with her interpretations. Throughout the interview process, Alison made the arrangements via email.

**Family 3: Daryl’s family.**

Daryl was 49 years old at Study 2 (13 years post-injury), living with his wife Sharon; 20 year old daughter Susan and her baby; 19 year old daughter Selina, and Selina’s partner; and sons Jason (23) and Andrew (17). Jason and Andrew did not participate in the study. A family friend Sandra participated, and was present at the family interview. Sandra had been a support for Daryl and Sharon after the injury, and was considered part of the family. At the time of Study 2 Daryl was working in logistics. Daryl sustained a severe TBI in 2000 as the result of an assault, and he was in inpatient care for approximately 8 months. Daryl’s injury affected his memory, balance and eye-sight, and he was unable to drive or work for approximately 2 years post-injury. Daryl had regained most of his lost function, but had permanent memory deficits which he compensated for at work with diaries and written notes. Daryl had also experienced significant anxiety and depression post-injury in part due to the violent nature of his injury. The meeting was arranged through Daryl, which provided an opportunity to develop rapport. Daryl contributed equally to the interview.

At the time of Sharon’s individual interview, Sharon and Daryl had separated. Daryl had remained in the family home with his daughters and his Mother. Sharon
reported that break-up was not related to the injury, but rather due to pre-injury issues that had re-surfaced. I had observed at the time of the family interview that Sharon had seemed troubled at times, and I was unsure if she privately disagreed with what was being said, or if she was a reluctant participant (see Appendix J). However, she later explained that she had known at the time of the interview she was planning to leave, but had not wished to reveal this at the time.

**Family 4: Neville’s family.**

Neville was 43 years old at the time of Study 2 (13 years post-injury), living with his partner Jo and their children Jacob (16) and Emily (14). I interviewed Neville and Jo together at their home. Although the children were in the house they did not actively participate in the interview. Neville had maintained his pre-injury employment as a panel beater, having taken approximately 9 months off work after his accident. Neville had been the primary breadwinner at the time. In 2001, at the age of 29 Neville sustained a severe TBI in a cycling accident. The children were aged 1 and 3 at the time. Neville was in an induced coma for 1 month, and then spent 3 weeks in rehabilitation as an inpatient, continuing as an outpatient for six months. Neville’s injuries were primarily cognitive, with impairments to his memory and executive function. There were no outward signs of Neville’s injury. However, to people who knew him he was described as “a different person”. Neville did not agree with that assessment. Neville was highly dependent on Jo, and at the time of arranging the meeting he had handed the responsibility for arranging the meeting over to Jo.

**Family 5: Nathan’s family.**

Nathan was 29 at the time of Study 2, living at home with his parents June and Len. His sister Lynne, 27, no longer lived with the family, but had been living at home at the time of the injury. Len’s job involved significant time away from home, and
therefore June ran the household, and was also Nathan’s primary carer. Nathan had worked at a number of different jobs since his accident. He had completed his higher school certificate post-injury, and had attempted further study, but had been unable to continue. Nathan did not have visible signs of injury, and his family reported on his lack of awareness of his cognitive impairment. Nathan was 16 ½ and preparing to commence year 12 when he sustained a severe TBI in a motorcycle accident. Nathan was in hospital and rehabilitation for seven months. Nathan continued private rehabilitation into 2003.

Nathan’s family declined a family meeting. I met with June individually, and later with Nathan alone at a later date. I did meet and converse with Len and Lynne, however they did not participate in the family interview. Len indicated that he felt June could adequately represent his and Lynne’s perspective. Len appeared sceptical of research, however without his consent and participation, I was unable to investigate his reasons. Leading up to the interview June had taken control of the consent process, returning the consent to contact form without Nathan’s knowledge. For ethical reasons, I requested that she inform Nathan prior to our meeting. It was her preference that we meet alone initially as she felt she could not speak freely with Nathan present, and that he would probably argue. Further, she explained that Nathan’s account would likely be inaccurate, and that he would tell me what he thought I wanted to hear. Consequently the data for this family represents June and Nathan’s individual perspectives rather than the family perspective as might be told in an interactive context.

Family 6: Ronald’s family.

Ronald was 33 years old at the time of Study 2 (13 years post-injury), living at home with parents Ludmi and Federico, who were both participants. Ronald’s sisters Wanda and Linda had left home, with Wanda living interstate, and Linda overseas.
Neither of the sisters was invited by the family to participate in the study. Ludmi and Federico spoke English as a second language, and communication was often difficult. Federico was also experiencing communication difficulty as a result of Parkinson’s disease, so his contribution to the interview was minimal. Ronald was unemployed at the time of the interview, and had not been able to return to work since his accident, which had been a source of great stress for the family. Ronald was 20 years old when he was injured in a roof fall. Ronald’s injuries resulted in primarily cognitive and behavioural disabilities. Prior to the injury, Ronald had been living at home and at his girlfriend’s house. Ronald continued to live with his parents after his injury, with his mother Ludmi acting as his primary carer.

Ludmi and Federico had misunderstood the purpose of the family interview, in part due to language barriers, and also due to miscommunication between themselves and Ronald. Consequently when I arrived for the meeting they immediately enquired how I would be able to help them. It became apparent that the family were still struggling and desiring assistance. I explained again that I was not from a service, and revisited the participant information sheet prior to the consent process. After the meeting, with the family approval, I passed on details to a suitable service. The family later reported, that they had been in touch with a brain injury support service and that this had been of great help to them.
### Table 3
*Injured Person Details*

<table>
<thead>
<tr>
<th>Participant</th>
<th>DOB</th>
<th>DOI</th>
<th>Age @ injury</th>
<th>Injury</th>
<th>Inpatient LOS</th>
<th>Pre-injury employment</th>
<th>Time off work</th>
<th>Occupation @ 2014</th>
<th>Age @ 2014 (Years post-injury)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brendan</td>
<td>13/09/1981</td>
<td>03/11/2000</td>
<td>19</td>
<td>MVA</td>
<td>4 ½ months</td>
<td>Carpenter</td>
<td>2 Years</td>
<td>Retail</td>
<td>33 (14)</td>
</tr>
<tr>
<td>Alison</td>
<td>23/01/1981</td>
<td>05/06/2001</td>
<td>20</td>
<td>MVA passenger</td>
<td>12 months</td>
<td>University student</td>
<td>NA</td>
<td>Brain injury service volunteer</td>
<td>33 (13)</td>
</tr>
<tr>
<td>Daryl</td>
<td>05/10/1965</td>
<td>17/03/2000</td>
<td>35</td>
<td>Assault</td>
<td>8 months</td>
<td>Pawn Broker</td>
<td>2 Years</td>
<td>Logistics</td>
<td>49 (13)</td>
</tr>
<tr>
<td>Neville</td>
<td>16/12/1971</td>
<td>19/04/2001</td>
<td>29</td>
<td>Push bike fall</td>
<td>4 months</td>
<td>Panel beater</td>
<td>9 months</td>
<td>Panel beater</td>
<td>43 (13)</td>
</tr>
<tr>
<td>Nathan</td>
<td>07/06/85</td>
<td>06/01/2002</td>
<td>16</td>
<td>MBA</td>
<td>3 months</td>
<td>HSC student</td>
<td>NA</td>
<td>Casual</td>
<td>29 (12)</td>
</tr>
<tr>
<td>Ronald</td>
<td>22/11/1981</td>
<td>16/12/2001</td>
<td>20</td>
<td>Roof fall</td>
<td>3 months</td>
<td>Retail</td>
<td>NA</td>
<td>Unemployed</td>
<td>33 (13)</td>
</tr>
<tr>
<td>Family</td>
<td>Family Structure (P= participant)</td>
<td>Pre injury accommodation status</td>
<td>Accommodation status @ study 1</td>
<td>Accommodation status @ study 2 2014</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Brendan</td>
<td>Kate, mother, carer (P) William, father (P) Rose, sibling</td>
<td>Family home with parents, sister and her partner</td>
<td>Family home with parents. Sister and her partner also living with them</td>
<td>Self-contained area of parental home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alison</td>
<td>Mary, mother, carer (P) John, step-Father Father</td>
<td>Renting with friends</td>
<td>Moved into mother’s home. Later moved with mother and Step Father</td>
<td>Living independently</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daryl</td>
<td>Sharon, spouse, carer (P) Sandra, friend, carer (P) Selina, daughter (P) Susan, daughter (P) Jason, Andrew, sons</td>
<td>Living with spouse and 4 children at home</td>
<td>Living with spouse and 2 adult daughters, and 1 son. Also 1 grandchild and male partner of 1 daughter. Eldest son living out of home</td>
<td>Daryl still in family home with daughters and his mother. Separated from Sharon who lived with youngest son</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neville</td>
<td>Jo, spouse, carer (P) Jake, Emily, school children</td>
<td>Living with spouse, and 2 children at home</td>
<td>Living with spouse, and 2 children at home</td>
<td>Living with spouse, and 2 children at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nathan</td>
<td>June, mother, carer (P) Len, father Lynne, sibling</td>
<td>Family home with parents and sibling</td>
<td>Living with parents in Brisbane</td>
<td>Self-contained area of parents’ home parents in Brisbane</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ronald</td>
<td>Ludmi, mother, carer (P) Federico, father, (P) Lyn, Maree, siblings</td>
<td>Family home with parents and 1 sibling/ sometimes with girlfriend</td>
<td>Family home with parents Sister left due to behaviour issues</td>
<td>Family home with parents</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Chapter 4 Results: The Family Response to TBI

This chapter reports on the stories of the 6 families and how they responded to brain injury. Results are discussed in terms of the structure and function of families; how these were impacted by the injury and how they influenced the family response. Structural factors included the extent to which pre-injury family structures were supportive, and any structural changes that were made; family roles and the ways families’ organised themselves to accommodate the injury; and the availability and mobilisation of informal supports. The functional response pertained to the impact of the injury on family functioning and relationships. The family culture and their attitudes and beliefs in relation to the injury are discussed. Psychological and emotional responses to the injury from the family and individual perspectives were explored, which included a consideration of associated characteristics of the injured person and primary carer.

Family 1 Brendan’s Family

After Brendan sustained a TBI, his family responded by rallying around him, and working together to maximise his recovery and independence. The family structure could be described as a nuclear family, with Brendan and his sister Rose residing in the family home with parents Kate and William. Rose’s partner was also living with the family at this time. Brendan’s injury did not significantly impact on this family structure. Rather, the existing family structure was well suited to accommodating the injury. Although Brendan had been an independent adult prior to the injury, his young age, and the fact that he still lived with his parents meant that becoming dependent on them again did not constitute a significant structural change. Kate had taken on the role of Brendan’s primary carer and advocate, acting to manage any family conflict or
problems arising from the injury. William’s role was that of Kate’s support, and he also assisted Brendan, playing a significant role in Brendan’s work re-integration.

The data suggested that Brendan’s family had consistently operated as a close team to support Brendan following his accident. The language used during the family interview underscored this, with participants often speaking in terms of “we” rather than “I”. They talked about adapting to the injury as something they did as a family, describing how they managed by working together and supporting each other. This point is illustrated in the following text from the family interview (2014) where they helped each other to tell the story; revealing a shared experience and a shared story:

Kate: Well as I said, just - you just come together as a family...
William: support and love from the family, yeah...
Kate: and you support each other and you just...
Brendan: everyone's got to do something.

Brendan’s care and recovery became the family’s main focus after Brendan was injured. Brendan was determined to return as much as possible to his pre-injury life, and his parents were highly involved in supporting his physical recovery, independence and employment re-integration. The family described Brendan’s recovery as something they were all involved in:

We used to get so excited when he got to the point where he could do up his buttons and tie his shoelaces and do all that, because he had to learn to walk again and all that as well in the beginning, too, and feed himself and all that
(Kate, mother, 2014).

Kate and William saw it as their responsibility to support Brendan, and this was done without question. At Study 1, Kate explained that caring for Brendan meant that their lives were on hold; however there was no resentment apparent:
Because he's the main issue here, the main person and we have to make sure he's right first. Even though we've sort of put our self on hold with a lot of things, we don't mind. William and I would do anything to help him in any way we can (Kate, mother, 2001).

The role of primary carer appeared to be natural for Kate, as seen in Study 1, “So I just wanted to be here with him through the whole thing. I won't go back to work until I know that he is sort of right and he's settled in himself” (Kate, mother, 2001). At study 1, Kate had recalled a family history of female carers, which meant she had a familiarity and confidence with the role:

My mum and William’s mum have all been through similar things, because my dad has had a few nervous breakdowns and his health is not very good. So mum sort of has always had to look after dad a lot. So I talk to her a lot and she talks to me. And William’s mum too, she had to look after her mother that had nervous breakdowns too when she was younger. So we just all have a good talk and it does help (Kate, mother, 2002).

Kate’s capacity to adopt the carer role allowed the rest of the family to return to pre-injury roles and activities, which brought stability to the family, as William explained:

But it's taken a bigger toll on Kate than it did me because I actually had to go back to work. I had a month off when Brendan...first had the accident and we were up at the hospital every day, but Kate's been there 24 hours a day, seven days a week (William, 2014).

There were close connections with extended family on both sides, as well as a strong network of friends who had been a source of practical and emotional support. For Brendan and the family, as Kate had explained at Study 1:
Mainly myself, [assists Brendan] but my husband is there to help as well, and my daughter too. And he also has all the family- will get in and help with things too and take him places if he wants to go somewhere. And his friends, they'll take him for drives and invite him over for barbecues and things like that (Kate, mother, 2002).

Brendan had been distressed by the changes in his physical ability, and frustrated by the limits this placed on his leisure activities and social life. He described being upset about, “just the fact that I can’t do things that I used to do. It gets a bit boring. Not being able to go out and do things with me mates that I used to do” (Brendan, 2001). In Study 2, Brendan explained that his friendships had been maintained after his injury, “My mates have been pretty big, too, for me. They’ve all stuck by me” (Brendan, 2014). Brendan’s friends played a particularly important role in his wellbeing, assisting in practical ways, and enhancing his self-esteem, as described in the family interview (2014):

Kate: If they think it's something that he can't do, they'll either help him with it...

Brendan: They push me, yeah.

Kate: Or they’ll say, come on, see if you can do it. But at the same time they're watching him and if he does - if they think he can't manage it, well they’ll help.

The family also described support from the wider community. Brendan was well known and liked in the local community, as Brendan explained:

The thing we're lucky with up here, though, this whole street knows each other. So we're all - it's a pretty tight street, this one. We're all friends so if no one's
here, Mum and Dad know that - they’ll let next door know or something, ‘Brendan's going to be home’ (Brendan, 2014).

This support had further bolstered Brendan’s self-esteem, and reduced reliance on his parents. Kate and William worried less when Brendan was alone because they knew the community were aware of Brendan, as William described:

He had a fall one night coming home from work here. One of the people he serves there [at work] seen him. She's come over to help him and there's another couple we know own a little restaurant up there in town. They were coming home and they seen him, so they came over and helped him up and got his groceries and put him in the car and drove him home. So there's a lot of people keeping an eye out (William, father, 2014).

The family presented as a close family unit. They all reported short-term incidences of depression, and noted that Brendan’s ongoing anger outbursts had been challenging. However, the data showed that the family had been adept at managing these negative impacts and conflicts. During the family interview, they displayed a culture of humour, open communication, and gratitude for one another. There was laughter, and an apparent enjoyment at being together. This was underscored by Brendan’s comment that he preferred not to work on weekends in order to have time with his father, who was away mid-week, “It's like, well I don’t want to be bloody working all the time because then I don’t even get to see him…it's nice to have some family time” (Brendan, 2014). There was no obvious underlying tension, and they all agreed on the same version of events. The family talked about having positive family dynamics which prevailed in the years since Brendan’s accident. Brendan described his family as close, stating that family means “pretty much every-thing” (Brendan, 2014). William agreed and added that “family comes first” (William, father, 2014). Kate
described them as “loving, caring, would do anything for anyone and respect each other” (Kate, mother 2014).

Kate and William acknowledged a post-injury change in family dynamics in relation to the attention focussed on Brendan compared to his sister Rose, as William explained: “because the daughter, she sometimes felt a bit left out because we were concentrating on Brendan” (William, father, 2014). Kate also described the challenges of this unequal attention on Brendan: “it was hard because you felt you were having to share - we were having to share ourselves between us all that can get very hard” (Kate, mother, 2014). Kate explained that Rose had spoken to her parents about these feelings of being left out. Kate reported assuring Rose that “we never meant for that to be that way” (Kate, mother, 2014). Unfortunately as Rose did not participate in the study her perspective could not represented. It was significant that the family had been aware of this unequal focus on Brendan, and that they had communicated about it. The family said that open communication had always been very important to them, as William explained:

*But we always instilled in both Rose and Brendan that if there was a problem, no matter how bad it was, you still have to come and talk to us and we will work through the situation. As we said, even though we may be cranky if it might be something not too good, but we will work through it, and to always tell us things* (William, father, 2014).

Brendan also noted the role of communication in avoiding family conflict, “If we’ve got a problem we talk about it. You don’t just build up on it and don’t say nothing, because the other person doesn’t know what’s wrong if you don’t say something” (Brendan, 2014). This family culture of open communication, and commitment to positive family
relationships was helpful for managing these areas of potential conflict, and contributed to meeting the emotional needs of all family members.

The family described how Brendan’s anger, had been challenging for the whole family. This was a far greater problem in the first few years, but Kate reported that he could “still have bad days,” and that he had only recently learned to better manage his agitation, “it's taken him quite a long while to be able to realise if he's in a situation, to get out of it - if something's agitating him, to back away from it. That has taken quite a long while” (Kate, mother, 2014). As Brendan’s primary carer, Kate bore most of the brunt of his anger, and she had become adept at diffusing Brendan’s anger and disengaging from it herself. She attempted to instil similar strategies in other family members. Family members found it difficult not to react to Brendan’s anger outbursts which created further conflict, and as Kate explained, “so it’s [Brendan’s anger] not only one problem, it creates other problems elsewhere as well” (Kate, mother, 2002). Brendan reported feeling that other family members did not understand what he was going through, as he had also expressed at Study 1, “they don’t seem to fully understand. A lot of the time I think they think we’re making excuses for me. Like oh yeah, it’s always something” (Brendan, 2002). Kate had played an important role as an advocate for Brendan within the family, and a mediator for family conflict:

And it’s just like with my daughter, she tends to find that hard to not say any more to agitate him. There have been some times when we’ve been out and she might have said something and he will go off. And I’ll just say ‘please don’t say any more’. But she sort of finds it hard not to and Brendan just explodes. And I say Rose, ‘well, I did tell you’. So it’s sort of, it does get difficult (Kate, mother, 2002).
At times, Kate also reminded William not to respond to Brendan’s outbursts; acting to diffuse conflict between other family members:

Even with William sometimes, things still do hurt him with what Brendan will say sometimes. And even though he knows that Brendan doesn’t mean it. Sometimes I’ve got to intervene and say ‘look, come on that’s it. No one say anything else, just leave it’ (Kate, mother, 2002).

Kate avoided becoming overwhelmed by recognising when she needed respite, explaining, “you try to snap yourself out of it if you’re feeling a bit like - if I feel like everything's getting on top of me, if I just have a little bit of me time” (Kate, mother, 2014). The relationship between Kate and William was important for sustaining Kate in the carer role, and William had provided important respite for Kate:

When William came home or something, I’d just - I’d say, I’m just ducking out for a little while, or something like that. Yeah, just to have that little bit of quiet time. It mightn’t have been for a long period of time, but just whatever you could grab here and there (Kate, mother, 2014).

For Kate, being understood and emotionally supported by William was also an important factor in her ability to manage:

I talk to William about different things. Like sometimes he’ll come home and just look at me and know that it’s been one of those days. He’ll say ‘has it been one of those days?’ and I say ‘yup’ (Kate, mother, 2002).

Additionally Brendan’s awareness of his own behaviour, and his tendency to apologise significantly decreased Kate’s stress:

I must admit he always apologises afterwards. If he has an outburst he’ll always apologise, because he says things he doesn’t mean. Sometimes they might not be
very nice, but then he'll turn around and say, you know I didn't mean all that?

I'll go, yeah I know (Kate, mother, 2014).

Kate said that she coped because she “had to” as there were no alternatives. William further explained the lack of formal supports available for Brendan had left them with no choice but to manage. The family saw it as their responsibility to care for Brendan, with residential care not seen as an option:

Kate: You just do what you have to do, as I said.
William: Because you can't put him in respite with all old people.
Kate: No, that’s not...
William: You just can't do that. (2014)

They were confident in this role, and believed that they knew what was best for Brendan, and as William noted, “there's not a great deal of help out there for people anyway, except for family” (William, 2014).

The family had been highly engaged in Brendan’s recovery and rehabilitation, and had worked as a team to maximise his outcomes and independence. William had been instrumental in getting Brendan back into the workforce, which had been a turning point in Brendan’s emotional recovery. The family had set goals to work towards, and looked for new options where others had failed. Brendan had been highly motivated in his own recovery, determined to get back as much as possible to his pre-injury life. Brendan’s focus had been on regaining his physical capabilities. As a healthy active young man before the accident he found his changed appearance and compromised physicality extremely difficult. Although the family reported that the worst of the experience was now in the past, there were continued challenges in terms of Brendan’s moods, and vulnerability. From Brendan’s perspective he was still working at keeping his weight down which was frustrating and exhausting. Concerns regarding his eyesight
and ability to care for himself in the future were also ongoing, as Kate described, “It’s never going to finish, but you have to deal and cope with whatever situations [arise]” (Kate, mother, 2014).

**Family 2 Alison’s Family**

At the time of Alison’s injury she had been living independently, and reported a close relationship with her mother Mary. Although Alison’s injury meant a considerable shift in practical terms (with Alison moving back in with Mary) it did not significantly change the family structure. Mary had been single at the time of the accident, with no other children, and Alison and Mary identified their family as being just the two of them. Mary’s marriage had ended approximately 4 years prior to the accident, and Alison’s relationship with her father had included periods of estrangement. This family structure meant that initially Mary cared for Alison as a single Mother. The circumstances of the divorce had strengthened the bond between Alison and Mary, and their relationship had been one based on mutual support. They operated as a team of two, which was helpful when Mary and Alison needed to work closely together over many years on Alison’s recovery. Although it was initially extremely difficult for Mary to care for Alison on her own, this structure was helpful in that Mary was willing and able to devote all of her attention to Alison, as Mary noted, “I really didn’t have to think of anyone else except myself and Alison” (Mary, mother, 2014). In the years after the accident the family expanded to include Mary’s new partner John, but this team of two dynamic between Mary and Alison prevailed.

Mary explained that she was well supported by work colleagues and friends. This support was important to her and came in the form of emotional and social support. Mary said that this support had been fundamental to her ability to cope, and vital to her ability to support Alison, “I think that was a fundamental thing of being able to cope,
that I was so lucky that I had the support of my family and good friends for me so that I could support Alison” (Mary, mother, 2014). Family was important to Alison and Mary, and Mary explained that even though most of her family were in Scotland they were a source of emotional stability and reassurance for her. Although Mary was a single mother, she explained that she had never felt alone due to the close bonds with her family. Mary suggested that it was her maternal Grandmother who instilled this idea that family should support each other:

...from my mother's mother, it's always been about family because she didn't have a good childhood so maybe for her it was all about making sure you look after one another and I think that's probably come down. We may not see one another for a few weeks, a couple of months. For my sister, I don't see her - maybe once a year or once every 18 months when we've gone home but the support is always there (Mary, mother, 2014)

There were positive and negative aspects of Alison’s family functioning post-injury, which were reflective of pre-injury functioning. The relationship with Alison’s father had been strained, and this was exacerbated after the accident. At Study 1, Alison and Mary explained that he had wanted to spend more time with Alison, but Alison was resisting this interaction. Alison was grateful for his interest and his financial support but she found him to be “hard work.” At Study 2, they reported that the relationship had continued to be difficult, “So he's been supportive in some ways and then Alison and her dad have disagreements... it's been a very up and down rocky relationship with her father yeah” (Mary, mother, 2014).

Alison indicated that she believed the accident was indirectly related to her response to her parent’s break-up, as this had influenced her choice of partner:

Alison: I probably wouldn't have had the accident.
Mary: Why do you think that?

Alison: Because I was looking for someone different to Dad.

Mary: You think you would have met someone else?

Alison: [Nods, yes] (2014)

Mary’s relationship with Alison’s’ father had remained unfriendly. In both studies Mary did not refer to him or his partner by name, but rather used “Alison’s dad/father” and “that female [step-mother].” The accident had forced Alison’s parents to interact which had been difficult:

Because I hadn't spoken to Alison's dad for four years, when the accident happened, I didn't want anything to do with them, I just got on with my life and they got on with theirs (Mary, mother, 2014).

Alison and Mary explained that his contribution had been primarily financial, and that he had little involvement in the practical aspect of Alison’s recovery and care, which Mary expressed some resentment about:

Support would have been nice, he used to give Alison money and think that as support, I'm hands on and that's the sort of relationship that he's not had [with Alison].(Mary, mother, 2014).

Conflict had arisen around the question of Alison’s independence. Alison indicated that her father had not listened to her perspective about wanting to live independently, which she had found frustrating. Alison’s father had viewed Alison as being more vulnerable and less capable than Mary and Alison did, and attempted to block their progress in this regard, as Mary explained, “[he] blames me for not being a good mother, it's been a long rocky road trying to be positive with her dad who wants to just wrap her in cotton wool” (Mary, mother, 2014). Mary attributed this to what she saw as his negativity, “he's a very negative person. He didn't want Alison to come and live on her own, and
thought I was doing the wrong thing” (Mary, mother, 2014). He had criticized Mary, suggesting she was trying to “get rid” of Alison, which had been upsetting for Mary. Although it had been stressful, this conflict had strengthened the bond between Alison and Mary. Although Alison’s father disagreed with Mary’s approach, and this caused conflict, he was not in a position to influence this outcome, so the impact was negligible.

The relationship between Alison and Mary appeared close, and they expressed gratitude and respect for each other. Affection was evident in the family interview with Alison saying, “I'm happy that I have your support, to which Mary replied, “Oh, I know that. I get some lovely hugs” (2014). Mary described how she and Alison expressed their love for each other when Alison was still in hospital:

    Alison couldn't articulate to you how she was feeling and it was always - we always had this little sign, I love you and we used to just - I used to do that to her all the time and she'd do it back. So just - I think letting Alison know that I am there - you know, mum's here (Mary, mother, 2014).

Mary and Alison had spent many years working very closely together and Alison indicated that she felt her relationship with her mother was closer as a result of the accident.

    Maximising Alison’s independence had been a shared goal for Mary and Alison, and had provided a focus for them to work towards. For Alison an important turning point in re-gaining her independence involved getting back to University, about which she said, “I could see my freedom” (Alison, 2003). Mary and Alison had worked incrementally towards their goal of Alison living independently. Mary believed that Alison had shown her capacity to achieve this goal, and felt it was important for her future not to depend on others:
To me it was important that Alison could live on her own. I used to work at a Hospice and I saw lots of brain injury people there being really not well treated by the staff. I thought that’s the last thing I want for Alison (Mary, mother, 2014).

For Alison, living independently meant freedom and autonomy, as she described: “I have my freedom to go to bed, when I want to walk around naked” (Alison, 2014).

Mary had been adept in the role of primary carer and advocate for Alison, devoting herself without question to Alison’s recovery. Mary showed a high capacity to engage with rehabilitation specialists and understand the medical aspect of Alison’s injury. Mary was a highly driven, motivated carer and advocate for Alison, and saw herself as the only person fighting for Alison’s rights and her future:

To me that’s everything, yeah, not to give up. I’m the only person she’s got on her side. Everybody else is saying she's not going to make it or they're not saying anything. The fact that they're not saying anything means that I'm the only person in her corner fighting to make sure that she gets the best that's available to her (Mary, mother, 2014).

The fact that Alison had lost her speech meant that Mary had been determined that she not lose her voice. She had worked hard at supporting Alison to speak for herself in public. During the interview Mary consistently checked with Alison that she was representing her perspective correctly, and was mindful of not speaking for her, saying for example “I don’t know how Alison feels about that because that’s her perspective” (Mary, mother, 2014). At Study 1, Alison and Mary had spoken about a presentation Alison delivered for first year occupational therapy students about different ways of communicating. It had been important for them to show others that Alison’s lack of speech did not make her insignificant or “stupid,” as Mary explained:
And to have Alison there as well, saying, ‘I am not stupid, I am not dumb’ You know, they see this person from a car accident or some kind of brain injury who can’t speak. They have certain ideas, yeah. It’s all going on up here, it’s just getting it out in different ways (Mary, mother, 2003).

Mary and was confident in her role, and displayed a commitment to ensuring Alison received the best care possible, even taking on care responsibilities herself when she felt standards were lacking. This early move to take control and responsibility for Alison’s care and wellbeing characterised Mary’s response, and was maintained throughout Alison’s recovery. Mary’s ability as a carer and her determination to maximise Alison’s physical recovery and independence contributed to Alison’s positive outcomes.

Mary reported feeling emotionally supported by family and friends; however she undertook the practical tasks of Alison’s care largely unassisted. Moreover, Mary explained that much of the informal support from friends “sort of fell away” once they had returned home, leaving a significant care responsibility with Mary. Mary initially took time off work, however financial reasons dictated that she resume work whilst still caring for Alison. Mary described a hectic and relentless schedule:

Yeah, the carers would come in during the day and I might throw in the sheets, can you hang that out for me, so that you know, we end up having commodes, but Alison - I was toilet training, working. On my days off I would organize hand therapy, we'd be going in to PA for speech therapy for yeah. The assistance was yeah I probably didn't know where to go, where do you go? (Mary, mother, 2014).

This was an extremely difficult time, and as Mary explained in Study 1, she had begun to feel tired and concerned for her own health:
I’m tired. It’s been two years and it’s been a long journey supporting Alison. My concerns are probably my health. Hopefully it will stand me in good stead for the next few months as well. But I am tired. I can see that— I think my tolerance levels, yeah, I can feel them getting a bit low (Mary, mother, 2003).

Mary explained that she used “a lot of self-talk and trying to have time out” as coping strategies, and she emphasised the importance of “knowing the triggers” (Mary, mother, 2003). However, as Mary revealed in Study 2 she had reached breaking point shortly after this time. Having been told she could not receive any additional at home care support Mary described how she was forced to threaten to abandon Alison in order to get the help she needed:

...well that’s when I had the breakdown, three years later...I was working full time, I was caring for Alison at nights. Alison was still a baby up until what - she was still in incontinence pads, so I was still trying to get Alison off of incontinence pads basically toilet training an adult...I just went you know what I can't do this anymore...I said I'm three years down the track, you can have Alison. I said you can put her in to a nursing home, and I knew it wouldn't happen, for the fact of it would cost them an absolute fortune to put Alison in to a nursing home, to be looked after 24 by seven, whereas I was doing it and I wanted six hours (Mary, mother, 2014).

This crisis eventually resulted in increased care support hours, however Mary felt she should not have had to reach this point to receive the assistance she required.

On top of the demands of caring, Mary also described a significant emotional trauma associated with nearly losing her only child and having to adjust to the extent of Alison’s injuries, “For her, having twenty years of speech and then not having speech at this time is very frustrating. And to watch that frustration, as a mother, is very
heartbreaking” (Mary, mother, 2003). During the interview Mary had spoken a lot about this emotional trauma and grief, often crying as she related her experience: “Well we were told seven days after the injury they were going to turn off the machine. So that was probably the worst day ever” [crying] (Mary, mother, 2014). Mary had coped by focusing on Alison’s recovery, and drew strength from Alison’s achievements.

Mary spoke about being inspired by Alison’s capabilities and determination:

Oh, I’ve got nothing to complain about. Alison is an inspiration to me. The fact that she can do so much for herself. And she doesn’t complain. She never complains about it. She gets frustrated at time. But she copes really well (Mary, Mother, 2003).

For Mary this helped her to cope with her own sense of grief and loss, which was expressed in her reflection, “if Alison can manage, then I can manage” (Mary, mother, 2014), underscoring the reciprocal relationship between them.

Mary indicated that Alison’s lack of awareness of her losses served as a buffer because she did not dwell on her deficits. However, there had been a significant emotional impact associated with feeling abandoned by her partner and friends after her injury. Alison’s relationship with the driver of the vehicle ended within the first year, the circumstances of which were distressing for Alison. Alison described him a “big jerk”, saying “he doesn’t want to know me” (Alison, 2002). As a result, Alison felt excluded from the group, and rejected because of her disability. Mary believed that this abandonment was a bigger issue for Alison than recovering from her injuries:

So that, to be let down has been huge, and if you look at it on the scale, that outweighs any rehabilitation Alison has done...that outweighs it. It’s huge. It’s absolutely huge. And people don’t understand that. They think, ‘oh he’s gone’. But it’s not that easy for Alison (Mary, mother, 2003).
Alison’s comments support this view, as she noted, “I did feel angry about it. That was ages ago, but I still feel angry” (Alison, 2003). With Mary’s support, Alison had focussed away from these sources of distress, and onto her future goals of physical improvement, travel, and activities in the community.

**Family 3 Daryl’s family**

Daryl’s family structure was that of a nuclear family within which he was the husband/father. As a result of his injury, the family structure shifted slightly as Sharon took on the role of sole income earner while Daryl was off work for approximately two years. Sharon had worked prior to Daryl’s injury so this did not constitute a major change. However, the loss of Daryl’s income was a significant stressor, with Daryl describing the family as having been “financially destroyed.” Sharon had needed to take control of the family finances from Daryl which added further stress, as they explained:

Sharon: *before it happened he had control of the finances.*

Daryl: *I wasn't very...*

Sharon: *He wasn't very good at it, the house was behind the repayments*

Daryl: *We were in trouble*

Sharon: *I didn't know until afterwards, when you get a letter from the bank saying your mortgage is this. That's all of a sudden it's - apart from what you're suffering and then have to go through that too.* (2014)

Sharon described her role as that of a single mother when Daryl was first injured:

*I was working at the time, and I had plenty of support through work as well. So if I had to take time off work or anything with the kids - because I was on me own - then that was fine by them, they didn't - I didn't lose anything for that* (Sharon, spouse, 2014).
At the time of the family interview, the family were supportive of each other and appeared happy in each other’s company, with humour often being used to relieve the seriousness of their stories. Daryl and Sharon explained the importance of their friends who assisted the family when Daryl was recovering. Two female friends in particular, Sandra and Cheryl, were highly involved in Daryl’s recovery. They were considered part of the family and Sandra participated in the family interview. Daryl’s mother was also involved in Daryl’s care when he first came home from hospital. This team of extended family and friends where viewed as being critical to the Daryl’s recovery.

Daryl expressed enormous gratitude for this support as he explained, “and I still think that was my saving grace, was I was lucky. Because I had a supportive wife and I had a supportive mate” (Daryl, 2014). At Study 1, Daryl had also described the importance of the support from family and friends:

My wife is sort of always there for me as could be expected. I’ve got a real large support group of my mate around the corner and couple of my wife’s girlfriends. That sort of thing. So it’s only a matter of saying, hey I'm stuck, and three or four people put their hand up and say we'll come and help you (Daryl, 2001).

As a result of this team approach, Sharon was able to able to focus on the children and continue working, which was necessary for the family financially. Daryl joked that the family were “pretty dysfunctional,” but family was seen as the place of refuge for family members when they most needed help. This belief that families should stick together and support one another in a crisis was evident in Sharon’s decision to stay with Daryl at the time of the injury.

Sandra described Sharon as a “strong woman,” and Daryl said she had “very big shoulders,” suggesting that they viewed Sharon as having brought the family through
the crisis. Daryl had referred to Sharon as “the Goddess” and both Daryl and Sandra described Sharon’s role as having been crucial to Daryl’s recovery, and keeping the family together:

Sandra:  *It definitely took a toll on Chrissie, definitely took a toll on her. I think just from the - I don't know, I think the love that she has for Daryl and the support that she gave Daryl was amazing...*

Daryl:  *Phenomenal yeah.*

Sandra:  *...absolutely amazing.*

Daryl:  *Because she got me through it.*

Sandra:  *A lot of people would have just packed up and walked away*

Sharon appeared uncomfortable with, what appeared as reverence from Daryl, responding with, “*No, I don't know about that* (Sharon, spouse, 2014). From Sharon’s perspective she was simply doing what she felt was her duty to the children. Sharon also explained that she had been too “*proud*” to be seen as a failure in the eyes of her father, which had added to her determination to keep the family together:

> Yeah, and I think it's my upbringing more than anything else. I'm too proud to go down that road and ring up me father and say, look with what everything he's done for us and everything to help us get where we are, I couldn't ring him up and say, look Dad I've lost everything. I'm - I've had enough, I'm coming back. I guess I just wanted to show that I was stronger than that (Sharon, spouse, 2014).

Despite this praise and gratitude, data from Study 1 suggested that Sharon was not actively engaged in Daryl’s recovery, but rather delegated that role to others. For example when asked if Daryl had emotional support Sharon was unsure:

> *His mother actually lives with us at the moment. She’s home- like I work during the day. I don't know if he talks to her. I'm at work all day. He wouldn't tell me*
if he did and neither would she. I guess he can get support from her (Sharon, spouse, 2002).

Daryl reported a significant emotional and psychological impact associated with his injury which he described as the most debilitating aspect. He suffered anxiety and depression due to the violent nature of his injury. He described himself as being a “nervous wreck” when he transitioned from inpatient care to home, “I wasn't worth two bob when I got out of the [Brain Injury Rehabilitation Unit], I was just a nervous wreck. Oh I wasn't worth two bob. I had a lot of trouble dealing with that” (Daryl, 2014).

Daryl had become fearful of being around people, and found himself isolated and depressed to the point where he was at risk of suicide, “I could never understand why they said, you're on - I was on suicide watch. Now when - now when you look at it, I understand why I was on suicide watch” (Daryl, 2014). Daryl had displayed an awareness of when he needed support, and had strategies for seeking help, “When I feel that I’m striking on the bottom of the barrels I just ring up [psychologist] and say you’ve just got to slot me in somewhere” (Daryl, 2002).

Daryl had noted his frustration at being dependent on others at study 1:

...my lifestyle that I used to lead has changed and come full circle. I do everything different now. Where I used to be fully independent and do pretty much me own thing all the time now I sort of rely on other people (Daryl, 2001).

According to Sharon, Daryl had continued to be highly dependent on her. Sharon indicated that she had not wanted to mention this during the family interview, but at the individual interview she explained that Daryl had remained highly dependent, “he never wanted to do anything alone...he’d prefer someone be with him” (Sharon, spouse, 2015).
Daryl and Sharon’s relationship had been at breaking point prior to the injury, and Sharon stated that it was only due to the injury that she had stayed at that time. At Study 1, both Sharon and Daryl had noted positive relationship changes post-injury. Daryl had commented that he had been a better husband and father after the injury. Sharon had noted similar positive shift, going so far as to comment that the assault may have been “for the best”:

> So probably in the long run it’s all sort of been for the best because things were pretty bad before it happened. And it’s made him realise that I was a mother, I worked, I did all the chores. Daryl was out with his mates drinking. This was all beforehand and it’s really changed him. It’s really turned him around. Now he sees what I went through for most of the years of our marriage (Sharon, spouse, 2002).

At the time of the injury, Sharon’s focus had been on keeping the family together, and protecting the children. Sharon had explained at Study 1 how she had tried to spare the children any trauma from seeing their father injured:

> It’s been pretty hard on the kids. You know when it first happened I wouldn’t even let the kids in to see him because it was something I didn’t want them- you know he was in such a mess. You know, you couldn’t tell who he was. It was something I just didn’t want to put the kids through. It wasn’t worth it. So they didn’t actually see him until he was taken out of intensive care and admitted to a ward. And even then it was bad enough. They commented on- especially his eyes (Sharon, spouse, 2002).

Daryl had also expressed concern at Study 1 that the children could often bear the brunt of his frustration:
Yeah, the kids rather dad not stressed out than stressed out because then I get really wound up and the kids cop the brunt of it. Not so much the brunt of it. But once I get stressed out then I get aggravated and grumpy as they say, ‘grumpy dad’ (Daryl, 2002).

Daryl had reported at Study 1 that the children understood what was happening, and described the ways in which the family were able to integrate Daryl’s memory deficits into their lives:

*They deal with it. They know dad has got a problem and they help. The best thing about the kids is that they’re always prompting me. Not so much testing me I suppose, they’re always there to help me and prompt me- ‘dad you were going to do this’. I still have a bit of a short problem- a short memory problem* (Daryl, 2002).

Daryl explained the important role the family’s informal support network played in helping the children:

*And we had, my little, not so much family support group, but I’ve got a little group of people here around me. A group of friends who have always been there. Fortunately they’ve always been on the right track most of my friends. So they’ve been able to steer, well not so much steer the kids, but just explain some things the kids don’t understand when Sharon is not around. It’s worked out pretty well* (Daryl, 2002).

The children who participated in the family interview did not have clear memories of the time Daryl was injured, and did not report feeling distressed by it. Daryl’s daughter Susan described that part of their lives as feeling like “a week:”

*In my memory I feel like it happened for a week. I feel like Mum was on the phone, at the door, we walked in, I went and picked him flowers out of our*
garden. I remember seeing him lying there and then after that, that's all. That's why I felt like it was like a week, kind of thin (Susan, daughter, 2014).

Daryl’s daughter Selina described good memories from the time of Daryl’s early recovery, saying “I can remember the good things but not the bad” (Selina, daughter, 2014). The memories that Daryl’s daughters described were often positive. For example they could recall laughing about Daryl being a pirate when wearing an eye patch. They also related how Daryl would forget he had fed them:

Selina: You'd feed us like six times. ‘Oh didn't I just feed you?’

Susan: Yeah, but we're still hungry dad.

[Laughter]

Sharon believed that in the long-term, Daryl’s injury had not affected the children, “I don't really think it made a lot of difference, because the kids were all - like I said, they were only young then, so I don't think they fully understood” (Sharon, spouse, 2014). Sharon and Daryl were grateful for this as Daryl explained, “we're probably fortunate that kids don't remember a great deal of it, because it was a pretty torrid time” (Daryl, 2014).

Daryl’s family described the immense stress, emotional trauma and financial hardship they had faced following Daryl’s injury. However, for this family it appeared that the injury was experienced as something in their past, that they had overcome and no longer thought about. Sharon and Daryl frequently described it as “so long ago.” Daryl had described himself as being “lucky’ in terms of his outcome, and his capacity to “deal with most that's been coming towards me” (Daryl, 2002). The turning point had been reported as when Daryl recommenced employment approximately two years post-injury, and beyond this point they did not perceive the injury as having impacted significantly on their lives. Although Daryl’s memory impairment had not improved, it
appeared that the family had come to view it as part of Daryl’s personality, no longer seeing it in the context of his brain injury.

**Family 4 Neville’s Family**

Neville’s accident represented a significant structural and functional change for this family, due to personality change in Neville and the necessity for his wife, Jo, to take over Neville’s previous family roles. Although the structure of nuclear family ostensibly prevailed post-injury, the family functioned more as a single-parent family, with Jo in charge. During the interview, Jo frequently spoke in terms of “I” and “me” rather than “we,” underscoring her experience as that of a single parent, for example “…because Neville was no longer working and I had two dependents, they [Centrelink] were supporting me then. So they supported me every fortnight” (Jo, spouse, 2014).

Both Neville and Jo reported that a strong informal support network of extended family and friends had been available to them following the accident. Their parents were divorced and remarried, and all played a role in supporting the family. Neville credited Jo’s late father and step-mother as being the family’s closest supports at the time of the injury, along with his two sisters. Jo discussed how important it was for her to have that support at the time of the accident, particularly in relation to explaining the situation to the children:

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I just think the support of family is very important. It helps a lot I think, especially when you have little ones that don’t understand. And you don’t understand much yourself what’s going on at the time. And you try to explain it.
I think very close friends and family are very important (Jo, spouse, 2002).
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Jo detailed how Neville’s parents had shifted their focus from Neville’s sister, who had been experiencing post-natal depression, to Neville at the time of the accident. Jo discussed how the accident was the catalyst for deepening her relationship with one of
Neville’s sisters, explaining, “I think stemming from the actual accident, the friendship that I - it was only a very new friendship, but it grew from there” (Jo, spouse, 2014). Beyond the family, Neville reported that he found support through work colleagues, while for Jo it was from friends, and their church social network. Although they received little formal support, the family’s informal supports had been crucial to their stability:

So it has been a struggle. It has. It’s been a very big challenge. I think without the support of friends and my family and also my faith, I think I probably would have crumbled a lot worse (Jo, spouse, 2014).

Observations of the family suggested that the members were relaxed and happy around each other, with Jo and Neville showing obvious affection for each other. Jo appeared to be the authority figure in the family, organising the children and assisting Neville. In organising the interviews, Neville directed me to make arrangements with Jo, and he frequently deferred to her during the interview. At Study 1, Neville appeared to be very dependent on Jo to explain things and help him make decisions. This dependence was still evident at Study 2 with Neville often checking the validity of his responses with Jo. For example, at one point, Neville described some of the challenges they had faced after his accident, but was not confident about his answer:

Neville: see I slept most of the time, from what I've been told. Jacob and Emily were quite young, pre-school and being looked after while Jo came up and saw me in hospital. So yeah, would you agree? Finding someone to help look after the kids.

Jo: Yeah, there's probably a lot more involved as well.
Neville’s lack of awareness after the accident meant he did not have the same perception of the injury as others:

*I probably don’t think I’m any different and Jo seems to think I'm different, which is fair enough. But also the guys at work seem to think I'm different as well, and so does my parents. So they must be right. I think they're still wrong* (Neville, 2014).

Neville appeared not to trust his own judgement, and frequently deferred to Jo. This dependence on others and lack of confidence in his cognitive abilities was frustrating for Neville. During the family interview, Jo described how her role had change and how this altered relationship with Neville had remained the same to the present day:

*I then had to become the mother and the father, so to speak, I was everything. I'm still very much like that and Neville relies very much on me doing that too…I just sort of slipped into the role and it stayed that way kind of thing* (Jo, spouse, 2014).

Jo said that Neville had become more of a *third child*, and Neville described Jo as the *brains of the family*, indicating a diminished role for Neville within the family, and a concomitant loss of self-confidence. Neville had noted low self-esteem as a concern at Study 1, and Jo had also explained how Neville’s confidence was diminished generally, but particularly in terms of his role as a father, “*Maybe his confidence as a father and overall. I guess his confidence and self-esteem has dropped a lot I’ve noticed*” (Jo, spouse, 2002).

Neville and Jo had experienced considerable relationship conflict for up to 6 years post-injury. Neville alluded to this conflict, and his own frustrations in Study 1, as he described how the family adjusted 12 months post-injury:
...and the things my wife picks that I’m not as tolerant as I used to be. And I get frustrated sometimes. I’ve just got to be careful I don’t get too frustrated with my wife and the two kids. Because we’ve got a two year old and a five year old (Neville, 2002).

Jo explained how the pressure of her new role with Neville becoming dependent on her contributed to relationship conflict:

*I just felt like I was doing everything and I wasn’t having that husband support that used to be there, that kind of thing. I felt like a lot was all on my shoulders, that sort of stuff really. I suppose it’s the little things that explode then, don’t they? So yeah, we did have a few arguments* (Jo, spouse, 2014).

Personality changes in Neville were the most challenging aspect of the injury from Jo’s perspective. Neville came home from hospital as a “different person”, meaning Jo felt she had lost her husband, as she explained:

*But it is hard and especially at the start, when you bring home this man who was one way and then he’s suddenly a different way. I think that was the biggest battle for me, was trying to deal - because it was basically like bringing a different man home. It was like, well can’t I take him back and get a refund, or it’s like, you’ve sent me the wrong man home* (Jo, spouse, 2014).

Jo had responded to the situation by focussing on the wellbeing of the children. Her primary motivation was to keep the family unit together for their sake, and to minimise any possible trauma for them. She explained how her desire to protect her children was a source of strength for her at the time of the accident:

*I mean I had a very lot of support, so I was very fortunate. But I think what clicked more for me was the children...They need at least one functioning parent. They need someone to rely on and to look up to* (Jo, spouse, 2014).
Later, Jo’s belief that the children deserved to have a father and be part of a family unit served as a strong motivation to stay in the marriage:

Look, the easy thing would have been to pack up the kids and run away, but that’s just not me. That’s not who I am. So I had to deal with what I had. The children deserved to have their father. So they deserved to have a solid family environment (Jo, spouse, 2014).

Jo’s Christian faith and her beliefs about marriage further supported her resolve to keep the marriage together, despite the challenges:

But I have a lot of faith as well and I’ve grown up in a Christian background. So I’ve always tried to say to Neville, I do take my vows very seriously, in sickness and in health, and unfortunately we had a very bad kind of sickness that we had to deal with (Jo, spouse, 2014).

Jo described how, although Neville’s life was on hold while he recovered, she needed to keep moving on with life to ensure a stable environment for the children:

I mean, as much as you don’t want it to, life still goes on, you still have bills to pay. I tried to keep the children, I guess, as normalised as I could...tried to keep them in their normal day to day routine (Jo, spouse, 2014).

Adapting to Neville’s personality change and cognitive deficits had been difficult for Jo, and although the relationship had improved, she continued to experience ongoing frustration. Neville felt similarly frustrated, as he did not perceive himself as being different, and the couple reported a high level of conflict for up to six years post-injury. They described eventually reaching a compromise where they came to accept that they saw things differently:

I probably had to try to accept what Jo was saying to me, that I was different, even though I didn't agree. I probably had to try and accept and live in
naiveness to think well, I'll just agree with you or disagree with you (Neville, 2014).

Similarly Jo came to accept that Neville had permanently changed. This happened over many years, and as Jo explained, “it’s definitely been a challenge, and it certainly didn’t happen overnight. It took years” (Jo, spouse, 2014). The family reported that they had not received any formal support relating to their relationship, or what to expect when Neville returned home. Jo explained that the only advice she was given regarding her relationship was that “It normally takes seven years and you'll be right,” which had not provided her with any useful information or strategies. Instead they were left to manage the relationship problems themselves.

A coping strategy for Jo had been to move on from the accident, and focus on the positive aspects of their life, and she had attempted to instil this in to Neville. Neville had agreed at study 1 that he wished to move on and not talk about the accident. This was the reason Neville and Jo withdrew from that study, as they felt dwelling on it created more problems. However, Neville had struggled to maintain a positive attitude. He described a range of ongoing issues and concerns. He expressed cycling through periods of regret and negative emotions about his injury:

I go through stages. Some weeks I feel good. Some days I feel terrible. I still go through stages like when I get real bad headaches. I think why me? So I still go through stages where I think, I wish I could just step back in time. We all just disappear and go back to being - so we're a lot happier and more content with life than I should be, than I actually am (Neville, 2014).

Although Neville reported that he was not aware of changes in his personality, he did report difficulty adjusting to the cognitive changes. He conveyed a lack of confidence and low self-esteem, expressing disappointment and frustration with himself:
Yeah, because I used to get disappointed - I know I've done that wrong. I can't brush it under the carpet. But then later on, I do the exact same thing again, so I try and brush it under the carpet, but the carpets too high, I can't fit it under any more (Neville, 2014).

Neville described feelings of self-blame and distress about his injury, and was not able to find comfort in the belief that there was a reason or meaning behind his injury in the way that Jo had done:

You do blame yourself, say well why did I do whatever I did wrong to end up in this situation... why me? A lot of the time is, why me? Why did I have to get that? What have I done wrong to deserve what I've got? (Neville, 2014).

Neville also expressed disappointment in himself as a father and husband, “Yeah, certain things in home life I think I probably should have done much better” (Neville, 2014). He was highly critical of his himself comparing himself unfavourably with his son:

Especially when Jacob's 16, you think, well the way that he's gone about doing something, I probably should have been logical enough to do it the same way as him (Neville, 2014).

Neville also spoke about fears he had for the future in terms of shortened life-span or further cognitive decline. Neville had voiced almost the same set of concerns at Study 1, suggesting he had been unable to move past these concerns. Jo had been surprised to hear Neville’s comments. She had been unaware that Neville still had any concerns, revealing Neville’s tendency to supress negative thought and emotions. At Study 1, Neville explained that he did not have any strategies for coping with his anger and frustration, other than “I try and switch off” (Neville, 2002). In light of his
revelation of ongoing problems at Study 2, after the family interview, Neville and Jo decided that they would contact a brain injury service.

**Family 5 Nathan’s Family**

Results for Nathan’s family primarily reflect the views of Nathan’s mother June’s perspective, as it was the family’s wish not to participate in a family interview and family members reported that June could represent their views. June requested separate interviews for herself and Nathan, highlighting the differences in awareness between Nathan and his family regarding his injury. Although Nathan felt there was “nothing wrong with him,” the family were acutely aware of executive function impairments, which they believed made him vulnerable, and unable to live independently.

At the time of Nathan’s injury, he had been living at home with his parents and sister, and this nuclear family structure was maintained following the accident. Prior to the injury, June’s role was that of running the household and organising the children’s lives while Len was the main breadwinner and regularly worked away from home. These roles were well established pre-injury, and they did not change as a result of the accident. Although there were extended family members in Brisbane they had not played a significant role in relation to Nathan’s accident. At the time of the accident June had been caring for her mother who was suffering from dementia. June was no longer able to provide care for her mother as well as Nathan, resulting in June’s sister taking on this role at the time. Apart from this early shift, the family roles remained unchanged.

The family’s response to Nathan’s injury was heavily focused on June’s individual response, with her taking complete responsibility for Nathan’s care and recovery. The other family members supported her and agreed with her actions, but
were not overly involved. This was consistent with the family’s pre-injury functioning, and served to keep the family stable over time. June absorbed any changes arising from the injury insofar as she gave up work, and assumed a carer role, which allowed for the rest of the family to continue their existing routines, as June explained:

There weren't any changes. I mean, my daughter still went to school; Nathan went to school the following year, did year 12…My husband worked away, so he went off to work and I was by myself (June, mother, 2014).

Due to Len’s absence, June viewed Nathan’s care and recovery as something she had to manage herself. This is evidenced in her language which often referred to what ‘I’ did rather than what ‘we’ did, for example, “I was on a learning curve, although I had seen documentaries about head injuries, but now it was happening to me” (June, mother, 2014). June was confident in the carer role and her ability to do it well: “Well, I know I’m strong. I’m not stupid. I know I’m coping with a big job, and I know I’m doing it pretty well” (June, mother, 2014). She was highly self-reliant and did not seek help from others, seemingly not needing family support even when Nathan was in hospital: “and I just said to Lynne - I went to the hospital every day - I said, you can come if you want or don’t come” (June, mother, 2014). Initially, June felt the need to shut friends out as the involvement of others was experienced by June as a burden: “I kept all my friends away. I didn’t want to see them, I didn’t want to talk to them, because they all asked the same question: what's going to happen - and you don't know” (June, mother, 2014). For June, it was helpful that friends had been available after Nathan’s injury to offer practical support, but she was not looking for emotional support, and rather sought solitude at a way of coping, “I liked company at the hospital, so I enjoyed people coming to visit at the hospital, but I didn't want them in my house. It was too much
(June, mother, 2014). June viewed herself as the most appropriate person to fulfil the carer role, describing it as her duty as a mother:

    So it was my job and my duty, and I did it...Because that's just the sort of person I am...Well, I'm dutiful. I have a sense of duty, and that was my duty. I couldn't have done anything else (June, mother, 2014).

June appeared to accept this responsibility; however her responses indicated some tension and resentment in that she felt she had no choice, stating “my husband works away, so someone had to be home full time” (June, mother, 2014). She commented, “so my husband took the opportunity to go back to work as soon as he could. But that's always a mother's job (June, mother, 2014). Saying that Len “took the opportunity” to get away leaving her to manage alone suggested some anger, but at the same time she restated that it was her duty as a mother. June also suggested that Len’s absences contributed to their marriage staying together as it gave them “breathing space” from each other.

    June explained that at the time of Study 2, her friends and social life were a source of enjoyment for her, and an important factor in her ability to cope with the pressures of Nathan’s situation. However, her tendency to keep a separation between her role as Nathan’s carer and the rest of her life continued to the present. June indicated that she preferred not talking about Nathan with friends, relying on them as a form of escape rather than a source of direct support, explaining, “I don't discuss Nathan very much with any of them. They are my recreation (June, mother, 2014). This indicated that June’s early response of relying on herself rather than others had been maintained over the long-term. June said that she had been able to cope most of the time, acknowledging that her financial situation had helped, “because we've obviously got
money [indicating the home], so I can get myself a holiday or pack myself off to the health farm if I want to” (June, mother, 2004).

June explained how the family had approached Nathan’s recovery as “a marathon”. She described how life did not stop because of Nathan’s accident, but rather how they had to get on with their lives despite Nathan’s situation, “Well, yes, you try to keep Lynne's life running along, and the people at the hospital said, oh, you know, just keep living life, this head injury is a marathon. (June, mother, 2014)

June indicated that Nathan’s behaviour had created conflict in his relationship with Len, and that she had become adept at mediating this conflict. June explained that Len lacked patience with Nathan, and described her role as mediator and advocate for Nathan within the family:

Well, I'm the one who sorts it all out. I'm the one who says, you know, 'just think’ - well, the last time he was out there, he wanted Nathan to do something and he didn't do it right, and he yelled at him, and then Nathan rang me and said: ‘I'm not staying out here, Dad's a bastard, blah, blah, blah’. I said, ‘oh Nathan, I'm sorry to hear that, but you can't come back in right now because, you know - so try to make the most of it. Just remember, I'm going to pay you for doing that work out there, and you'll get your PlayStation’ or whatever it was he wanted. He goes, ‘oh yeah, that's right.’ Then I sent my husband a text and said: ‘today is January 5, 12 years ago your son came off a motorbike out there, and just think, he's lost the best years of his life, and you're yelling at him’ (June, mother, 2014).

June explained that she felt Len was capable of behaving more patiently with Nathan, but that he was lazy in this regard:
He's the boss of an oil rig where everybody jumps any time he looks at them and families don't operate like that. So he's, you know - he knows, but he could be more disciplined, but he isn't, and that's because he's got me (June, mother, 2014).

The responsibility to manage Nathan’s injury sat with June, and her response was akin to that of a martyr. June resented having to explain strategies to Len but she did it all the same, “I do resent the fact that I have to remind him. But, I do” (June, mother, 2014).

At Study 1, Nathan and June’s relationship was typical of a mother and young adult son, with their comments indicting a slight conflict over Nathan’s “she’ll be right” attitude towards his studies, and his push for greater independence. At Study 2, the relationship was still characterised by this conflict about his independence and choices, as June explained, “It's good. I mean, he hates me because I am the big boogie man, but he loves me” (June, Mother, 2014). Nathan’s relationship with his parents still appeared to be that of a teenager. June explained that she felt he did not listen to them, and that in contrast with his old friends who had grown up that Nathan was still a “boy.”

And because he had his accident at 16 and a half, there's an element of him who's still 16 and a half - the boy, and they've moved on. They don't just want to go out because they're out of their parents' jurisdiction. He still does (June, mother, 2014).

The interview with Nathan appeared to confirm much of what June had said in terms of Nathan’s awareness about his disability. He saw himself as having recovered very well from his injury:

Not saying that you know, everyone with a brain injury has rebounded from their accident as well as I probably have... well I'm very able to speak properly. A lot of people who have damage, brain injuries especially, have a huge
difficulty with speaking, or understanding things in the right sort of way (Nathan, 2014).

Nathan noted his appreciation for the support his family had shown him, in providing food and accommodation, and also in terms of providing support which he could trust, “Having someone who you can go and talk to, without any fear of repercussions, or - and you know that their opinion is in your best interest” (Nathan, 2014). In contrast, he expressed frustration at what he described as pre-conceptions in others about his injury, “or they just go oh, well that's right, you had a head injury so you can't do this, you can't do that. I've experienced too much of that” (Nathan, 2014). When speaking about contributing to household chores he commented:

...doing the dishes, doing laundry. I'm very capable of doing all those sorts of things. When I'm asked I do it instantly, but yeah, and also there's rules. So I can't go having parties here, or bringing some unsavoury people over (Nathan, 2014).

This description contrasted with June’s account where she had spoken about Nathan not following their rules. June had relayed a story about family conflict created by a female with whom Nathan had a relationship. The relationship had become so destructive that June had threatened police action if the female came to the home again. Nathan’s response to my questions about any family conflict did not reflect this recent, pertinent and highly salient situation:

Nathan: Issues? There's always issues, it's like how you work through those issues.

Interviewer: And how do you? How does the family work around things?

Nathan: Well, I obviously take their considerations on judgement. I analyse it, then usually we come to an understanding. Or I realise that my
behaviour was completely - this isn't a situation I don't - I can't think of any particular situation, but if my behaviour was irrational or in - no excuses for it, then you stop it.

June indicated that there had been conflict between Nathan and the family prior to his accident, and June had performed a similar role at that time:

*He was out there* [risk-taking]. *He was totally out there, and see, I used to work in social work a long time ago. His father used to think he needed a kick up the arse, whereas I used to talk him around. I did things like drag him off to a solicitor to say, listen, if you don't pull your head in, you're going to end up - you know, get the solicitor to give him a big talking to* (June, mother, 2014).

June spoke about her attempts at increasing Nathan’s independence following his injury, but her doubts about his capacity, and fears for his safety had inhibited this. June had expressed concern for Nathan’s future at Study 1:

*His future. I mean everything about his future. See he was only 16½ when he had his accident. So really, what he was going to be like when he was 25 was an unknown quantity anyway. But, yeah, of course I worry about that* (June, mother, 2002).

At Study 2 solutions for Nathan’s future were still elusive:

*So really, you sort of think, oh well, where am I going to be in 10 years’ time? Probably with my son. My husband has his head in the sand a bit about that. I don't think he really digs it. But I think he'll be with us for his - I mean, if I knew how to go about the Filipino housekeeper, I would, because that would be good. That would be good* (Mary, mother, 2014).
June’s responses and her management of the consent process indicated that the family did not believe that Nathan had the capacity or awareness to take responsibility for himself. June explained that Nathan lacked awareness of his own condition, and was therefore vulnerable:

\textit{Nathan was told the brain takes two years, so all of his friends thought, in two years Nathan will be back to what he was. Well, of course, we’re 12 years down the track and that's not the case. During those two years, he was good; he didn’t drink or anything. He was pretty responsible. But once the two years was up, he thought he was just like everybody else, but of course he's not} (June, mother, 2014).

Results suggested that the family felt the need to control Nathan for his own wellbeing. June appeared confident that she and Len knew what was in Nathan’s best interests and that society needed them to perform this function. In this respect, June felt it was prudent for her to monitor Nathan’s behaviour:

\textit{...because I'm a snoop. I don't believe in privacy. No, I don't believe in privacy for children, and I don't believe in privacy for teenagers, and I don't believe in privacy for people with a mental problem, because they need someone to look after them - look out for them, because they aren't really in a position to make good decisions} (June, mother, 2014).

June explained that Nathan would object to living in a group home situation with other people with a disability, because he did not see himself as having anything wrong, but that he was not capable of living alone, \textit{“But he could never, in my opinion, live independently, work out the money he needs, buy the food at the supermarket, come home, cook”} (June, mother, 2014). June described Johnathan’s inability to manage his
own money, and her and Len’s belief that it was in Nathan’s best interest that they control his money:

> Well, he used to spend all his money in the first three days he had it. He has money. The only reason he has money is his father and I take it off him and invest it for him. Or else he would have nothing. He will try anything. He will try drugs, he will try anything. The only way to control that is to keep the money away from him (June, mother, 2004).

The discrepancies between Nathan’s and his family’s views meant that his experience was not shared by his family. Len’s absence meant that June managed in isolation. Her concerns about Nathan’s lack of responsibility, his vulnerability, and his poor future prospects had not diminished from Study 1 to Study 2.

**Family 6 Ronald’s Family**

At the time of Ronald’s accident the family took responsibility for managing his care and recovery. Ronald’s mother, Ludmi, took on the role of primary carer, which was not incongruent with her pre-existing role as mother. The existing family structure had the potential to accommodate Ronald’s injury, and his parents were available and willing to help Ronald. The family reported a large network of family support. The care shown by Ronald’s extended family provided an important source of emotional support for Ronald:

> It’s a big list. It’s like- Dad. My father, he’s the biggest one. He’s the first one that’s on my list. Mum, dad, my two sisters. All my relatives in Argentina. In Sydney, auntie and uncle and my twin cousins. They look after me—they really care about me (Ronald, 2004).

Similar to other families where the injured person was not a parent, family roles were not greatly affected, and the family structure did not undergo significant change.
However in Ronald’s case there were behaviours and relationship conflicts with his sister that the family were unable to manage.

The data suggested that the family had functioned well prior to the accident, and Ronald explained at Study 1 how he felt valued by his family:

> You know, like really just, like my mum and dad, they really care and they love me and I love them too. All my family, you know...they get like behind me and they keep bending over backwards just to help me find a job and medication wise and all that kind of stuff (Ronald, 2003).

After the injury, Ludmi and Federico had endeavoured to support Ronald, however Ronald’s behavioural problems meant the family struggled with the caring role. They appeared to have a poor understanding of Ronald’s injury, and although they believed it was the family’s responsibility to care for Ronald, they did not feel confident in this role. Ludmi had explained at Study 1 how she felt the family were not able to teach him the things he could learn through a brain injury service, noting also the language barrier between themselves and services:

> We don’t help much to him in this because our English is very poor see. And that’s how he is involved to other people and is speaking very well. Teaches something different see, not from the home (Ludmi, mother, 2003).

The family had experienced significant hardship in the first two years post-injury due to Ronald’s behavioural issues, which involved anger outbursts directed towards the family, particularly his sister. This conflict had put an immense strain on the family, which Ludmi described as making her and Federico “sick.” Ludmi described a situation of a family under siege, with little understanding of the behaviour or how to manage it:

> Yeah he's grabbing the car keys, my daughters, and run and sometimes I have my youngest daughter here, Linda, she's still in the school...He didn't want to
see her and get angry when he'd see her. I don't know why. He tried to hit, tried to push and that's not nice and oh he's doing a thousand things here to us (Ludmi, mother, 2014).

In 2003, Ronald’s family had reached a crisis point. As well as verbal outbursts, Ronald had kicked holes in the walls in response to being asked to do things like shower. He was frustrated with his condition, and felt he was being treated like a child. He was also angry at his lack of independence, and that he not been allowed to get his driver’s licence back, stating “I’m not spastic” (Ronald, 2003). Much of Ronald’s anger was directed at his 16 year old sister, and consequently she was practically confined to her room. This conflict culminated in her moving out of the family home. At this point, Ludmi and Federico felt they could not manage Ronald’s behaviour and believed he should be living away from the home. Ronald’s anger outbursts meant that he had lost a new job, and the family reported ongoing conflict with neighbours during this time. Ludmi reported feeling very stressed and worried, and had been frightened at Ronald’s level of aggression:

Ronald: Didn't you ring the Police sometimes as well?
Ludmi: Yeah one day because he - one day he's - I don't know what he did here, something, and I just walked past I did like that to him. Don't do it like that and he's following me and tried to shove me, move to the kitchen. I have to call the Police because I said to my daughter call the Police because I didn't want to see anymore because he's been terrible (2014).

Ludmi’s initial response to Ronald’s behaviour problems was to attempt to reason with him, and explain the impact the conflict was having on the family, as she described in Study 1:
I say to Ronald, ‘I don’t want you in the home yelling...just to say talk normal, yes dad or no I don’t know. Things like that. But when you just go ‘blah, blah, blah, blah!’ and yelling, I no want this at home’... I said because it makes me sick. It’s makes me problems for my husband and me, everything (Ludmi, mother, 2002).

At Study 1, Ludmi had expressed that the family could not cope with Ronald. She suggested that it would be in Ronald and the family’s best interest for him to live in a residential complex for a while, as the family members did not have the skills to help him, “It helps to him even a couple of months for him or something—teaching other people, see. Yeah, stay away. Yeah (Ludmi, mother, 2004). Ludmi had also noted that he tended not to listen to them, suggesting that health professionals would have a greater impact on Ronald, “because he doesn’t hear or didn’t listen when I tell him something or other. He just get angry and just you know, things like that (Ludmi, mother, 2004).

Ronald’s relationship and friendships had not been maintained post-injury, and he felt considerable grief about this:

...before like the accident—like everyone used to come over my house after work and we’d hang around with each other and that. And when I went in hospital, only a few come and saw me. And then the rest didn’t see me. Like they’re at home now and they’ve got a car...So why don’t they come over here? That’s what really hurts me...They know, they know I don’t work. So I don’t even know what I done to them. Oh it is. It’s a real tragedy (Ronald, 2004).

Unemployment added to Ronald’s social isolation and unhappiness with his life. In all four of the Study 1 interviews, unemployment was Ronald’s over-riding concern; “Oh, it’s just, I’ve been telling you this for ages, but I like really like a job is just like the most
important thing in my life” (Ronald, 2004). He was frustrated that a lack of money inhibited his freedom and independence, commenting, “Like if I was to go out now, like none of my parents are home. Like I’ve got no money on me at all. Like I can’t catch a bus into town or anything to go see a movie” (Ronald, 2002). This lack of independence and autonomy was damaging to Ronald’s self-esteem, and he explained how repeated rejections further undermined his confidence:

You know, everywhere I go, I just go just put some resumes in and cold calling and do heaps of cold calling and that. And they just tell me, ‘yeah, we’ll get back to you within five minutes’. And they just don’t bother ringing back (Ronald, 2003).

At Study 2 Ronald’s, employment situation remained unchanged, and this was still concerning for Ronald and the family.

Ronald’s family appeared not to fully understanding the neurobehavioral impact of Ronald’s injury. Ludmi seemed bewildered that his anger “didn’t make sense” or was “for no reason.” At Study 1, Ludmi had expressed a desire for Ronald to behave more “normally.”

And he lives- this morning he just wake-up and shower and make breakfast and he make sandwich and he was so happy today. Nothing, see nothing, normal, normal. See that is sometimes, but I wish it like that all the time (Ludmi, mother, 2002).

Ludmi’s comments revealed that the family had been unprepared for the problems they experienced when Ronald returned home. They were unaware of possible behavioural issues, and it was not until the transition to home that they realised the impact of injury:

...he's walking, he's eating, he's talking and I thought well he'll be okay. But the nurse says or the doctors as well whatever time you want to take him home he
can go home. I thought he’s getting better and better see. Oh my goodness.

When he's coming here we have very hard time. Very hard all the time (Ludmi, mother, 2014).

Ludmi describing being at a breaking point around the year 2005. At this time, she appealed to Ronald’s psychologist who changed Ronald’s medication, I said to Dr Rata I don’t know what doing because I've had enough because we can't live like that (Ludmi, mother, 2014). Ronald responded well to this change in medication, and the family conflict subsided. However, this time had impacted greatly on the family and the schism with Ronald’s sister took many years to repair. Moreover, Ludmi believed that the stress of this time had contributed to Federico developing Parkinson’s disease. This discussion took place in front of Ronald, and he was aware of the burden he had been to his family. Ronald appeared to switch off at these times, disengaging from the conversation and shutting his eyes.

Although anger outbursts were less of an issue in 2014, the family reported ongoing difficulty insofar as Ronald was unemployed, unmotivated and had little in the way of social engagement. These problems had not improved since Study 1:

...it [my life] would be better if I got a job. That would get me away from there watching that [points to television]. So when I go here I've just got to wake up, have breakfast, get the paper, sit here and watch that and listen to my music (Ronald, 2014).

Ludmi had been asking for help at Study 1, “he do nothing bad. But he’s not all right as well. Whatever he does, I just want somebody’s help (Ludmi, mother, 2002). At Study 2, she was still seeking solutions to the same problems: “yeah I'll just ask what else is going to help with Ronald, you know what has happened and that's my question. Just in what way, anything, what will help him? (Ludmi, mother, 2014). It appeared that
language barriers had prevented Ludmi and Federico from accessing services, and understanding what may have been available. Moreover, poor communication between Ronald and his parents meant that information was not relayed back to them.

**Conclusion**

The six families in this study responded to traumatic brain injury in multiple ways, with great variance in their experiences and outcomes. This variance can be attributed to a number of factors broadly including family characteristics, injury characteristics, and external factors such as financial circumstances and supports. However, the families fell into three clusters. Brendan and Alison’s families reported the most positive experiences and demonstrated the least residual distress. Daryl and Neville’s families experienced the injury as something they had overcome, although the data suggested a continued high level of dependence in both Daryl and Neville, with concomitant issues for families. Neville also revealed ongoing emotional distress, which had been unexpressed for many years. Nathan and Ronald’s families reported continued hardship and worry, and Ronald was depressed, isolated and physically unhealthy.

All the families were comfortable with the decision for their injured member to remain in the family home. Brendan, Alison and Nathan’s families indicated that they believed that it was the families’ responsibility to care for the injured “child” at home. Although the challenges were acknowledged, these families believed it was in the injured person’s best interests, and that residential care was not an option. These families believed that they knew what was best for their loved one, and that they had the capacity to undertake this responsibility. In the case of the husbands, Neville and Daryl, there was a similar conviction that the injured person should return home. However, for these families, this conviction centred on beliefs about the importance of preserving the family unit rather than on the recovery of the injured person. In all of these families
there were positive psychological benefits from perceiving they were doing what was right, and that they were capable carrying out the necessary functions. In contrast, Ronald’s family shared similar beliefs about the importance of family, but did not believe they had the skills to care for Ronald, which created significant distress.

Although still relying on family, Brendan and Alison had achieved a higher level of independence and community engagement than the other injured participants, and they continued to set new goals. For example Alison had studied, travelled, given presentations, lived independently, and controlled her own finances and life decisions. Brendan was in paid employment, had travelled, and had a social life beyond his immediate family. These outcomes were attained despite severe injuries and socially limiting disabilities (i.e., communication and mobility disabilities).

Although Daryl and Neville’s families were managing well at Study 2, their situations were slightly less positive. Daryl and Neville had both reported significant emotional distress at Study 1. Daryl described his loss of confidence and anxiety due to his assault. Neville had experienced depression, low self-esteem and worry for the future. Although families reported that these problems had been dealt with in the past, Neville indicated that he still suffered emotional distress and worry, and Sharon described Daryl’s ongoing lack of confidence. Both men appeared to have a heavy reliance on their partners. These problems had existed since the injury and were not currently being addressed. This situation contrasted with the families of Brendan and Alison where there was a continual focus on improvement and planning for the future.

The long-term situation was the least positive for the families of Nathan and Ronald, with this impact being most obvious in Ronald’s family. Nathan’s lack of awareness meant that the distress appeared to be experienced primarily by his family, who viewed him as being vulnerable, and incapable of looking after himself. In
contrast, Ronald was aware of his impairments, and experienced these as a loss of his former life. This resulted in depression and a lack of motivation, which impacted negatively on his family. Although both these families reported improvements and achievements over time, many of the concerns expressed at Study 1 were repeated in Study 2. For these families, the lack of solutions and their concern for the future was evident. Both of these families had felt let down by services. Nathan’s family found services to be inappropriate to their needs and chose not to seek outside help. Ronald’s family were still seeking assistance at Study 2 but had been unable to access services themselves.

This chapter described the different ways in which families experienced and responded to TBI. It highlighted the unique experiences of TBI across families, but also exposed some commonalities across the families and some clusters of responses. These clusters appeared to relate to a combination of factors, including the family structure, the consequences of TBI and processes in which families engaged over time in order to manage TBI. These processes will be explored further in the next chapter.
Chapter 5 Results: Building a Theory of the Family Response to TBI

Analysis of the data across families revealed that adapting to TBI was not something that happened only in the immediate wake of the injury, but rather it involved multiple processes of adjustment over time. Two core processes were identified in the stories of all families; namely reconnecting and reinventing, and making the unbearable bearable. These processes took place within individuals and in the families collectively; each interacting with the other. The first process involved the ways families attempted to establish a sense of normalcy and identity amidst the change and uncertainty following the injury. Following on from and overlapping with this process was the second process of making the unbearable bearable. This process involved the inner and outer adjustments families made to manage loss, and deal with the ongoing stress caused by the injury.

The Process of Reconnecting and Reinventing

The first core process of reconnecting and reinventing was evident after injured participants returned home, and families adjusted to their post-injury realities. The process of reconnecting and reinventing transpired in what might be labelled a liminal space; in that families were in transition from who they were, but not yet knowing precisely who they would become. From the time of the injury, families experienced enormous change, and uncertainty for the future. They described their lives as being “on hold” as they waited, initially to learn if their loved one would survive, and later the extent of the injuries:

you're just so raw, your emotions are so raw, you don't know what's going to happen, you don't know if she's going to survive, what the future’s going to be like (Mary, mother, 2014).
Kate described the information families needed to process at the time of the injury as overwhelming and shocking:

As I said, the doctors are telling you all these things and you're thinking, hang on a minute. You're still trying to get the grasp of what they've said the first time and then they're telling you other things (Kate, mother, 2014).

Comments made by Jo at Study 1 illustrated these early feelings of not knowing in relation to the impact of the injury on the children:

I thought well, I don’t know what's happening to their dad. I don’t know whether I’ll bring him home, and if I bring him home, what state he'll be in (Jo, spouse, 2002).

The experience of change and uncertainty continued when injured participants returned home. Change was experienced by families in terms of new roles, routines, and relationships. For the injured person, change and uncertainty centred on physical and cognitive deficits, differences in behaviour and personality and altered social and employment circumstances, all of which impacted on perceptions of independence and sense of self:

Well finding out what I could do and couldn’t do. You didn’t know what you couldn't do until you tried to do it. People are like, can you do this? It was like, this is first time I've had a brain injury, I don’t know what I can do (Brendan, 2014).

Uncertainty was experienced in relation to unknowns about the injured person’s expected recovery, and future vocational and social outcomes. Daryl described the situation experienced by participants in having to “wait and see” in relation to their recoveries:
...so Dr H. tells me, me two years isn’t up yet so I won’t really know until I’ve
done me two years, and then I can sort of assess meself from there. And I’ll
pretty much understand where I’m at. That’s what they tell me (Daryl, 2002).

Daryl’s comments suggested a powerlessness in relation to health services which was
echoed by Brendan, “That’s the hard part...They’re going to find out what I’m capable
of doing. What I can and can’t do kind of thing” (Brendan, 2002). Injury
characteristics, and the injured person’s response to his or her situation played a key
role in the experience of uncertainty for families, with personality change, and
behavioural problems having significant impact.

Amidst this uncertainty, there was a drive in families to experience life as
normal again. For some this involved returning as much as possible to pre-injury life
(reconnecting), while others were focussed on establishing a new normal (reinventing).
In either case, families sought to feel that life was under control, manageable, and
familiar. This desire played out at the level of the individual and the entire family unit.
For instance, Brendan had been highly driven to get back to his pre-injury life. He had
expressed frustration at his losses, “I just get real frustrated sometimes when I can’t do
the things that I want to do. Like really peeves me off. Like real bad” (Brendan, 2002).
Brendan recognised that his awareness of his pre-injury self was an important motivator
to work hard at his rehabilitation:

I knew where I wanted to go and how I wanted to be, but I’ve seen a lot of them
[people with brain injury] give up. I don’t think they remembered who they were
before they had the accident. I’ve always known who I was and how I wanted to
get, so you’ve got to have that drive and focus. If you don’t have that, you’ve got
nothing (Brendan, 2014).
Brendan’s goal to return to his former self was a shared family goal, and supporting Brendan in this goal became a focus for the family. Comments from William revealed the shared family vision about this issue:

> Because you’ve got to try and get their lifestyle back to where they were before and in a routine. That helps a lot, I think, because if everything changes, well they’ve got nothing to focus on or get back to (William, father, 2014).

Brendan’s friends had played an important role in connecting Brendan with his former self, “because my mates are sort of helping me remember what I was like and that, you know what I mean? It’s been real good” (Brendan, 2002). For Brendan, it was his continued friendships had helped him to feel “normal” again, “I don’t like being around people with bad disabilities. It feels like it brings me down. If I’m around my mates - not being bad - but normal, I feel normal” (Brendan, 2014).

Brendan’s desire to get back to his former life became a catalyst and motivating factor for him and his whole family. Kate noted that, “he had always said that he was going to get back to as good as he could be” (Kate, mother, 2014). William underscored the family’s drive to get back to normal through a focus on pre-injury activities:

> I think the other thing is, too, to try and treat the person as normal as you can, and still try and do activities that you were doing prior to it. Getting back to a normal lifestyle is the main thing (William, 2014).

Ronald and his family had shared the same desire as Brendan’s to reconnect with their pre-injury lives; for things to go back as much as possible to the way they had been. Ronald had been similarly aware of the ways in which his injury had changed his life, particularly with regard to his relationships and independence. Ludmi and Ronald had repeatedly expressed a desire for their lives to feel “normal” again, as Ronald
explained, “I appreciate my family – everyone that just loves me and is really enthusiastic about me coping, to get back to the normal way I was before” (Ronald, 2002). However, for Ronald, the desire to return to his former life was more a source of distress than a motivator. He was regretful of the accident, and mourned the loss of his relationship and planned future:

...the night I fell off that roof, if I hadn’t have gone into the nightclub that night, the next morning, I would have signed a piece of paper and we [Ronald and his partner] would have got a brand new house... And then a week after that, I had bought a ring for her to get engaged, and I had to sell that. See, it flipped a normal life around—yeah, I used to wake up in the morning side by side with her. She used to ring me, she used to message me. And it’s just completely flipped around (Ronald, 2004).

In contrast with Brendan’s comments that being with his friends helped to feel normal, Ronald had expressed that he no longer felt himself to be normal at Study 1:

But it was really really severe what happened to me and I wish you know, I wish it wouldn’t have happened. Because it’s changed. Like I used to be normal. Now, I was normal back then but now it’s completely the opposite way now (Ronald, 2004).

Unlike Brendan and his family, Ronald’s former life was experienced as no longer being attainable, and at Study 2, his family had failed to regain the sense of normalcy they desired. Although Brendan and Ronald both experienced themselves as dramatically changed by their injury, Brendan reported a higher level of continuity with his former self than Ronald. Significantly Ronald’s friendships had not been sustained post-injury, which had also represented a failure of his life to return to what it had been.
For Brendan, it was from these sustained friendships that he was able to derive a connection to his pre-injury life:

_That’s what I said to my friends too, I wouldn’t be where I am if they sort of didn’t stick by me and make me think that there was something to get out for kind of thing, but not just lying there thinking I don’t have any friends outside any more. What’s the point kind of thing, when I told them that they all said ‘yeah, that makes us feel real good, eh_ (Brendan, 2002).

To a large extent, the experience of the injured individuals were mirrored in the experience of the families, so as Brendan’s life resumed normality, so too did his family, who reported at Study 2 that they did not feel significantly changed as a result of the injury. This was not the case in Ronald’s family, where ongoing chaos was experienced at both the individual and the family level.

In contrast with the families of Brendan and Ronald, Alison’s family had not focussed on her former life, but instead expressed a desire to move forward, or reinvent. Perhaps due to the severity of Alison’s injury she did not feel a connection to nor a longing for her former life, but rather focussed on what she could hope to achieve in the future, as Mary explained:

_A Alison doesn’t think about it [the past], she just looks forward, whatever has been you know, and I wish we could bottle whatever she has that just goes, ’this is where I’m going’_ (Mary, mother, 2014).

Mary’s comments all either implied or overtly expressed admiration for Alison’s attitude, which had been helpful for them both to manage the sense of loss. Alison’s high care needs when she came home heralded a significant change in their lives. Rather than looking back, Alison focussed on her future, and was driven to maximise her physical recovery, independence and community engagement. Mary shared these goals,
and was adept at guiding and supporting Alison. Despite her future focus, like Ronald, Alison expressed grief over what she perceived as the abandonment by her boyfriend (the driver in the accident). In contrast to Ronald, this grief became motivation for Alison to achieve her goals. Alison’s motivation to share her story for example was driven in part by a desire to tell others what a “jerk” her boyfriend had been. This anger and feelings of abandonment contributed to Alison later telling her story in a presentation to first year occupational therapy students, about which she commented, “It’s good that I can tell them” (Alison, 2003). For Alison this was significant because, “I want them to know that [ex-boyfriend] is a bastard” (Alison, 2003). This theme of catalysing their grief and anger into motivation to achieve future goals, and create the best life possible was something Mary actively encouraged:

That’s what I used to say to Alison, 10 years down the track you’ll probably see him somewhere and go you know what, my life’s a lot better than yours (Mary, mother, 2003).

Although Mary quickly came to share Alison’s future focus initially she had needed to seek signs of the “old” Alison. Mary described a significant turning point for her ability to cope with Alison’s injury was in realising that Alison had enough awareness to remember pre-injury family dynamics. This realisation occurred when Alison comforted Mary when her ex-husband (Alison’s father) and his partner walked in to the hospital:

Alison put her right arm around me, and she gave me a cuddle because she was looking at them, and Alison was protecting me. She knew, and I knew then that she knew the circumstances prior to, and Alison was protecting me (Mary, mother, 2014).
It was through this gesture that Mary “realised Alison was - she was actually there - my Alison was there.” This connection to the old Alison was profound for Mary, and was crucial to her ability to cope, and to continue to support Alison.

Mary described the newness of their world of disability, and the process of slowly adjusting to their new normal. The importance of the role of the rehabilitation staff in normalizing this experience for families, and equipping them with the skills to self-manage was underscored:

...because you've never been in this environment before and they see this all the time and then they give you the tools to say, ‘well, Alison can communicate through a Lightwriter, she can communicate through emails, she can do text messages and all that,’ and that slowly becomes your norm (Mary, mother, 2014).

Daryl and his family did not experience the injury as having significantly changed their lives in the long-term, and after the early challenges associated with Daryl’s recovery they felt themselves to be unchanged from their pre-injury selves. For them, reconnecting with their former life came from the feeling that they had overcome the injury, and that the changes it created were behind them. Sharon had spoken at Study 1 about changes in Daryl due his memory impairment, and her hope that he would return to his pre-injury functioning:

Little things you tell him, you might tell him something and an hour later he’ll ask again and you’ve already told him. That’s sort of the main issue because he never used to be like that. I don’t know what will change but I hope he gets back to 100% (Sharon, spouse, 2002).

In the final interview in Study 1, Sharon revealed that she believed Daryl had recovered to the level of his pre-injury self, saying, “I don’t think he’ll improve more than he is.
That’s just my opinion. Because he’s pretty much back to normal now” (Sharon, spouse, 2002).

Daryl had also sought to get back to his pre-injury life, describing at Study 1 how the injury had changed his lifestyle, and diminished his independence:

*it’s hard because my lifestyle that I used to lead has changed... I do everything different now. Where I used to be fully independent and do pretty much me own thing all the time now I sort of rely on other people* (Daryl, 2001).

For Daryl, getting back to work was an important aspect of returning to his pre-injury self, as he explained, “Well I’ve always worked 13-14 hour days since day dot. Now I don’t do much at all. I wanted to go back to work yesterday” (Daryl, 2001). Work was linked with a feeling of life starting again for Daryl, as his later comments about starting work showed, “I’m quite pleased. I need to get on with my life something fierce. So yeah, it’s been good” (Daryl, 2002). This comment suggested Daryl’s desire to move on from the injury experience and get on with his life, a sentiment echoed later by Sharon, “Yeah, I guess you just don’t want to - oh I don’t know how you’d say it...pause your life...just keep moving on” (Sharon, spouse, 2014). This push to move on and put the injury experience behind them was evident in their perception that the injury had been dealt with in the past, and was not part of their current lives, or as Sharon explained, “Like it hadn’t happened;”

Daryl:  
*Once I got a bit of self-confidence back in the workforce, then it sort of really got going for us, didn't it?*

Sharon:  
*Mm-hm, it just went from strength to strength after that......once you got your confidence back within yourself...then it was sort of like it just hadn't happened.*
Similarly Neville and Jo had expressed a desire to move on from the injury, however different perceptions of the injury between them meant they did not have a shared experience. Jo experienced Neville as a completely different person, and this lack of continuity in her relationship with Neville left Jo no choice but to move forward and reinvent her life. Neville did not report this same experience of change. Although Neville was frustrated with aspects of his injury, he did not perceive himself as fundamentally different. Having returned to the same job, and with continuity in his social networks, Neville did not acknowledge the changes in his character that were noticed by others in his family and social network. As a result Neville lacked the drive to reconnect or reinvent that was found in Brendan, Alison and Ronald. While this meant he did not experience the same distress as Ronald due to an unattainable past, it also meant he lacked the motivation of Brendan and Alison to work at his recovery. Further, Jo’s response of moving on for the children meant that Neville was not her primary focus. Neville’s recovery was seen as something for him to work on himself:

*I definitely believe there will be more improvements, in his confidence and things like that. I think it’s something that (he) will have to deal with and get through* (Jo, spouse 2002).

This response contrasted with the response seen in Brendan and Alison’s families where the injured persons where the injured person’s recovery was seen as a shared family experience.

Like Neville, Nathan had a different perception of his injury from that of his family. A similar pattern was observed in these two families with the family moving forward from the injury, while the injured person appeared inert, with little progression beyond early recovery. Ronald’s family also displayed this inertia; unable to regain who they had been, but also unable to move on.
The Process of Making the Unbearable Bearable

The second core process of making the unbearable bearable involved the adjustments that families made to cope with the psychological and emotional impacts of TBI. Families experienced grief and loss as a result of the injury, and ongoing demands and stressors added further to their distress. In order to cope with these challenges families developed strategies which reduced mental overload and suffering. Two core categories of contracting and recalibrating were identified. Contracting was observed as an early response to the injury. Over time there was evidence of some loosening of the various forms of contraction, however there were instances of ongoing contraction for some participants. Recalibrating involved the strategies used by participants to enhance their enjoyment of life, and view their circumstances more positively.

Contracting.

The results showed evidence of contraction in participants which functioned to reduce stress, also serving as a protective buffer against emotional distress. Contraction was observed as an early response to the injury, and was maintained to varying degrees over time or re-emerged at different times. Three distinct types of contraction were observed; spatial contraction, temporal contraction, and emotional contraction.

Spatial contraction.

Contraction was evident in families’ relationships with others. At the time of the injury, families appeared to “close ranks” as they assessed their predicament, and determined appropriate action. Families indicated that they felt others did not understand what they were experiencing, and engagement with the world contracted to include only those who were involved with the injury response; the medical teams and the trusted inner circle. In this sense, families were isolated from the rest of the world and encapsulated in the injury experience. June’s reaction to her friends was the most
overt representation of this process. Rather than being a source of comfort or assistance she experienced their presence as an added demand on her already stretched emotions:

Well, because they say, well, what's going to happen? I don't know. I shopped at a different shopping centre because I couldn’t stand running into people who’d ask me. They were all concerned. It was all very lovely and all of that, and I understood that, but I couldn’t stand it. So I avoided my local shopping centre and I went to another shopping centre (June, mother, 2014).

All of June’s mental capacity was focussed on the crisis with Nathan, and those not directly involved were experienced as adding to her burden. In June’s case, this need to shut people out even extended to other family members, who she tended to exclude.

Comments from William echoed June’s experience:

The hardest part used to be - just after Brendan had his accident - as I said, I had a month off work, and you go back to work and everybody's asking you about it. You’ve got to go through it and relive it all the time. You just think to yourself, I wish they'd bloody stop asking, but then they're only asking because they're concerned (William, father, 2014).

It appeared that participants acted to simplify their social worlds as management of the injury became their primary focus. Brendan for example felt it was necessary to end his relationship in order to attend to his recovery:

I couldn’t focus on getting better because you're too focused on the relationship.

It was like; well I have to put 110 per cent in getting better, so I can't really think about [a relationship] (Brendan, 2014).

Compared to Brendan, Alison, and Nathan’s families the families of Neville and Daryl showed a greater tendency to seek help from extended family and close friends.

However the perception that others did not understand, and consequently the experience
having to manage by themselves was evident in all families. This belief about not being understood contributed to participants’ ongoing tendency to contract or shut others out. Brendan’s family spoke about not having time for friends who “didn’t want to understand:”

   We have friends too that - some of them you just feel that they really don’t want to understand. We’ve gotten to the point where we think, oh well, if they don’t want to we’re not going to waste our time talking about it (Kate, mother, 2014).

Results showed that families shared the belief that people who had not experienced TBI would not understand what they had gone through, as Kate highlighted:

   And really Brendan and I have really noticed too that there are a lot of people out there that don’t understand. He’s even said that to me too. I say to my husband, you talk to people and they don’t realise what Brendan has been through and what we’ve been through (Kate, mother, 2002).

Neville described the experience of not being understood from the injured person’s perspective:

   No offence to you and no offence to anyone else, but you’ve got, the only idea that you’ve got going is because you’ve spoken to a lot of people. Like if you had head injuries you could understand what I’m saying, if you know what I mean (Neville, 2003).

Mary reiterated similar sentiments describing one health professional who had been helpful within a broader experience of not being understood:

   Yeah well [Rehabilitation counsellor] was the first person that really understood yeah, and tried to help me. Because it was such early days and where do you go, who’s going to understand, nobody understands except you or somebody else who’s been through it (Mary, mother, 2014).
June described how the invisibility of Nathan’s injury meant that others failed to understand the severity of his cognitive deficits, “My son presents very well. He's well mannered, he presents well, and everybody thinks he's not that bad. He is that bad. He just presents well” (June, mother, 2014). Conversely, Mary described a feeling that Alison’s obvious disability and lack of speech meant that people would assume she was “stupid.” For all families, this belief that others did not understand contributed to feelings of being different from others, as exemplified by Kate:

I know myself you used to hear of accidents on the TV and that and you see someone has been seriously injured in a car accident and you think, oh that would be terrible- but you really don’t know the inside of it all until it happens to you (Kate, mother, 2002).

This experience of difference was underscored by Ronald, who experienced himself as not only being different to how he was before, but that his injury marked him as being different from others:

Like I’ll walk out of the house and down the street and everyone looks at me and stares at me. It’s like ‘look there’s that guy again, there’s that mark, that scar. There’s that huge scar,’ and I wish I had a rubber to rub the whole thing out (Ronald, 2004).

This individual-level feeling of being different and not understood translated to the family unit, particularly when the family was dealing with changes in their loved one’s behaviour or personality, which could easily be perceived by others as “not normal.” This was particularly highlighted in the case of Ronald and Brendan where public conflict and outbursts were highly visible. The families spoke of feeling shame and embarrassment during these times. Kate described how she disengaged from the perceived judgements of others in this context:
I'd have to think, oh God, what are people going to think? Then in the end I think, blow it, I don't care. I don't really care. If they've got a problem with it, I just say, well you don't know the full story, so let it be. I do that now and that's the only way, because otherwise you just drive yourself mad. I think, oh no, and then I think, no I have to deal with this. I have to get through it (Kate, mother, 2014).

It was necessary for Kate to mentally isolate herself from the social environment in order to not become overwhelmed by the situation and continue functioning as a family. From the injured person’s perspective, there was often a feeling of being misunderstood by others, as Brendan explained, “maybe just sometimes they think you're being an idiot or something” (Brendan, 2014). He talked about people being quick to judge, and underscored the belief shared by others that TBI is poorly understood:

*People* - I never realised - and I was probably one to do it as well - people are very quick to judge. You don’t think of what someone else has probably been through or what's happened to them. I never really would have thought of any of what's gone on with me before I had this accident (Brendan, 2014).

Brendan displayed a high level of confidence, and was no longer bothered by others’ opinions: “but now I've just got to the point where I just don’t care what people think now (Brendan, 2014). This confidence appeared to be based on the family’s approach to the external world and the acceptance shown by family members. Alison showed a similar level of confidence that was reinforced by her mother Mary. Both were in contrast to Ronald, Neville and Daryl, for whom this confidence was lacking. Ronald and Daryl appeared ashamed of their injury. Daryl had a tendency not to disclose his injury to others for fear of being judged. There were also examples where the injured person or the primary carer felt that other family members did not understand. This was
seen in Brendan’s extended family, in Ronald’s family, and also in Nathan’s where June had spoken about Len’s, lack of understanding, “but his father is impatient, you know: ‘I don’t believe that boy’ – ‘yes Lawrie he's got a brain injury, he is not that bright’ - I can’t believe him (June, mother, 2014). This situation and the lack of a shared family understanding resulted in a spatial contraction that involved sub-elements of the family rather than the whole family.

Although feeling shut off or different from others could be isolating, one corollary was a strengthening effect on families; where families looked to their own internal resources. Most families came to see themselves as the experts of their situations. Particularly for the primary carers, the idea that they knew better than anyone else how to manage their injured family member was evident, as Kate explained:

I just sort of know more or less how to control the situation. And it’s just sort of getting everybody else to understand the same thing. But then it’s hard. That’s the hardest part sometimes (Kate, mother, 2002).

June and Mary similarly expressed a high level of self-efficacy in terms of knowing their injured family members’ needs better than anyone. Mary, for example, described how her intimate knowledge of Alison meant that she was able to perceive subtle shifts in Alison’s recovery where health professionals may not, “probably because I live with Alison, yeah, I see most of it (Mary, mother, 2003). Even in Ronald’s case, where the family members were not confident carers, there was evidence that they felt people outside the family would fail to understand Ronald’s needs as well as them, and were frustrated by their difficulty communicating with services due to language barriers.

Resistance to services.

Families’ experience of not being understood, and the belief in some that “family knows best” had implications for their engagement with services. There appeared to be a
resistance to services, in that families viewed them as being unnecessary or ill-matched to their needs. Brendan and Neville’s families for example reported that they had not engaged with formal supports beyond physical rehabilitation. William explained that they did not rely on services, but rather “we tried to do everything by ourselves.” Jo said that in hindsight she believed they may have benefited from some family counselling after Neville came home. However, as revealed at Study 1, at that time they believed that talking about the injury was unhelpful as it “just brought it all back up again” (Neville, 2002). Both families commented that that there were few family services available, although the evidence suggested that they did not seek out services, but rather attempted to “go it alone.” For Jo and Neville, this decision was associated with a desire to move on from the injury and put it behind them. For Brendan’s family, it appeared to stem from the belief that were capable of managing, and that they knew what was best for Brendan.

Other Families also described experiencing services as impersonal, and that services did not know them. Daryl and Sharon, for example, had spoken about their tendency to seek help from within their trusted “inner circle.”

Daryl:    *Inner circle, inner circle group, don't even worry about talking to the shrinks and all that, they just waste your time. Because all of it is, that's that picture, there's that picture, now how long ago did you see that picture...*

Sharon:  *They don't know you personally, they don't really know...*

Daryl:  *They don't know anything*

Sharon:  *...any personal - they only know what you're telling them. Really they don't know your personal situation. Whereas like Sandra, we'd*
been friends since we moved up here. Cheryl, the other girlfriend. So they knew exactly what we were going through.

Sandra had further explained the family’s belief that they were more knowledgeable than services regarding the injured person’s needs:

They [rehabilitation services] wouldn’t have a clue week to week as to what you’re going through. Whereas somebody that you see three, four, five times a week, they can pick okay, it’s a down day today, we’ll work through that. The next day might be a really good day. It’s hard to - it’s sort of hard to work it (Sandra, friend, 2014).

As a result of not being known or understood by services, families reported that they were offered services that they did not need, and conversely were not offered what they did need. Neville and Daryl had both expressed frustration at rehabilitation tasks they perceived as meaningless, and unrelated to their lives, as Neville explained:

And they’d make me do puzzles and stuff like that. But a lot of the puzzles, whether I could do them before I had a thump in the head compared to now. See they can’t compare how quick I can do it now compared to how quick I could do it before because I never did it before...and trying to get them to understand that when they’re only doing their job. No offence to them, but reading and writing. The last time I had to read and write was when I was at school. So basically I had ten or fifteen years since I left school and physically use that part of the brain anyway. So now, that part of the brain probably hasn’t been working to its full potential for all that length of time and they’re asking me all these questions. This, that and everything else, which frustrates you because as soon as you left the hospital, no offence to them, I’ll never do it again anyway (Neville, 2002).
June had also spoken about her anger with services, which she had described as useless. She felt that services had failed to provide any practical help for the family:

> I used to go to everything because I thought it was my duty to go and work out blah, blah, blah, and they used to have these meetings, so we’d all sit in a circle... if for everybody else it was having the same effect as it was having for my son, it was useless (June, mother, 2014).

June further explained Nathan’s negative reaction to a later group, where he had not felt he belonged:

> Nathan just took one look around and said, ‘oh, I don't belong here’, and yelled at me all the way home, don't every take him to anything like that ever again. I must admit, it was pretty depressing (June, mother, 2014).

After these unsatisfactory experiences, families had given up on seeking assistance. Ronald’s family contrasted in that rather than resisting services, they expressed a feeling of having been abandoned by services. However, the belief about not be understood, and not being helped was similar to other families.

> I'm not happy with him [Ronald’s specialist] because he's...maybe he’s nothing to do with Ronald but at least if you help or tell me something, ‘look, you can do this...’. Or something. But he did nothing. Absolutely nothing (Ludmi, mother, 2003).

The severity of Alison’s physical injuries meant a long association with health providers, who became a part of the family’s life for many years. Mary and Alison reported mixed experiences of services, with key health professionals having had a significant positive impact:

> We've had some great people, which have been a great team of people, which has been probably the best help you know (Mary, mother, 2014).
Mary and Alison also described negative experiences with health professionals such as counsellors who did not understand their needs, and a difficult relationship with an occupational therapist who Alison described as “a bitch.” Negotiating new relationships with a string of different rehabilitation staff became another source of workload for Mary and Alison. Mary also described a lack of support at key points. For example, at the time Alison was discharged home the continuity of professional support appeared to be lacking:

*Alison was in a wheelchair when she came out of hospital, she was on a PEG, she’d just learned to swallow prior to coming out. They [hospital brain injury] just went we can’t do anymore for you, see ya.* (Mary, mother, 2014)

This recollection of having had excellent inpatient care, and then being abandoned by the healthcare system was echoed by all families. However, in all but Ronald’s family, participants appeared to be yearning to take back control of their lives from services, rather than continue to engage with them. Services were experienced as outsiders, or intruders to the family. Moreover, continued association with services impeded families’ desire to feel “normal” again.

*Temporal contraction.*

In the immediate aftermath of the injury, families’ experience of time appeared to contract around the injury. With their loved one’s survival in question, life took on a “present moment” focus. This contraction was evident in Mary’s description of the days following the accident, “*when it first happens it consumes every second, every minute, every hour and we’d work from hour to hour*” (Mary, mother, 2014). This contraction remained after participants returned home and continued their rehabilitation. The burden of rehabilitation, and uncertainties in relation to their recoveries could be overwhelming for families, and participants talked about the need to take one day at a time. This step-
by-step approach was exemplified by Daryl and Neville, who both described a need to focus on the tasks a day at a time: “I’m taking every day as they come and I’m definitely not making no long-term plans” (Daryl, 2002), and Neville, “Just take it day by day. Get out of bed, go to work, come home, go to bed, get up, go to work and have a weekend off. Daily grind” (Neville, 2002). For both it appeared that the work required to get through each day was enough of a burden, and to focus on the future at this stage would be overwhelming. June similarly displayed this realisation that recovery from TBI was not something that could be achieved quickly, but rather that “it’s a marathon” (June, mother, 2014). Implicit in this comment was the understanding that they would need to adjust their lives to accommodate Nathan’s injury over the long-term. Mary similarly explained how she and Alison approached Alison’s recovery incrementally, “we never really thought about it, just what’s the next step, and it’s always okay what’s the next step” (Mary, mother, 2014). Mary described a softening in this contraction over time as progress was observed, to accommodate a broader perspective:

Then you’d work from day to day, then week, month as things got – developed, and became a bit more positive. We were thinking there is a future, you can do this and it’s forward thinking, rather than just taking, at that point, a day at a time (Mary, mother, 2014).

This shift was also evident in Brendan’s family where a future focus eventually replaced a day-by-day focus, and the family began setting more long-term goals. Other families did not explicitly state this shift to from temporal contraction to a future focus. In the families of Daryl and Neville, the focus on current needs remained dominant and in the families of Nathan and Ronald, future goals were experienced as being unattainable.
**Emotional contraction.**

The results also revealed an emotional contraction in participants which functioned as a buffer against emotional or psychological distress. Two aspects of this contraction were resignation and compartmentalising.

**Resignation.**

Resignation was observed in families as a response to circumstances for which they felt they had no choice but to endure, as Kate and William described:

William:  *There's nowhere for Brendan to go to give Kate a rest when the times were hard.*

Interviewer: *So what do you do in those times?*

William:  *Well you just put up with it.*

Interviewer  *How do you find strength to do that?*

William:  *You've got to come to grips with what's happened and just live with it.*

Kate:  *You've got to say to yourself, well this is it. We've got to pull together and do the best that we can.*

Families all reported that they managed because they had “*no choice.*” June’s sense of what she described as her “*duty*” to her family, for example meant that she did not feel there were any alternatives, “*but you know that you have to do it and you just find the strength to do it*” (June, mother, 2014). A sense of duty was also evident for Sharon and Jo, who felt obliged to maintain the family unit for the sake of their children. Jo’s innate sense of responsibility for her children was a driving force, and left her with “*no choice*” but to get on with life:

*I guess it was just something in me, I don’t know what it was, but I just felt I think I had no choice. It's just something I had to do. The kids are there, they*
still need to live. I still have to provide for them, so I have to try and do it as best as I can (Jo, spouse, 2014).

Resignation was a cognitive process that signalled an absence of resistance in families to their circumstances, which appeared to reduce the stress associated with challenging and unrelenting circumstances over which families had no control. Jo for example had described a turning point in the many years of conflict with Neville when she stopped fighting Neville and accepted that he could not help his behaviour:

You have to realise that he wasn’t going to be any different. That’s the way he was, so then it was up to me to make a change, otherwise we'd just keep arguing. I wasn’t getting anywhere and it was like beating my head against a brick wall. So it wasn’t healthy for either of us (Jo, spouse, 2014).

Compartmentalising.

Another strategy for making the unbearable bearable through emotional contraction was that of compartmentalising unwanted thoughts and emotions. By compartmentalising trauma in various ways families were able to avoid or suppress difficult emotions. For some, this compartmentalisation was evident in their desire not to talk about their emotions, both external and internal to the family unit, as a way of remaining strong for the family. June explained being annoyed at a telephone counsellor who asked her how she was feeling when she had rung for advice about Nathan:

June: I was saying blah, blah, blah to the Lifeline person, and then she went: and how about you, what are you doing? I said: do not give me the spiel. I've had the spiel a hundred times. If you want to reduce me to a crying mess, give me the, you sound so strong and wonderful. Don't piss in my pocket. I'm not interested.

Interviewer: What do you mean by that? What makes you upset about that?
June: Because - I don't know, it makes me feel like - I just don't like it. It makes me feel terrible. It makes me cry. I'm no good to anyone if I'm a crying mess. So, I don't like it. I know some people love to have their egos stroked: oh, you're so wonderful, blah, blah, I don't like it.

June had suppressed or avoided her emotional response in order to keep functioning. June she felt that she wanted practical support not someone to talk to. She believed that if she allowed herself to feel the grief she would be overwhelmed and unable to manage, which would damage her ability to support the family. Her husband Len avoided distress by disengaging from issues relating to Nathan, leaving the responsibility with June. Although this arrangement was not necessarily helpful to June, it was a form of contraction that allowed the family to continue doing what was needed.

Suppression appeared to be a strategy that the families of Neville and Daryl had used to help them to “move on” from the injury. Neville and Jo had had discussed their strategy to move on from the trauma by not talking about it: “so as a whole, no offence to people, but the less you talk about something, the better you are. You know what I mean” (Neville 2003). Like Daryl and Sharon, Jo had wanted to forget about the injury, and Neville had agreed, as he explained: “but once it's left and forgotten about, you’ll get over it quicker. That’s the way I pick it. So that’s just an easier way (Neville 2003). Neville explained that Jo had also wished to “put it aside and forget about it. Forget about it as much as she possibly can” (Neville 2003). Neville and Jo had not provided data for the later interviews in Study 1, giving the reason that they believed dwelling in the past was not helpful for them, as Neville explained to the interviewer in 2003:
Neville: So basically that’s why Jo had the problems, she just wants to get over it, but the more she keeps dragging it out, it just prolongs bad memories and that sort of stuff.

Interviewer: Ok, and you feel similarly to that as well?

Neville: Probably, yeah

Similarly Daryl and Sharon had expressed a desire to put the injury behind them and “forget” about it, which suggested an avoidance or suppression of uncomfortable psychological or emotional reactions. Although this contraction may have been helpful for the families to avoid experiencing emotional trauma, the data also suggested that there was less agreement about this strategy, resulting in negative consequences for Neville and Daryl. The results suggested that both Neville and Daryl had continued to experience negative psychological impacts which were not being addressed, suggesting that the suppression of their emotional and psychological distress had negative consequences.

There was less evidence of suppression in the families of Brendan and Alison. Comments from Brendan’s mother Kate had shown more balance between expressing and suppressing:

It's good to talk, too. We'll discuss things sometimes, over things that have happened. It's good to just air it every so often, I suppose, but you don’t like going on and on about it. But you can't just ignore it either. You have to deal through it in the best way that you can handle it (Kate, mother, 2014).

Kate’s comments further revealed the open communication in the family which was less evident in the families of Neville, Daryl, Nathan and Ronald.
Compartmentalising was also evident in a process of cognitively separating from the emotional trauma and containing it in a place and time that could be revisited. This was particularly evident in Mary. During the interview, Mary repeatedly revisited the time point when Alison was fighting for life. The shock and trauma of this time was still very fresh for Mary, and she often became emotional as she spoke about it. Mary had had not “gotten over” the trauma but rather had compartmentalised it in order to function and derive happiness from her life despite these memories:

Alison’s great aunts from overseas sent letters and said things like the ladies at her church groups were praying for Alison so [crying] - yeah, going back there. You go back in time and that feeling. It doesn't go away... That doesn't go away, the feeling of while Alison was sleeping (Mary, mother, 2014).

Mary had also described writing a diary at the time Alison was in hospital, as a way of documenting the experience. She spoke about only looking at it once since that time, because she did not wish to re-visit that period where there was “no hope:”

I kept putting it down because I thought Alison might want to know what has happened and how I felt about it but I’ve only ever gone - I've only ever read them once and that was when we were going to mediation for the insurance company and I thought I'll just refresh my mind how bad it was and it was terrible. I haven't actually looked again because it brought up how bad things really were, when there was no hope and that's a sad - and it was a sad place to be. (Mary, mother, 2014)

It appeared that in order for Mary to function, and continue to do what was required to support Alison she had needed to separate from the trauma experience; a slightly different strategy from those who supressed or avoided.
Related to this separating or splitting from the trauma was a tendency for some participants to speak about their injury lives as distinct from their every-day lives. This was revealed through a shifting in tenses as June, Mary, and Kate shared their stories. This was not evident in Ronald’s family where the challenges were still very present, nor in Neville and Daryl’s families where the injury was consistently discussed as a past event. However the language used by June, Mary, and Kate frequently shifted between the past and present tense when speaking about the time of injury and its early aftermath, as exemplified by Kate:

William: *but Kate's been there 24 hours a day, seven days a week.*

Interviewer: *How was that for you Kate?*

Kate: *Well I have to. It was hard*

In speaking about the time of the injury it appeared to become a contemporary story again, suggesting that the injury experience is embedded in, but distinct from their present day experience. Although the trauma was in the past, its impacts were ongoing, and aspects of it were part of contemporary life. The line between past and present was blurred in relation to the injury aspect of people’s lives.

**Recalibrating.**

Results showed that over time, families *recalibrated*, tending towards more positive emotional and psychological responses including humour, hope, determination, and positive framing of the injury.

**Humour.**

Families spoke about the importance of humour as a strategy for alleviating distress. Despite the seriousness of their circumstances humour provided a respite from unwanted feelings such as loss and worry. Kate and William had noted that Brendan
had not lost his sense of humour, and that this had helped him cope. For the rest of the family too, humour was a means to experience happiness amidst trauma:

But when he had the post-traumatic amnesia, the things that he would come out with. They - it just had us in fits of laughter. You'd have to see the funny side of it, even though it was a terrible situation. But yeah, it was just incredible (Kate, mother, 2014).

All families either spoke explicitly about the role of humour, or displayed moments of humour during the interview. Humour functioned to create unity; re-forging the bonds between family members which hardship had sometimes damaged. Humour provided a family-based reference point that was shared and special. It served as a tool to unite families.

Hope.

Hope was a way of thinking displayed by all families, and it was crucial to participant’s ability to cope. Hope was evident from the time of the injury in families’ hope for their loved one’s survival and it continued to play a role in their emotional buoyancy over their post-injury lives. At Study 1, with much relating to outcome still unknown, all participants had expressed hope for the future. Over the long-term, hope continued be play a role in helping families to manage difficult circumstances. The families in this study advised other families experiencing TBI to remain hopeful, “so there is always a light at the end of the tunnel. But it’s just sometimes it might take a while to get there” (Kate, mother, 2002). Similarly, Daryl’s advice for other families going through brain injury was “there is a light at the end of the tunnel, it's a long tunnel but you get there in the end” (Daryl, 2014). Hope was particularly vital in Ronald’s family where ongoing hardship meant opportunities for positive framing of the injury were limited. Despite the absence of significant positive shifts in Ronald’s
circumstances, the family did not let go of the hope that solutions would emerge. They hoped this solution would come in the form of professional intervention rather than believing that they had the internal resources to change Ronald’s circumstances.

There was also evidence of families holding on to hope despite an absence of medical advice to support those hopes. The need to retain hope in these circumstances often fuelled a further contraction of the external environment to exclude those who failed to support these hopes. Participants had survived despite a poor prognosis, and families had spoken about never giving up hope at that stage. Families also utilised hope to reassure injured participants:

Brendan: *But I'm pretty good, but it's just this weight issue's driving me insane.*

*Just different things - I know the vision thing, I can't change that.*

*That absolutely drives me nuts. It frightens the hell out of me. If I lose my eyesight I'm stuffed.*

William: *Well they did say there in the hospital, too, that nerves sometimes can find their way back. So we've always had a bit of hope there that they might come back to his eye (2014).*

Mary explained how Doctors avoided giving families false hopes, “*like they never ever give you hope, they never ever said because they didn't know* (Mary, mother, 2014). For Mary and Alison the experience of always exceeding health professionals’ expectations, from surviving, to walking, to completing University and living independently, gave them even more reason to remain hopeful despite medical advice:

*No, they don't know. [if Allison will regain speech]. Basically they said that probably 99% of it won’t. But doctors don’t know everything. We hope that it does come back* (Mary, mother, 2003).
The desire for hope often led families to question the prognosis given by the medical system. Information from doctors was assessed and aspects that did not fit with family’s desired outcomes were rejected. The families of Brendan and Alison both rejected the idea given to them by health professionals regarding reaching a “plateau” in their recovery, rather remaining hopeful of ongoing improvements at Study 1:

*They say two years, they say 18 months to two years then plateau. But I reckon the way she’s been going we’ll go for a few years. There will be small things, as well as major things for her* (Mary, mother, 2003).

At Study 2 Kate continued to express similar hopes for Brendan’s continued improvement, explaining that the family believed he had improved beyond the plateauing window, “because they usually say after - by two years they're going to be as good as they're going to be. But Brendan did keep improving in certain things. (Kate, mother, 2014). In contrast, other families had been more accepting of the notion of reaching their recovery plateau. Neville’s family, for example, did not question the idea of having plateaued, and did not believe he would improve any further at Study 1:

*From what I’ve been told, I’d be surprised if much changes because the level that I’ve got to is about it. So basically, how I am now is how I’m pretty well going to stay except I’m just going to get older. That’s about the only thing* (Neville, 2002).

Daryl and Ronald had similarly shown little hope in recovery beyond what they had achieved at Study 1. The impact of prognostic predictions made by health professionals varied across the families in a bi-modal trend, galvanising some families and debilitating others.
**Determination.**

There were a number of instances where injured participants and family members showed great resolve and determination in the care and recovery process. Mary described this as stubbornness, which she felt was an important aspect of her ability to cope. It was this quality which was behind her capacity to keep fighting for Alison, and the unwillingness in Mary and Alison to give up:

**Interviewer:** so looking back over all of those challenges that you've talked about, what got you through do you think?

**Mary:** Stubbornness. I said to Alison one day you're just like your Grandmother. Then Alison goes - she points at me! I suppose you'd have to have a bit of that in you just to get through it. We can achieve this and if we can't then there must be something we can do different. (2014)

Mary spoke about her determination not to give up on her child, saying, “I don't think you want to give up, especially a child, to be the best in strength and mentally the best they can be” (Mary, mother, 2014). This had been the same driver for other families where the injured person was a child. Determination in the injured person was also important. Brendan and Alison had both showed a high degree of motivation and determination to achieve their goals, as exemplified by Brendan’s comments at study 1:

*You’ve got to have focus. You’ve got to know where you want to go. At first I was setting goals that I knew I could do. Then after a while you set goals that you don’t know if you can do because you’ve got to push yourself to do it, where I found - and then you just keep making them harder and harder* (Brendan, 2014).
Alison and Mary had displayed a similar capacity to set goals, and follow through until they were achieved. There was evidence of a reciprocal relationship between the injured person and the family in relation to determination. Injured participants gained strength from the unwavering support of family, and the family gained inspiration from witnessing their loved one as motivated and determined. Kate explained their family’s resolve to “*stay strong*” to preserve the integrity of the family unit, underscoring the interdependencies between family members:

> If I lost it, William lost it, we'd be no good to ourselves, we'd be no good to each other, we wouldn't have been any good to Brendan or Rose, so you think, well hang on, I have to. I have to just stay strong (Kate, mother, 2014).

Sharon had also described her determination to protect the children, and not to fail in the eyes of others. Jo was similarly determined to protect her children and maintain family stability, and this had been a strong motivator for her. Ludmi had similarly displayed this sort of determination or resolve to endure ongoing difficulty. Having described the challenges the family were facing regarding Ronald’s TBI and Federico’s illness, I asked her how she managed, and she shrugged and replied, “*I’m fine, I can do it*” (Ludmi, mother, 2014). Determination had been less evident in Neville, Daryl and Ronald. Neville and Daryl had less of a perception of having things to achieve, so long-term goals were not set, and Ronald had experienced his goals as unattainable, so had been discouraged and unmotivated.

**Positive focus.**

While all families clearly wished that the injury had not happened there was evidence of families shifting to a more positive framing of the injury over time. Some families commented that the accident had strengthened family bonds, and enhanced their appreciation of each other. Brendan felt that the accident had brought his family
closer together saying “I think - well we've always been close, but I'd say we're probably a bit closer now” (Brendan, 2014). Mary and Alison had expressed a similar belief that they had come to know each other more intimately as a result of the accident, and that they were more involved in each other’s lives:

I think living through it has probably made Alison and I closer because she really knows who I am because there's no hiding. When you're living hour to hour with one another, day to day and week to week and we would have - Alison would have probably been overseas working and doing her own thing (Mary, mother, 2014).

Daryl’s family had reported improved relationships post-injury, although this was not maintained over the long-term. Kate talked about the importance of trying to stay positive despite adversity. She described this not as a denial of the difficulty, but rather as a way to avoid burn out and overwhelm:

And I find too, if you tend to, if I try to think of not make it such a negative thing when he has been agitated and has taken it out on me. Even though it does get to me, sometimes I try to think of a brighter side, you know what I mean? Not sort of try to think of the real down side. Like, I know he doesn’t really mean it, and try to take it lightly. Because otherwise it just wears you out too much. And just try to pass it off and think, ok, once he gets that out of his system he’ll be right. And usually he is. And I'll try to change the subject about something else and try to get him talking about different things to try and lighten the mood (Kate, mother, 2002).

Kate explained further the importance of maintaining some positive hopes for the future as a way of coping:
I think you just have to do it the best way you can. But I think you do have to try to have that positive outlook and just know that things are- they are going to get better but you just don’t know how much. But you just got to keep that positive thought in your mind and do it that way. I think you need something like that to keep you going (Kate, mother, 2002).

Finding positives in their circumstances functioned to allow participants to recalibrate their expectations and pre-injury imagined futures, and re-gain a sense that life can be experienced as good despite seemingly dire circumstances, as exemplified by Mary:

* I always thought if Alison can be responsible for herself, then she makes the decisions on how - where her life goes. We've been able to achieve that, we've been lucky we've been able to achieve that which has been great* (Mary, mother, 2014).

Participants often spoke about feeling “lucky” in comparison to others, or that “it could have been worse.” Brendan for example felt lucky that he retained his awareness and self-identity:

* I remembered everything, too. I didn’t - I knew everyone, which I think probably made it a little bit better. If I woke up and didn’t know anyone or anything, it would have been a heck of a lot worse* (Brendan, 2014).

Sharon had also spoken about Daryl being lucky, exemplifying the tendency in participants to prefer not to see their circumstances as disastrous:

* Daryl was lucky really. Yeah, he had a brain injury but when you see some of those people that are in there, we were lucky, he was just nowhere near as bad as that* (Sharon, spouse, 2014).

Participants showed a capacity to “look on the bright side.” Although they were upset, or angry about what had happened to them in order to have any ongoing enjoyment of
life there appeared to be an inclination towards positive framing of their situations, as exemplified by Neville:

\[ I \text{ could be a lot worse than what I am, because I’ve seen quite a few people, met quite a few people that had the same sort of injuries as me and have been a lot worse than me. so I’m pretty well happy with how things are going for the stack my body’s had} \text{ (Neville, 2002).} \]

Jo had also stressed the importance of keeping positive and avoiding self-pity, which had helped her to accept their situation. She described this as something different in her thinking now as a result of the accident:

\[ \text{But I think I look at life a lot differently now too. You just never know what’s around the corner. You never know what's going to happen from one day to the next. So you try and make the best of what you have. Always look at, well you might feel sorry for yourself, or that you're in this position, but there's always someone worse off. You look at a program and see a man who’s functioning wonderfully and has no arms and legs. You've got a look at life from a different perspective and just take the positives out of what you have} \text{ (Jo, spouse, 2014).} \]

Focussing on her family and her faith were ways Jo was able to maintain a positive attitude:

\[ \text{And I’m a believer in God, so that helped me as well. I believe that that helped me through it. If I didn’t have that faith, I wouldn’t stay in the marriage I don’t think. It was a real struggle and it was a real easy way to say that’s it, I’m not having this I don’t know this man. I’ve known him for ten years and he comes home and he’s just totally the opposite to what I knew and married. Yeah, I think without my faith or the support of family, definitely} \text{ (Jo, spouse, 2002).} \]
Jo and Sharon both spoke about finding meaning in their circumstances in the belief that things “happen for a reason,” as Sharon described:

_Maybe in a way it was meant - not so much meant to happen that way but it was a wake-up call. And he sees that and I definitely see it because I do have a different husband_ (Sharon, spouse, 2002).

These examples contrast with the families of Nathan and Ronald where positive emotions and experiences remained elusive. For June, it appeared to be something she endured, describing Nathan’s injury as “it was pretty fucking awful, and if I didn't have money, it would have been awfuler. There’s nothing good about it” (June, 2014).

One of the ways participants were able to experience positive emotions in relation to the injury was through the expression of gratitude. Gratitude was felt for the injured person’s survival, and also in relation to the presence of family unit. For the injured person there was gratitude for the support of loved ones. Daryl for example expressed immense gratitude towards Sharon and Sandra. His capacity to feel and express gratitude appeared to be healing for this family. Neville also expressed gratitude for Jo, and Alison for Mary. Alison described gratitude for her own life, “_being so close to death makes you want to live_” (Alison, 2003). For the injured person’s family the relief and gratitude that they had survived was sustaining, “_we did pull on each other for strength back then, but the main thing was to get Brendan well, to pull through_” (William, father, 2014). Neville also expressed gratitude and appreciation that Jo supported him. Mary expresses gratitude for Alison’s survival, and the degree of her recovery. Some participants also described experiencing a positive experience in the kindness and support offered by others:

_Yeah, it makes me emotional to think that people gave me so much [crying], you know, and not in a monetary - I was given money from work. People fund raised_
at work but - and they were excellent. My workmates were - everyone was really good, yeah. The support, yeah was for me because I'm a giver and to get back was very much (Mary, mother, 2014).

Although the presence of gratitude was less evident in Nathan’s and Ronald’s families, they had both expressed gratitude for their families, as Ronald’s comments showed:

*I’ve seen when I was in hospital like there’s people that were in that same little ward as me that had no family at all. They, you know they just had an accident and every weekend they didn’t go anywhere. They just stayed there and their life was just boring and nothing at all to do. And at all - wiped completely and blankly out. And I didn’t like that and I appreciate my family* (Ronald, 2004).

Ronald described the importance of this support to his self-worth and wellbeing saying, “*It just puts a smile on my face every day*” (Ronald, 2004). Daryl and Neville expressed gratitude that their partner had stuck by them.

Another observation about participants’ relationship with positivity was a tension between their need to find positives on one hand, and their desire not to misrepresent their experiences to others, seeming to say “*we’re OK, but it’s not OK.*” This was observed across multiple participants who, after describing their situations in positive terms would pause, and then qualify those statements with statements about difficulty. For example William laughed after Brendan’s positive comments and said, “*It was a lot of stress*” (William, 2014). Positive framing may have benefited families, but they were careful not to misrepresent their experience. Neville’s comment at Study 1 reflected similar qualification:

*Well I’m satisfied but I’m dissatisfied because if I didn’t fall off my pushbike I wouldn’t have this problem. It’s one of these things that I’m still alive so I’m satisfied for that* (Neville, 2002).
This comment points to the tension between the desire to feel positive emotions on one hand, with the ongoing resentment, regret or grief about the injury. Families appeared to become adept and holding these two seemingly opposite sets of emotions simultaneously.

**Conclusion**

The processes described have shown the various ways in which the six families in this study responded to TBI over time, and how individual factors interacted with or mirrored family factors (see Table 5 and Table 6 below). The ways in which families responded were influenced by family characteristics and circumstances, and had implications for individual family members as well as for the entire family unit. The process of reconnecting and reinventing explained the processes families engaged in to regain a sense of normalcy in their post-injury lives. The process of making the unbearable bearable described the ways in which families attempted minimise unwanted cognitive and emotional reactions, and maximise opportunities to experience happiness, despite trauma and ongoing adversity. The two processes overlapped and interacted; with the combined effect impacting on both the family and individual experience.
Table 5

*The Process of Reconnecting and Reinventing*

<table>
<thead>
<tr>
<th>Reconnecting &amp; Reinventing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brendan</strong></td>
</tr>
<tr>
<td>Reconnect to former self; Getting back to normal</td>
</tr>
<tr>
<td>Family team shared goals</td>
</tr>
<tr>
<td><strong>Alison</strong></td>
</tr>
<tr>
<td>Reinvent- looking to the future</td>
</tr>
<tr>
<td>Family team shared goals</td>
</tr>
<tr>
<td><strong>Daryl</strong></td>
</tr>
<tr>
<td>Reconnect- “put it behind us”</td>
</tr>
<tr>
<td>Family team/ Different agendas</td>
</tr>
<tr>
<td><strong>Neville</strong></td>
</tr>
<tr>
<td>Jo- reinvent; moving on</td>
</tr>
<tr>
<td>Neville: “I’m not different”</td>
</tr>
<tr>
<td>Different perceptions</td>
</tr>
<tr>
<td><strong>Nathan</strong></td>
</tr>
<tr>
<td>Family- reinvent; moving on</td>
</tr>
<tr>
<td>Nathan: “There’s nothing wrong with me.”</td>
</tr>
<tr>
<td>Family conflict/Different perceptions</td>
</tr>
<tr>
<td><strong>Ronald</strong></td>
</tr>
<tr>
<td>Cannot get back to normal</td>
</tr>
<tr>
<td>Family conflict/ Different agendas</td>
</tr>
</tbody>
</table>
### Table 6

**The Process of Making the Unbearable Bearable**

<table>
<thead>
<tr>
<th>Family</th>
<th>Making the unbearable bearable</th>
<th>Recalibrating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contracting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spatial contraction</td>
<td>Temporal contraction</td>
</tr>
<tr>
<td><strong>Brendan</strong></td>
<td>Family knows best</td>
<td>One day at a time</td>
</tr>
<tr>
<td></td>
<td>“we like to do things ourselves”</td>
<td>Transition to future planning</td>
</tr>
<tr>
<td><strong>Alison</strong></td>
<td>Family knows best</td>
<td>One day at a time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transition to future planning</td>
</tr>
<tr>
<td><strong>Daryl</strong></td>
<td>Only trust the inner circle</td>
<td>One day at a time</td>
</tr>
<tr>
<td></td>
<td>Others do not understand</td>
<td>Future not planned for</td>
</tr>
<tr>
<td><strong>Neville</strong></td>
<td>Jo- I have no manage this myself</td>
<td>One day at a time</td>
</tr>
<tr>
<td></td>
<td>Others do not understand</td>
<td>Future not planned for</td>
</tr>
<tr>
<td><strong>Nathan</strong></td>
<td>June- I can do it myself</td>
<td>One day at a time</td>
</tr>
<tr>
<td></td>
<td>Others do not understand</td>
<td>Concern for future; solutions elusive</td>
</tr>
<tr>
<td><strong>Ronald</strong></td>
<td>We are alone</td>
<td>Still taking each day as it comes;</td>
</tr>
<tr>
<td></td>
<td>Others do not understand</td>
<td>Concern for future; solutions elusive</td>
</tr>
</tbody>
</table>
Momentum or inertia was seen, at the family and individual level, as families engaged in the processes to regain functional and emotional stability. These processes either brought families closer together or increased distances between members, depending on specific circumstances. In the families of Brendan and Alison, momentum occurred at the family level, as a result of shared perceptions of the injury and shared goals, which strengthened the family bonds. This family strengthening was less evident in other families, where differing perceptions and foci resulted in more individualised responses that separated family members.

Daryl’s family did display a shared team perception of the injury, and reported being strengthened initially. However, Sharon’s focus had primarily been in the children, and she had not been engaged in Daryl’s recovery. This, combined with the family’s desire to put the injury behind them, meant an absence of the ongoing shared experience and family level momentum seen in Brendan and Alison’s families. There was momentum, but not as a family. Although there were positive relationship changes reported these related to Daryl’s post-injury behaviour being seen as “less bad” than it had been pre-injury, and had not resulted from the family working together to overcome adversity as seen in Brendan and Alison’s families. Moreover, Daryl had suppressed his emotional trauma, resulting in inertia in that aspect of his recovery.

For the families of Neville and Nathan, the experience and response of the injured person did not match that observed by other family members. Increased distance was seen as family members pursued different agendas, and momentum was not evident at the family level. Like Sharon, Jo’s focus had been on the children, and like Daryl, Neville had suppressed his emotional problems. The differing awareness between Neville and Jo meant an absence of a shared experience and family level momentum. In Nathan’s case, it seemed that already established divisions between family members
were exacerbated by Nathan’s injury. Family members did not display a shared perception of the injury, and June’s carer role was a solitary one. Unlike the other families, this family did not appear to be a place of refuge. Nathan’s awareness was so different from his family’s that there were not opportunities for a shared experience, or shared goals. While the families had moved on Neville and Nathan appeared stuck in the same place they had been at Study 1.

Ronald’s family differed again, in that the experience was of a “failed” team, with concomitant negative impacts on the family. The family conflict and hardship experienced as a result of Ronald’s neurobehavioural issues had been beyond the resources of this family to manage alone. Difficulty understanding Ronald’s situation, and barriers to accessing appropriate services had meant the family had not received the assistance they needed. Consequently there was inertia at the family level, with the family system was stuck where they had been at Study 1.
Chapter 6 Discussion and Implications

The current research explored the long-term experiences of families following TBI. Although there is a significant body of research exploring families after TBI, this predominantly consists of quantitative point-in-time assessments, which fail to illuminate the totality of the experience, and omit the perspectives of families. As a result, understandings of the long-term experiences of families after TBI, and the ways families manage over time are poor. This knowledge is an important missing piece needed to guide future service provision and policy formulation. This chapter will summarise the results of the current study, and discuss how these add to the current discourse pertaining to families and TBI. Recommendations for practice, policy and future research will be made. Limitations to the study will also be discussed. The overall aim of this thesis was to gain a better understanding of the long-term family experience of TBI from the perspective of families. This study was based on a unique opportunity to follow-up with families over approximately 13 years. A number of important findings emerged from this perspective that will be summarised.

Review of Findings

**Family responses are maintained over time.**

The ways families organised themselves and assigned roles as an early response to the injury was maintained over time. The structures and power relationships seen as a response to TBI at Study 1 were generally maintained at Study 2, with varying implications for families. The mutually supportive team structure evident in Brendan and Alison’s families at Study 1 remained at Study 2. These structures and roles were in place prior to the injury, and had not constituted significant change for these families. In Ronald’s family, intractable problems strained relationships and this was maintained over time. In the families of Daryl and Neville, the spouses took charge of the family in
ways that changed family dynamics. Where Daryl and Neville had previously had more control of family finances and decisions, their injury prompted their wives to take over this control at the time of the injury. It appeared that these changes in power and control never fully shifted back, with a high level of dependence seen in both men. June similarly took control in Nathan’s family, and this had not changed over the two studies.

All families had a key person who took charge after the injury. In this study, each of these key family members was the family matriarch. These women appeared to be motivated either by wanting to ensure the best outcome for their injured child, or in the cases where the husband was injured, to minimise the emotional damage and preserve the family unit for their children. Walsh (2006) referred to family organisational patterns which act as “shock absorbers” in times of crises. The families in this study organised themselves such that this pivotal person acted as a shock absorber within the family, working to balance relationships and maintain family stability. Kosciulek and Lustig (1998) described this “re-balancing” within the family system as part of the process of positive adaptation to TBI. These key family members were also the lynchpin between the family system and the health system, advocating for the injured person, and in some cases influencing the nature of support sought and received by the family. In cases where the matriarch was not able to fulfil this role (i.e., Ludmi was unable to manage the family due to her language difficulties), family re-balancing did not occur.

**Recovery and family adaptation is ongoing.**

In many cases, the problems families reported at Study 1 were still impacting at Study 2. This was most evident in the families of Ronald and Nathan where there was seemingly no change in the challenges these families faced from Study 1 to Study 2. Concerns about the injured person’s behaviour, employment opportunities, vulnerability
and fears for the future continued to stress these families. Other families who reported fewer problems at Study 2 still showed long and continual processes of adjustment. Neville and Jo reported at least six years of post-injury conflict. Kate explained that Brendan had only just learned to manage his agitation, and that it did still cause problems. Although Daryl’s family framed the injury as something they had overcome, Sharon’s comments underscored the continued issue of Daryl’s dependence. The families of Brendan, Alison, Nathan and Ronald were still actively engaged in the injured person’s recovery. Positive results were still being experienced in Brendan and Alison’s families. Long-term positive changes in the injured person’s recovery were not evident in families where there had not been a focus on the injured person (Daryl and Neville), or where effective solutions had not been found (Nathan and Ronald).

**Families can be strengthened or weakened by the experience of TBI.**

Results indicated that over time the experience TBI can strengthen and unite the family system or it can create distance and disunity. The families of Brendan and Alison appeared to have been strengthened by their experience, and could be described as thriving. These families reported being closer as a result of the injury, and they expressed pride in their family’s ability to manage their circumstances well. Momentum was evident at the family level, with shared goals, understandings, and achievements contributing to family pride and unity. Daryl, Neville’s and Nathan’s families were managing, but they did not report the same long term positive experiences and family unity. Unfortunately Ronald’s family had endured continued hardship, which had created disunity in the family.

Siblings of people with TBI have been shown be profoundly affected, and their perspectives are necessary to fully understand the family response (Degeneffe & Olney, 2010). However, as the siblings in the families of Brendan, Nathan and Ronald did not
participate their perspectives are unknown. In the family of Brendan for example, his sister Rose felt distressed by TBI, but her family were aware of this challenge and had addressed it. Alison had no siblings so it is difficult to examine this issue further. However, in the other families, siblings were physically and emotionally distanced from the family. Similarly, the long-term experiences of Nathan and Ronald’s sisters cannot be assessed. The results suggested a number of factors impacted the sibling outcome, but conclusions cannot be drawn from this study.

**Kinship status.**

Families where the injured person was not a spouse had better outcomes. This could be attributed to the different responses from parents of an injured person as compared to spouses. Research shows that although parents experience more distress than spouses after TBI, spouses report “significantly less personal reward (Allen et al.1994, p.29). The current study shows that despite, or perhaps as a result of this distress, with the right conditions, parents are driven to achieve the best possible outcomes for their injured children. In the families of Brendan and Alison this drive to maximise recovery outcomes became a family focus, and consolidated family relationships. Although kinship status was the same in the families of Nathan and Ronald, factors associated with awareness and neurobehavioral impacts precluded the family from strengthening experience of working together and achieving their goals.

In the families of Daryl and Neville, the focus of the spouse had been on maintaining family equilibrium for the sake of the children. These families did not show the same degree of shared commitment to the injured person’s recovery as shown by Brendan and Alison’s families. For the wives, Sharon and Jo, the focus was primarily on the wellbeing of their children; financial issues; keeping the family together; and minimising the impact on the children. This is not to say that they were not concerned
with their husbands’ recovery, but rather that the impact on the children was the prime consideration and motivator. Consequently, the same process of shared family activity was not seen over the long-term. It appeared that for the two spouses, although they were an important source of support, there was a distance between themselves and their husbands that was not evident when the injured person was the child.

**Communication patterns.**

Positive communication has been shown to be associated with greater flexibility in families after TBI, resulting positive family adaptation (Kosciulek, 1996). Positive communication was characteristic of Brendan and Alison’s families. Brendan’s family relied on open communication to manage family conflict, and positive communication was evident in the family interview. Alison and Mary had similarly displayed a tendency to communicate and solve problems together, without Mary taking over. Conversely Daryl, Neville, Nathan and Ronald’s families were characterised by poor family communication. Daryl and Neville had not communicated with their spouses about significant emotional impacts. Communication in Nathan and Ronald’s families was also poor, and characterised by conflict and negative framing of their circumstances.

**Reciprocal relationships.**

There was a reciprocal relationship evident between the injured person and the family where individual factors interrelated with family factors. Characteristics in the injured person impacted on families, and the family response had long-term implications for the injured person. The nature of this reciprocal relationship determined the family outcome.

Brendan and Alison had shown great determination and motivation to maximize their recoveries, which had a positive impact on their families, and the support of their
loved ones, in turn, bolstered their resolve. Brendan explained how seeing improvements created further momentum to keep trying:

*I think seeing improvement helps you get through it as well, knowing that something’s happening. If you just had no improvement, it'd be - well there's no real drive* (Brendan, 2014).

The injured person’s achievements were perceived as family achievements, which had a strengthening effect on the families. Both families expressed admiration for their loved one’s determination, and there was evidence of family pride in the families’ capacity to manage well and ensure the greatest recovery possible, as Kate explained, “*we feel, with doing what we've done, it's helped Brendan get as good as he is today because without that family support, who’s to say?*” (Kate, mother, 2014). As Brendan and Alison improved, their distress was reduced and their independence, confidence and sense of value increased. There was a reciprocal relationship evident in these families where the injured person’s recovery was enhanced through the efforts of family, and the families in turn gained solace and satisfaction from this success. Worry about their loved one’s ability to cope, and concerns for their future were diminished. At the same time, beliefs that their circumstances were manageable, and that they had done the best job they could in helping their loved one had a positive impact. The experience of being stronger and closer as a family because of the experience engendered further family pride, and allowed families to frame the injury in a more positive light. Although none of the families ever ceased wishing that the injury had not occurred, the families that were strengthened expressed a drive to enjoy life regardless of the injury. This drive was evident in all families, as described in the process of recalibrating, but the circumstances in the families of Brendan and Alison provided more opportunities for positive outcomes:
...life's been a challenge, it's been fun, it's been funny. We've done some really lovely things together - gone away on holidays, went to Paris together, went to Rome, Pompeii, all Alison’s passions (Mary, mother, 2014).

In other families, the reciprocal relationship created unintended negative consequences, and the family response created inertia rather than momentum. For example Daryl and Sharon’s response of attempting to “get back to normal” and “forget” the injury contributed to a suppression in Daryl of the significant emotional trauma he experienced, compounding his social isolation and dependence. Daryl had suppressed his emotional trauma in order to function, but through this response opportunities to improve his confidence and independence may have been missed. Although Sharon noted pre-injury issues as the reason for their eventual break-up, she said his dependence on her was one of the problems that triggered the separation. Significantly, she no longer viewed Daryl’s dependence as an injury-related aspect of his personality. Although the family presented a shared view of the injury experience and its implications, a closer examination of their response indicated an individual response based on different assumptions. The family did not report the experience of shared achievements and family pride, both of which had been strengthening factors in Brendan and Alison’s families. Moreover, Daryl’s suppression of his emotional trauma meant that inertia was evident in this important aspect of his recovery. The example of Neville paralleled that of Daryl in that the primary focus of his spouse was on the stability of the family system. Neville and Jo did not have a shared experience of the injury, making it impossible to work towards a common goal. Jo needed to move on, and Neville appeared to be a “passenger” on her journey rather than an active participant in the family.
The tendency to attribute behaviour to personality traits rather than TBI was common in those families that chose to “forget” about the brain injury and move on. Over the long-term, these families integrated the TBI changes into their lives, attributing injury-related factors to the injured person’s personality. Evidence was found for this in the families of Neville, Nathan, Ronald and Daryl. This attribution reduced understanding and increased conflict when behaviour was seen as irritating or difficult. This could be challenging for injured participants, re-enforcing fears about there being something wrong with them. For example, at Study 1, Sharon had spoken about not understanding why Daryl would repeat questions:

- *You can understand him asking twice, but asking four or five times. It might be just a simple thing like what’s the date today and you tell him. And a minute later he’s asking again. And this can go on four or five times* (Sharon, spouse, 2002).

Ludmi had expressed similar frustration with Ronald’s inability to behave “normally,” and even admitted, “Yeah. *Even me sometimes I forget also he's got brain damage*” (Ludmi, mother, 2004). Although this tendency to forget the injury could be experienced as positive in the sense of life feeling normal again, there were negative impacts on the individual and the family.

A positive appraisal of one’s circumstances has been shown reduce stress and facilitate adaptation for families after TBI (Kosciulek, 1994; Carnes & Quinn, 2005). Finding some meaning in the events has been shown to result in positive appraisal for family members (Degeneffe & Olney, 2010). For the families of Alison and Brendan, this positive appraisal was clearly observed in their responses. The response of focusing on positives (as opposed to genuine positive appraisal) had some unintended negative consequences for Neville, where Jo’s positivity appeared to minimise Neville’s negative
experiences. Jo’s strategy of focusing on positives was crucial to her ability to adapt so successfully to Neville’s injury and to keep the family functioning. It was actually a strategy of contracting that allowed her to exclude negative thoughts and emotions. However, Neville struggled to keep his focus on these positive factors. At times it appeared that Jo’s positivity may have minimised Neville’s experience, and inadvertently silenced him. For example, Neville talked about his frustration with himself:

*I know some of the time, I will say something to Jo or Jake or Emily, or someone else, and I'll say, well why did I say that?, and probably didn't need to say that, but why did I say that? What did I mean by that? I don't really know* (Neville, 2014).

On hearing Neville say this, Jo identified that Neville’s propensity for self-criticism was a source of frustration for her, and that her response was to encourage him away from these thoughts and feelings:

*But I have to say that's one of the biggest things that frustrates me. Is how he is like that. Because how he's so down on himself all the time, and I keep reiterating to him, just appreciate what you have. You have such a good life. You've got a great family. We all love and support you* (Jo, spouse, 2014).

Jo’s intention was to support Neville, however it appeared critical of his expression, and bordered on blaming him for potentially making the rest of the family feel bad, isolating him from the family unit:

*I think a lot of the time, what frustrates me now more than anything, is that he seems to hone in on the negative stuff. To me, I don't see that that's a positive thing for him or us around him. Sometimes I feel like it drags us down a little*
bit. So I think too, that's why I've changed a lot, because I try and be more upbeat all the time. That probably frustrates you (Jo, spouse, 2014).

There did not appear to be any avenue for Neville to express his fears and doubts. Indeed, it was only through the process of the interview that Neville expressed ongoing feelings of depression, dissatisfaction and fears for his future. Jo had been unaware of that Neville had been unhappy, and appeared slightly embarrassed about this.

Jo: Well see, what he's saying to you, I didn't know about. See he doesn't communicate - I know that you do get times where you're down like that, but how it's still affecting you, he hasn't really communicated that to me. But I didn't know that you were feeling like that. So even now...

Neville: I go through stages.

Jo: All this time, well I didn’t know.

**Neurobehavioural sequelae.**

A significant individual factor which impacted on families was the neurobehavioural symptoms in the injured person. Consistent with the family and TBI literature, changes in personality and behaviour in the injured person created considerable stress for families (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986, 1987; Dell Orto and Power, 1994; Kosciulek and Lustig, 1998; Mauss-Clum & Ryan, 1981), significantly impacting the family experience of and response to TBI. Neville’s personality change dramatically affected his relationship with Jo, and much of her response was related to this aspect of her experience. Similarly Nathan’s lack of awareness meant he did not see his injury in the same way his family. Differing perceptions of the injury between family members have been linked with affective/behavioural factors in cases where family members report more problems than
the injured person (Cavallo & Kay, 2011). These differing perceptions of the injury in family members impeded the shared family experience which had united Brendan and Alison’s families. Ronald’s behavioural problems had been extremely challenging for his family, who felt they did not have the capacity to manage Ronald. This contrasted with Brendan’s family who had been adept at managing similar anger problems in Brendan. Ronald had been aware of the burden his behaviour placed on the family, which may have intensified his feelings of low self-esteem and worthlessness; perpetuating the negative cycles experienced in this family. The experience of a shared awareness and shared achievements had been crucial to the forward momentum, and family unity and pride seen in Brendan and Alison’s families. These factors are reflective of those noted by Walsh (1996) as associated with family resilience, which she described as “shared beliefs and narratives that foster a sense of coherence, collaboration, competence, and confidence” (p.1). Sachs (1991) identified similar factors in relation to family functioning, and noted open communication, cohesive relationships and a shared identity as promoting healthy family functioning. These factors were not seen in the other families for the reasons described. Although Daryl and Sharon had the same perception of the injury, they had missed the experience of family unity through a response which favoured “putting it behind” them. Brendan and Alison had appeared to have re-gained a level of independence and relationship with their parents commensurate with their age. Conversely, Nathan and Ronald appeared to be stuck at the level of perpetual teenagers. This experience of the eternal child was also evident in Daryl and Neville’s families where ongoing dependence had changed the spousal relationships (Table 7 shows these factors).
Table 7

*A Model of the Family Response to TBI and Implications*

<table>
<thead>
<tr>
<th>Family</th>
<th>Enduring Family distress</th>
<th>Managing Family equilibrium</th>
<th>Thriving Family strengthened</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Inertia</td>
<td>Momentum</td>
<td></td>
</tr>
<tr>
<td>Shared Experience Function as a team</td>
<td></td>
<td></td>
<td>Brendan’s Family; Alison’s Family: Shared perceptions, goals and achievements/ Family pride/ Maximised outcomes</td>
</tr>
<tr>
<td>Eternal Child</td>
<td>Ronald’s Family: stuck in distress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different Experience Function as a individuals</td>
<td>Daryl: supressed trauma</td>
<td>Daryl’s Family: put it behind them</td>
<td></td>
</tr>
<tr>
<td>Neville: Different perceptions/ left behind</td>
<td>Neville’s family: moved on/ focus on positives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nathan: different perceptions/ left behind</td>
<td>Nathan’s family: moved on compartmentalise/ avoid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compartmentalise trauma Mary; June; Kate</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Conclusion.

Overall the interaction of individual and family level factors meant that Brendan and Alison’s families appeared to have been unified and strengthened as a result of their response to TBI, whereas distance and disunity was evident in the other families. It appeared that the injured person outcomes were maximised in families with a shared focus on recovery, and that this outcome further strengthened families. In the absence of this focus it appeared that opportunities for recovery may have been missed, and the family benefits of shared achievements not experienced.

Implications and Recommendations for Practice

The results of this study suggest a number of recommendations for service provision. The results revealing the reciprocal interactions between the individual and the family system underscore the need for services to simultaneously consider the family at the individual and the family system level. At the family system level, a focus on unique family strengths, coping strategies, vulnerabilities and resources is necessary. Services must work to understand the unique circumstances of each family; the ways in which TBI has impacted in the family; the implications of the family response; and the areas this family feel they need to be supported. The importance of services that families perceived as being personalised and matched to their needs was highlighted by the evidence in the study relating to families’ resistance to services. Where families felt they were not understood, or not helped there was a tendency to “go it alone.” Although this may not always represent a problem, in some cases it can mean people with brain injury may not have access to potentially helpful services. Participants such as Neville, Daryl and Nathan may have benefited from services, but the family decision to resist external influences and contract meant that the injured individuals were denied assistance.
At the individual level, it is vital to identify and support the key person in the family, to enable them to fulfil the role of advocate and mediator; re-balancing the family system. With appropriate support this person can perform the role of case manager for the injured person as seen in Kate and Mary. Without support, critical opportunities are lost and family unity is jeopardised as seen in the cases of Sharon and Ludmi.

The challenges associated with neurobehavioural problems indicate that these need to be more actively managed and followed up when present. Families in this study found themselves at home with injured family members with significant personality changes and challenging behaviours with little or no advice about how to manage these aspects of the injury. This negatively impacted on the family confidence.

Results suggested the importance of early identification of family needs, strengths and capacities, given that this was unlikely to change much over time. Families need practical support at this time to enhance the sense that they are capable of managing. The need for long-term follow-up is also a key finding of this study. Ronald’s family had endured years of hardship due to language and communication barriers inhibiting access to services. Moreover, people with brain injury living in the community who are not assessed may be suffering with treatable secondary symptoms such as anxiety and depression.

Taken together the results indicate the need for long-term, personalised support. The importance of relationships and continuity in the provisions of care are highlighted. The family response to TBI is dynamic and varies widely across families. A one-size-fits-all approach to family support is not appropriate, and programmes must be responsive to the unique characteristics and changing circumstances of families.
Limitations

A number of limitations to this study are acknowledged. Although the family system was emphasised in this study it proved difficult to recruit whole families. The perspectives of the siblings in Ronald, Brendan and Nathan’s families, were necessary to reflect a true family system perspective, however this was not possible. Therefore I had to rely on the perspectives of other family members. Similarly, the older children in Daryl’s family did not participate, and they may have had a different perspective to the younger children who had little memory of the injury.

As the focus of the study was on the long-term experiences of families, their experiences with early rehabilitation and service delivery may not match those of families who are engaged with services today. The importance of family engagement and support is more recognised now, than it was when these participants were in the rehabilitation system. However, problems for services engaging with family as a system continue to be highlighted.

Although it is not the intention of this study to generalise the findings, the small sample size is acknowledged. The research design involved families from an earlier study of which six families consented to the research. Unfortunately there was a limited range of families in this convenience sample. There were two families where the injured person was the father, and 4 were adult children (3 male, 1 female). Although TBI is more prevalent in young males, the under-representation of injured females in this study is acknowledged. Furthermore, three of the participants were born in 1981 and injured at roughly the same age, so the lack of diversity within this group is recognised. The similarity between these participants is coincidental. Despite the presence of a family in Study 1 where the injured person was a female spouse, I was unable to access this
family. Despite these limitations, the unique opportunity to interview families 13 years after Study 1 constituted a valuable perspective and revealed new information.

**Suggestions for Future Research**

It is hoped that these findings will provide a foundation for future family system research with larger sample sizes. The findings need to be tested in future research with a wider sample of families examined. For example families from other non-English speaking backgrounds, Aboriginal Australians and various family constellations should be included. Investigations with more diverse families are needed to understand a broader range of responses in different contexts. For example, knowledge about the ways in which families respond when a female spouse in injured, or where the key family person is male does not form part of this study. It would also be useful to investigate families who did not remain together to compare with those who did, although one family in this study did eventually separate. Most importantly, this study has raised the notion of some key processes that are used by families in different ways over the course of time. These processes of, reconnecting, reinventing contracting and recalibrating now require further investigation.

**Conclusion**

This study constitutes an empirical contribution to current knowledge about the long-term family experience of and response to TBI through an in-depth analysis of interview data over a 12-13 year period. It offers a theoretical contribution to the extant discourse concerning family adaptation and resilience in the long-term after TBI. Together with the existing literature about family adaptation to TBI, the theoretical framework developed offers a detailed understanding of the family response to TBI, and the implications of this response for family members. It has articulated some critical processes that may now contribute to better understanding of family processes. It is my
understanding that there is no existing model that represents this unique long-term perspective of family adaptation to TBI. Finally, this research has practical utility as a basis from which to guide service provision and policy development relating to family support following TBI.

This study provides initial evidence that can guide family interventions, establish a case for funding to improve the provision of services to families, drive new policy for brain injury rehabilitation and contribute to future theoretical and clinical research. Few other studies have examined the long-term needs of families and none have provided the type of evidence found in this study. Thus, the current study is an important catalyst for a qualitative shift in the way rehabilitation services are delivered to support long-term family functioning following traumatic brain injury.
References


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10.1016/j.annemergmed.2011.06.009


10.1038/sj.sc.3102034


McCubbin, H. I., & Patterson, J. M. (1983b). The family stress process: The double ABC-X model of adjustment and adaptation. In H. I. McCubbin, M. Sussman, & J. Patterson (Eds.), *Social stress and the family: Advances and development in


consulting and clinical psychology, 44(6), 881-888. doi: 10.1037/0022-006x.44.6.881


Appendix A: Consent to Contact

Acquired Brain Injury Outreach Service
Princess Alexandra Hospital
3rd Floor Buranda Centro
Corner Ipswich Road and Cornwall Street
PO Box 6053 BURANDA Qld 4102
Phone: 07 3406 2311
Fax: 07 3406 2399
E-mail: abios@health.qld.gov.au

Dear [Insert name of Participant],

We are sending this letter to you on behalf of Griffith University who would like to contact you regarding a research project about the long-term experiences of families after traumatic brain injury. In 2001/2002 you took part in a research study conducted by Griffith University which looked at improving post-discharge support for people with traumatic brain injury. Researchers from the University would like to speak to you and some of your family members again, to find out about your experiences since the first study.

Participation in the study would involve a family interview at your home or an appropriate venue of your choice, with yourself and up to three family members. This would take place around February/March 2014. However, if you would prefer not to nominate any family members, or you would prefer to be interviewed individually, you are still eligible to participate, and the researcher will discuss these preferences with you.

If you are interested in hearing more about the project please fill out the following information and return in the reply paid envelope supplied OR fax to (07) 3382 1414, OR scan and email to m.mcintyre@griffith.edu.au and a Researcher from Griffith University will contact you to discuss your potential involvement. This is NOT a consent form for the study itself, just your agreement for someone from Griffith University to contact you and discuss the project over the telephone.

Kind regards,

[ABIOS staff member]
Consent to Contact

Understanding Families after Traumatic Brain Injury

If you are interested in participating in this research project or would like to learn more about the research, please fill out the following information and return in the reply paid envelope supplied OR fax OR email (see below) and a Researcher from Griffith University will contact you to discuss your potential involvement.

[please complete]

Yes, I agree for the researchers from Griffith University to contact me about this project.

_________________________________________________________________________ / / ______________________________________________________________________
YOUR NAME AND SIGNATURE DATE TELEPHONE/Contact
(print name)

Please return this form to Griffith University:

FAX: Ms. Michelle McIntyre, on (07) 3382 1414 OR

Scan and email: m.mcintyre@griffith.edu.au OR

Mail: PLEASE USE THE REPLY PAID ENVELOPE SUPPLIED

Thank you for your interest.

If you have any complaints concerning the manner in which this research is conducted, you can contact the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University on:

➢ Telephone: 07 3382 1077 OR
➢ Email: research-ethics@griffith.edu.au
Appendix B: Participant Information and Consent

Participant Information Sheet

Understanding Families after Traumatic Brain Injury

Griffith University PhD Researcher: Michelle McIntyre
m.mcintyre@griffith.edu.au

Principal Supervisor: Professor Elizabeth Kendall
e.kendall@griffith.edu.au

Associate Supervisor: Assoc. Professor Heidi Muenchberger
h.muenchberger@griffith.edu.au

What is this research about?
In 2001/2002 you took part in a research project at Griffith University, and we would like to meet with you again to interview you and your family to find out about your experiences of managing with brain injury since that first study.

Why is this research being conducted?
This research project aims to gain a greater understanding of the long-term experiences of families after traumatic brain injury. Families are often a vital source of support for people with brain injury, but a lack of appropriate and effective assistance leads to undue hardship and frequently negative outcomes for families. However, there is very little research looking at the long-term experiences of families following brain injury, so consequently little is known about what happens to families once formal supports finish. This study will focus on the stories of families who have experienced brain injury in order to learn:

- How families managed over time.
- What things contributed to family crisis, and what strengths and positives are experienced?
- What are the things that help families, and where is more support needed?

It is hoped that through the process of investigating your family stories, knowledge gained in this study will contribute to better supports for families facing traumatic brain injury in the future.

Who will see the results?
Any information that can identify you will remain confidential. It will not be disclosed unless you give permission to do so, and except as required by law. In any published information arising from the study, information will be provided in such a way that you cannot be identified. Only summarised data will be made publicly available so as to maintain your
confidence. Your results will be stored securely in a lockable filing cabinet at Griffith University Logan campus, and upon completion of the project will be stored on the EQUELLA Data Management System managed by Griffith University. Information you provide for this study will be retained for a minimum of 7 years. After this time, your results will be destroyed.

**What is involved?**

After this written consent form is returned, the researcher will contact you to discuss your preferences for the interview, and to organise a suitable time to visit. If you would prefer not to be interviewed with your family members it is possible for the interviews to be conducted separately. If you do not wish to involve any family members this is also acceptable. There is also the option of an individual follow-up interview at another time, which the researcher will discuss with you. If you choose to participate in the individual follow-up interview this can be done either over the telephone, via email, or face-to-face. You will also have the opportunity to view the interview transcripts and discuss the research interpretations to ensure the researcher has represented your views accurately.

**Do I have to participate?**

No. Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage, and there is a form attached to use if you wish to withdraw. Your decision not to take part will not affect your relationship with your health professionals. Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you would like. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

**Possible Benefits**

By taking part in this study, you will have the opportunity to talk about the experience of traumatic brain injury for your family, and to share the knowledge and wisdom you have developed over the years since the injury. The results of this study will potentially assist the way that services are delivered to families following traumatic brain injury.

**Possible Risks**

There are no major risks associated with your participation in the project, however it is acknowledged that for some people the interview may be distressing, and you are free to stop the interview at any time. All information will be de-identified and your responses will not be revealed to other parties.

**Ethical clearance**

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (2007) (see http://www.nhmrc.gov.au/publications/synopses/e35syn.htm) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. Any concerns about the conduct of this research project should be directed to the Manager,
Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (ph 3735 5585 or research-ethics@griffith.edu.au)

Questions / further information
If you have any questions about the study, please contact the research team on Email: m.mcintyre@griffith.edu.au or telephone Michelle McIntyre on (07) 3382 1077.

Future use of data
We would appreciate your permission to use your interview data in the following ways:

* For authorised members of the Centre for Community Science staff to access the de-identified data you have provided in this research for the purpose of further research. Y/N

* For my data to be stored in the Equella databank and used for the purpose of research other than the purpose for which it was originally collected Y/N

In giving permission for my data to be used in other projects:

* I understand that my data will be stored as non-identifiable recordings, transcripts, and/or notes

* I understand that the data will be used only for the purpose of research that has received ethical review

* I understand that my identity will not be disclosed at any time including in any written or verbal publication

**Thank you for your assistance with this research project**
Consent Form

Understanding Families after Traumatic Brain Injury

Participant with Traumatic Brain Injury

1. I have read the Participant Information Sheet regarding my involvement in the project.
2. I have had the opportunity to ask further questions and am satisfied that I understand the project.
3. I understand that if I agree to participate in this project, I will be asked to participate in a family interview.
4. I understand I may also take part in an individual interview at a later date if I wish.
5. I have been informed that participation in the project is voluntary and I may withdraw at my own request at any time.
6. I also understand that if I participate in the project, and choose to withdraw before its completion, no explanation is required.
7. I understand that information obtained will be stored in strict security and will not be disclosed to parties outside the project team. Confidentiality of the data collected or any personal records identifying myself will be maintained throughout the project and all data will be de-identified prior to sharing information with other researchers. Data collected will be stored securely in a lockable filing cabinet at the Centre for Community Science at Griffith University’s Logan campus. My results will only be identified by an ID number and will not be stored with this consent form.
8. I understand that if I have any complaints concerning the manner in which a research project is conducted, I may discuss this issue with the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (ph 3735 5585 or research-ethics@griffith.edu.au).

Your Name (print)........................................................................................................

Signature

Date..............................

Privacy Statement
The conduct of this research involves the collection, access and/or use of your de-identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the Griffith University Privacy Plan at www.griffith.edu.au/ua/aa/vc/pp or telephone (07) 3735 5585.
Family member

1. I have read the Participant Information Sheet regarding my involvement in the project.
2. I have had the opportunity to ask further questions and am satisfied that I understand the project.
3. I understand that if I agree to participate in this project, I will be asked to participate in a family interview.
4. I understand I may also take part in an individual interview at a later date if I wish.
5. I have been informed that participation in the project is voluntary and I may withdraw at my own request at any time.
6. I also understand that if I participate in the project, and choose to withdraw before its completion, no explanation is required.
7. I understand that information obtained will be stored in strict security and will not be disclosed to parties outside the project team. Confidentiality of the data collected or any personal records identifying myself will be maintained throughout the project and all data will be de-identified prior to sharing information with other researchers. Data collected will be stored securely in a lockable filing cabinet at the Centre for Community Science at Griffith University’s Logan campus. My results will only be identified by an ID number and will not be stored with this consent form.
8. I understand that if I have any complaints concerning the manner in which a research project is conducted, I may discuss this issue with the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (ph 3735 5585 or research-ethics@griffith.edu.au).

Your Name (print)........................................................................................................

Relationship to person with brain injury.................................................................

Signature ............................................................................................................... Date.........................

Privacy Statement
The conduct of this research involves the collection, access and/or use of your de-identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the Griffith University Privacy Plan at www.griffith.edu.au/ua/aa/vc/pp or telephone (07) 3735 5585
Appendix C: Assessment of Capacity to Consent

Brief Assessment of Capacity to Consent to Research
(Adapted from Jeste et al., 2007)

Has the participant read the Information Sheet?  □ YES  □ NO

Q1. What is the purpose of the research?
2 points = one of the following responses:
   i. To ask about my families’ experiences of traumatic brain injury
   ii. To help health professionals design better services for families

Q2. Do you have to be in this study if you do not want to participate?
2 points = no

Q3. Will there be any consequence to you if you decide to withdraw from the project at any time?
2 points = no

Q4. If you participate in this study, what will be asked to do?
2 points = one of the following responses:
   i. A family interview (1-3 hours).
   ii. Decide whether I want to participate in an individual interview

Researcher Name:  Ms. Michelle McIntyre  Participant ID:

Date:  ___ / ___ / 2014

Interview proceeded?  □ Yes  □ No
Action taken if understanding not clear:
Revocation of Consent (participant with TBI)

For a project entitled: Understanding Families after Traumatic Brain Injury

Griffith University PhD Researcher: Michelle McIntyre
m.mcintyre@griffith.edu.au

Principal Supervisor: Professor Elizabeth Kendall
e.kendall@griffith.edu.au

Associate Supervisor: Assoc. Professor Heidi Muenchberger
h.muenchberger@griffith.edu.au

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers of Griffith University.

Name of Participant (please print)_____________________________________________________

Signature_________________________ Date_________________________________________


Revocation of Consent (Family member participant)

For a project entitled: Understanding Families after Traumatic Brain Injury

Griffith University PhD Researcher: Michelle McIntyre
m.mcintyre@griffith.edu.au

Principal Supervisor: Professor Elizabeth Kendall
e.kendall@griffith.edu.au

Associate Supervisor: Assoc. Professor Heidi Muenchberger
h.muenchberger@griffith.edu.au

Declaration by Caregiver

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect the participation of my husband/wife/other family member/friend in this project or my relationships with the researchers of Griffith University.

| Name of Participant (please print) | | | |
|-----------------------------------|-----------------------------------|---|
| Signature                         | Date                              | |

Original text has been maintained in its natural form. No changes have been made to the content.
Appendix E: Family Interview Protocol Version 1

1. Run through participant information and consent
2. Capacity to consent “as part of my ethics approval I’m required to ensure you understand the project and your rights as a participant, so just need to ask 4 quick questions”

3. Ensure people understand the project & what we’ll be doing. “As you know this research is about the long-term family experience of traumatic brain injury. The interview questions are very open, there are no right or wrong answers- just what stands out to you as important- so if there’s something you think of that I haven’t asked about, please mention it. Also if I ask a questions that you don’t feel relates to you that’s fine too, just let me know

   - Your family structure- how you define your family, and what family means to you
   - The changes your family experienced after the injury (Different roles; relational dynamics- personality; financial; social).
   - How did your family manage these changes? Which parts were the most difficult? Who/What helped? Did you have the right support when you needed it, or did you have to manage things yourselves?
   - - it’s very informal”

4. Genogram. (data on family structure and developmental stage. “So as a start point, drawing a family tree is useful way to for me to get a sense of the structure of your family. After that we’ll look more deeply at relationships, as then talk about your families’ experiences using a timeline”

Genogram Data (starting with injured person)

   - Name
   - Birth date
   - Deaths
   - Illnesses or accidents (physical or mental illness) if significant
   - Occupation of immediate family current & past

5. Defining family: What does family mean to your family? How would you define it? Is it just the people you live with, extended family- does it include friends?

6. Concentric ecomap to get deeper into relationships and support networks. “Now we’re going to draw a diagram to map the relationships and where you found the most support since the injury- this can be family, friends, work, social groups etc.
The inner circle represents the people closest to you, who you most confide in, rely on; the middle circle represents close but not as close; outer circle people in your life but not that close”

7. Change: “So do you think relationships have changed since injury, perhaps some relationships become closer; or did conflict arise, or perhaps some people who used to be quite close become more distant?” “What other changes did you experienced?”

8. Timeline

- In the years since the injury, what have been the significant turning points or challenges for your family. (want to know lead up to crisis; trigger points;)
- How did you get through those times? (ask about internal strengths and qualities and external support).
- Is there anything that you think might have made it easier for you?
- What changes would you like to see to brain injury support services?
- Any advice for people going through a similar experience?

Stop recording and close: Assessment of need will be determined according to 3 brief follow up questions:

1. Did you have any concerns about this interview?
2. Would you like us to contact some-one on your behalf to discuss the interview?
3. Are you aware of, and understand that you can contact the researcher any time if you have any further concerns or queries in relation to the interview today?
Appendix F: Family Interview Protocol Version 5

Family Interview Question Prompts

1. Participant information and consent & Capacity to consent “before we start the interview as part of my ethics approval I’m required to ensure you understand the project and your rights as a participants, so I have to just run through that and ask a few quick questions”

2. Intro: So this interview is about your family’s experiences of managing brain injury- The interview questions are very open, there’s no right or wrong answers, just take you time- I’m interested in what stands out to you as important. Any questions before I start recording?

   - To start with it would be helpful for me to get a sense your family structure – who are the members of the family? Who lives together? Extended family?
   - What does family mean to your family? How would you define it?
   - Tell me a bit about your family-how would you describe your family? Changes since accident?
   - What things do you do together? Is that different from before the injury?
   - What changes did your family experience as a result of the injury? Where there any changes in your relationships or family dynamics?
   - How did you manage these changes?
   - What are the strengths of this family? Were they always there?

4. Significant chapters and support: So now I’d like to talk about the significant chapters for your family since the injury?
   - What were the greatest times of crisis or challenge?
   - What do you see as the strengths and qualities of your family that helped you to manage?
   - What about other support-did you have the right support when you needed it?
   - Is there any-thing that you think might have made it easier for you?
   - What were the turning points where things started to feel more manageable?
   - After having these experiences, what advice would you give to a family going through the same thing?
   - Is there any-thing you might not have thought about before that occurred to you during this interview?
   - Is there any-thing else you think I should know to better understand how families manage brain injury?
5. **Stop recording and close:** Assessment of need will be determined according to 3 brief follow up questions:

1. Did you have any concerns about this interview?
2. Would you like us to contact someone on your behalf to discuss the interview?
3. Are you aware of, and understand that you can contact the researcher any time if you have any further concerns or queries in relation to the interview today?
Appendix G: Risk minimisation Strategy

1. A Psychologist from within the GHI team will be available on call via telephone during each interview if participants become distressed.

2. Principal researcher will debrief all participants at the end of each interview to track emotional status and determine if further counselling needed.

3. 24hs post interview all participants will be telephoned by principal researcher to assess if professional follow up is needed.

4. 1 week post interview a further follow up call to all participants will be made as a check-up.

5. Participants will be referred to a Psychologist at ABIOS if they request this, or if they are assessed as being in need of follow up support.

Assessment of need determined according to 3 brief follow up questions:

1. Did you have any concerns about this interview?

2. Would you like us to contact some-one on your behalf to discuss the interview?

3. Are you aware of, and understand that you can contact the researcher any time if you have any further concerns or queries in relation to the interview today?
## Appendix H: Themes Study 1

<table>
<thead>
<tr>
<th>Categories</th>
<th>Codes</th>
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</thead>
<tbody>
<tr>
<td><strong>The Role of the Family:</strong> results showed families provided vital support to their injured loved ones, with a variety of roles carried out by family members: (GHI results)</td>
<td><strong>Personal assistant role:</strong>  &lt;br&gt;<strong>Care provider role</strong>  &lt;br&gt;<strong>Family support role</strong></td>
</tr>
<tr>
<td>• Personal assistant role: practical support with every-day activities such as paying bills, shopping, planning.  &lt;br&gt;• Care provider role: engaging with rehabilitation and recovery.  &lt;br&gt;• Family support role: providing emotional support and advocacy.</td>
<td></td>
</tr>
<tr>
<td><strong>Inter-connectedness:</strong>  &lt;br&gt;• reciprocal relationship  &lt;br&gt;• independent and self-sufficient  &lt;br&gt;• family response in turn impacted positively on the injured person</td>
<td><strong>Self sufficient</strong>  &lt;br&gt;Awareness of injury  &lt;br&gt;Strategies to manage deficits</td>
</tr>
<tr>
<td><strong>Change and Uncertainty:</strong> The experience of TBI in this post-acute phase was characterised by change and uncertainty for families.</td>
<td><strong>Personality change</strong>  &lt;br&gt;<strong>Changed roles &amp; relationships</strong>  &lt;br&gt;<strong>Uncertainty</strong>  &lt;br&gt;<strong>Worry for Future</strong>  &lt;br&gt;<strong>Emotional impact</strong></td>
</tr>
<tr>
<td><strong>Families respond differently:</strong> families responded to change and uncertainty in different ways.</td>
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<tr>
<td><strong>Accept:</strong> others adopted an attitude of wait and see. “Just take each day as it comes. There’s really not much more you can do but take each day as it comes.” (Participant with brain injury).</td>
<td><strong>Acceptance</strong></td>
</tr>
<tr>
<td><strong>Act:</strong> some felt the need to take action, setting goals, planning For some this was experienced positively, as a way to move forward, but at other times it was with a sense of wanting to get back to normal- to how things were</td>
<td><strong>Response to change Injured person +ve</strong>  &lt;br&gt;<strong>Response to change Family member +ve</strong></td>
</tr>
<tr>
<td><strong>Life on hold</strong>  &lt;br&gt;The theme of change was also experienced by participants in terms of the desire for change, for resolution and recovery. Many family members experienced a sense that their lives were on hold, and for many people with TBI and family members the opace of recovery was slow- p’s were impatient to get back to</td>
<td><strong>Frustration with deficits</strong></td>
</tr>
</tbody>
</table>
### Factors affecting family response to change and uncertainty

**Families are different:**

| **Family structure and stage**: Different family structures and the stage of the family impacted on their experiences. |
| **Relationship dynamics**: Some families tended towards collaboration while others more towards conflict. Sometimes families showed both of these at different times. |
| **Attitudes to injury**: There were differences in families' attitudes towards the injury. Some felt that “it could have been much worse” others expressed more negative feelings; attitude to carer role |
| **Attitudes to injured person**: Some families saw their injured loved one as vulnerable and sought to protect them, while others were more focussed on enhancing independence. |

#### Beliefs

- Vulnerability
- Determination
- Confidence

#### Spiritual beliefs

#### External factors

<table>
<thead>
<tr>
<th>Financial circumstances</th>
<th>Financial security</th>
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<tbody>
<tr>
<td>Managing legal matters</td>
<td></td>
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<tr>
<td>Formal support</td>
<td>Formal support</td>
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<tr>
<td>Informal support networks</td>
<td>Carer support</td>
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<td></td>
<td>Awareness in others</td>
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<td></td>
<td>Friends</td>
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<td>life events</td>
<td>Normative changes (life events)</td>
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<td></td>
<td>External barriers</td>
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</tbody>
</table>
Appendix I: Family Experience Interview Table

<table>
<thead>
<tr>
<th></th>
<th>IV1</th>
<th>IV2</th>
<th>IV3</th>
<th>IV4</th>
<th>Study 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1086 Brendan DOB 13/09/81 (33 @ Study 2), Single, living in self-contained area in parent’s home. Working at Woolworths; planning OS trip with friends. DOB 03/11/2000 19 @ Injury MVA (Driving?) Severe: GCS 3/15 @ scene PTA 46 days</td>
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</tr>
<tr>
<td>06/11/2001 12 months post</td>
<td>Q1. What concerns you most about your present situation? Identity change/loss of former self-appearance: Concerned about changes to his appearance- overweight, adds to low self-esteem and frustration Comparing himself to how he used to be- bigger appetite Sets goals: he sets goals to get fit at gym and regain physical abilities- gives him some sense of control, and of hope for the future Identity change-activities Just the fact that I can’t do things that I used to do physical changes- (balance; sight; fitness mean he can no longer do the outdoor activities he used to- reduced self-esteem and impact on socialisation) Hope/Determination/positive outlook: positive he can get back to activities from before: yeah, I definitely hope I will. I’m positive I reck I will Q2. What do you hope will change over the coming months? Positive/Goals: I reckon I will get into shape soon, properly, Get fit Q3. Who gives you most help at the present time? Me mum and me dad. She’s pretty much my carer Adds: Process of coming to terms with changes- he has strategies to manage anger/grief, but Sometimes it all hits you</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>10/07/2002</td>
<td>Q1. Identity change: Find new interests; Goals- getting fit. Q2. Hopefully a lot-his brain- Proactive/ motivated- has been doing brain training exercises. Q3. Positive about his recovery He thinks he’s much better - positive feedback from friends has helped. Regaining his confidence slowly: Slowly, yeah. Real slow but it’s starting to yeah. Q4 My parents. For sure Adds: Identity/loss of former self: Talks again at frustrations and anger when can’t do things he wants- has strategies like listening to music or getting away from others; punching bag Letting go of anger: Sometimes when you let it out you’re all right. Like as soon as you let that frustration out, you’re all right after that. Loss of former self: again as Brendan talks about the benefit of the punching bag for letting off steam he remembers he used to be much better at it, so can be annoyed by that- on the other hand this acts as a motivation to keep at it Getting fit- link to former self- continuity/ having some control</td>
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<tr>
<td>30/10/2002 2 years post</td>
<td>30/10/2002 2 years post</td>
<td>30/10/2002 2 years post</td>
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<td>Q1. Fitness; balance; fatigue; comprehension Q2. Hopefully I’ll get a bit more better Regaining former self: I reckon my personality is getting back the way it was Acceptance of deficits: Still wanting more improvements, but knows maybe some things (eg foot) won’t improve from this point. Physically lost previous gains: Feels like he has gone backwards a bit, and impatient with speed of results Determination tied to sense of achievement: Sometimes you have your good and bad days. When you see progress it makes you more determined to go, kind of thing. You think I want to go be I’m getting results. Q3. Overwhelmed: Thinks he’s gone backwards in his fitness. Change in routine difficult to adjust to, and he feels he lost previous gains. Also illness prevented him from working out- Gym has big impact on Brendan. Fatigued- doing too much- positive about spending time with friends. Regaining former self: Regaining confidence in social situations I think bc I’m starting to feel more like me-self again. Determination Drive to get back to how he was before acts as motivation: I’m not going to accept it be I don’t want to be like this kind of thing. But what I’m going to do is, I don’t want to say look I’m different, and accept it. I told her I want to try and, I’m not going to just</td>
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<td>Overall: Good outcome- family are close and relaxed; still managing some difficulty with Brendan’s moods, and worry about his future when they’re not around. Brendan motivated to keep improving, and has found his confidence again. Meaning of family: family means every-thing Team effort: shared story; use of “we”; sense of in it together Mutual respect/ gratitude/ admiration for others- couldn’t do it without each other Communication valued Doing it by ourselves: super family- we know best what to do Pride: our efforts have produced results- he’s better than he would have been/ better than expected- sense of mastery over problems- together we can do it. Also no support any-way- so no</td>
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at once. I get really annoyed.

**Also from IV4**

**Continuity- friends. Strong support from friends- also continuity with previous self** Yeah, I actually told my mates about that- that people say their mates ditch them. They said ‘that’s bullshit, that’s not a mate. Man we wouldn’t do that to you, eh’. Cause I think I was a really good mate to all of my friends too. I was the kind of person that helped my mates out.

See coding doc a lot added about reclaiming self and continuity

**Didn’t think he’d make it/ knowledge of own value:** They all thought they were going to lose me so they all wrote really good stuff. I was pretty stoked when I read it. Bloody hell.

give up like that and just accept it. I’m going to try and get back as close as I can to what I was before. And then I’ll accept it. Bc I am, everyday I feel like I’m getting closer. Bc my mates are sort of helping me remember what I was like and that. you know what I mean? It’s been real good.

Q4. Mum main carer, also dad & Friends

**Adds:** talks about his 21st party

**Sense of knowing what’s right for himself/ self-care**

**Positive sense of his recovery:** but they said that my brain has healed a lot better than it should have. And sort of a lot faster than normally. So I think, I can sort of tell how my body is. If it didn’t feel right, I wouldn’t drink or nothing. I feel like I can handle it fine. So I just don’t go overboard type of thing

**Study 2**

| choice, but to get on with it. Positive attitude - self-belief - hope for improvement |
| No choice: also for coping/ acceptance |
| Motivated to get “Back to normal” |
| Support networks- importance of Brendan’s friends- help him to feel “normal” |
| Biggest challenges: Brendan’s outbursts and inability to find work |
| Independence vs vulnerability |
| Fear for future - still uncertainty- sight; foot; relationship; work; independence |
| Brendan’s Determination- Reciprocal gained strength from friends, family & they rewarded by his successes |
| Humour as buffer to stress |
Family and friends Support from her, husband, extended provides the most help for … at the end might get things a bit confused. there are some times that I worry that memory is improving all the time but Uncertainty about damage: and becomes more confident. Hopeful over the coming months? Q1. Worry about the future: Concerned with how Brendan will cope and how he will manage in the future. Says he has good days and bad days, but may have improved a little in his confidence and independence. Q2. Uncertainty work: Maybe work will result from CRS meeting, but a lot of stress for Brendan around work – capability; physical issues; memory; temper; tiredness - fear of unknown. Identity Physical changes: Brendan taking action about weight going to gym - he’s lost fat, but he wants results faster. Heat and excess sweating causes Brendan to feel agitated - wasn’t like this before. Balancing independence & safety - not wanting to be overprotective Others don’t understand - services/ people Brendan’s anger a big problem - she has to explain to others and tries to help Brendan with relaxing, but he can be a bit negative. Advocating with services Close to losing him - can add worry/trauma, but also gratitude - helps to cope. Others don’t understand - people don’t know what we’ve been through - don’t know until it happens to you Awareness - Brendan aware of his anger probes - positive for Kate and Dr’s Advocating with others - keeping family balanced Q3. Who, apart from yourself, provides the most help for … at the present time? Support from her, husband, extended family and friends
Appendix J: Family Interview Reflection Sheet

**Participant ID: 1087 Daryl**  
**Family Interview 20/05/14**

| Interview date:       | 20/05/2014  
|                      | 6.30pm Duration 49:57 |
| Interview context:   | At family home after dinner. There were friends over for dinner, and quite a few children around- TV on, so slightly chaotic. |
| Present at interview:| Daryl; Sharon (Wife); |
| Observed Family Dynamics | Friendly/ humour/ in it together- “dysfunctional team” |
| Participant voice:   | Daryl represented himself |
| Dominant voice:      | Daryl/Sharon |
| Researcher rapport:  | Good rapport- I felt welcome; at times difficult due to noise and numbers; slight concern with Sharon- she seemed a little disengaged at times. |
| Main topics discussed: | First 2 years/ Daryl- emotional trauma |
| Non-verbal behaviours: | I had a sense that Daryl felt like they weren’t able to adequately convey how bad it had been- that the tendency not to dwell on negative in the interview, meant that I perhaps I didn’t realise what they had been through.  
Sharon seemed slightly aloof at various times in the interview; I was concerned that she wasn’t happy with the questions. At the end she indicated that she didn’t want to say too much in form on the children, and I think she very much wanted to have an individual interview, but didn’t necessarily want to say that in from of Daryl. |
| Researcher impressions of responses: | Worst in past- not residual problems/ people don’t understand if they haven’t been through it/ Seem to have better relationship as a result of injury/ Daryl more available |
| Other comments/ Follow up : | Need to hear more from Sharon/ How did her relationship with D change/ how did she adapt to this? |
Appendix K: Family Interview Reflection Memo

1143 IV1 notes

Participant with TBI Male. DOB 16/12/1971 DOI 19/04/2001

Family participant spouse

**Observed Family dynamics:** Initial thoughts were that this is a happy home. Spouse is the organiser of the family. 2 teenage children (14 & 16) Happy, calm, warm relationships. J does a lot of the talking for N, so harder to bring him into the conversation. She is protective of him, and he seems

**Structure:** family identified as being the two of them and 2 teenage kids, who were small at time of accident.

Support: lots of support from family and friends.

Psychological support: no family counselling or support. Just N’s rehab.

N’s parents had been dealing with sister’s post-natal depression, and then had to shift focus to N. Other sister a support (Possibly helpful to follow up with N’s parents).

J’s parents were split up and had respective spouses.

J’s father & step mother identified as a strong support. Father has since passed away (maybe need to follow up on when that was & what impact that had).

Fortunate financially- 8 months of mortgage repayments and assistance from Centrelink- meant they could keep house and

**Support networks:** they reported very good support network of both sets of parents, as well as friends and church. These have remained constant since the injury. Spouse particularly supported by church and her faith. N also found work a good support. N’s parents had been dealing with his sister’s post-natal depression at time of accident, then had to focus on N & J. (Maybe good to speak to them, possibly in next meeting?).

J’s father & step-mother identified as a strong support. Father has since passed away (maybe need to follow up on when that was & what impact that had??).

**Financial:** was not too much of an issue for them. There was fear of losing house initially, but were able to manage, 8 months of mortgage repayments ahead, and assistance from Centrelink- meant they could keep house. N able to go back to old job reasonably quickly.

**Changed roles & relationships**

J spoke about bring him home as a stranger. J had to take on the role of organising finances and running of the household “the mother and the father” “J’s the brain of the family” “I slipped into that role and it stayed that way”
Challenges and how they managed/ what kept family together

J says took years to adapt to change in N. The reason their family was able to survive- helped by her faith and belief in marriage vows- “had to deal with what she had”; children deserve to have their father and stable family home; those beliefs together with friends & family support, and financial security meant she “didn't crumble”

Spouse has positive outlook now, but first 5/6 years were very difficult. “Have to make the change within yourself to adapt to what you have- we have to adjust bc N now thinks differently- can’t expect him to change” Took a long time to shift to that way of thinking, and earlier there was a lot of conflict.

N says he goes through stages where some weeks he feels good, some days he feels terrible. Headaches makes him feel why me. Sometimes wishes he could go back in time and accident didn’t happen, and that he would be happier and more content with life than he actually is. Says he’s a lot better now, but has taken him a lot longer to accept what’s happened to him. Deep down hasn’t accepted it. He gets critical of himself not being able to think like others.

N says they argued a lot in the first few years- just the little things. N says the process of them getting through this period of conflict involved him coming to accept that he was different, as J was saying, even though he didn’t feel like he was. For J it was the same- had to realise that he wasn’t going to suddenly be able to understand. Finding the line between pushing him to help him improve, and realising what he is not going to be able to do. She realised which areas it was up to her to make a change. (again, says it would have helped if she had more info about this).

J reacts to N’s negativity- says we all love and support you, you have a great life- appreciate what you have.

J says the most frustrating thing now is that he seems to “hone in on the negative stuff”, and that isn’t a positive thing for him or those around him. She recognises that she’s changed a lot & tries to be more upbeat which she thinks might annoy N.

Later she says that the stuff he said in the interview he hadn’t said to her- he doesn’t communicate that usually, which is why she thinks he would benefit from some professional support.

Interesting how at this point the interview process has brought about this discussion. They haven’t really talked about things for a long time & the interview process has led to new insights for them.

P’s note that they had no counselling- lots of support from loved ones, friends, Centrelink, & rehab good, but no counselling provided- she thinks she would have benefited a lot from that in the beginning & so would N a bit later going back to work.

J also talked about problems of TBI not being obvious to people who don’t know the person, and how difficult that is in the beginning- would have benefited from counselling around
those issues. She thinks they should have all had it. Thinks if she had that support she may have managed better a lot sooner- she can understand why people do crumble.

Notes benefit of professional support in being able to talk an independent person- probably would have come to a better place sooner.

N thinks he would have benefited from more explanations about what was going on in his brain earlier. J says that did happen, but he doesn’t remember it bc it was too early. J thinks it would have been a lot better if she had been given more than a 10min explanation. Says she was only told about the medical side of it, but nothing about how to deal with it after. She says she had to find out the long-term impacts of the injury herself, through experiencing it first-hand. Doesn’t think she had enough information. J says would be good to have something the year after rehab finishes.

Also brought up need for this for N as well, in terms of what to expect going back to work etc- psychosocial support. He wasn’t mentally prepared for it.

After tape turned off N spoke about worry about further deterioration as he ages and experiences age-related memory deterioration- is he going to get worse. J said she hadn’t been aware he had been feeling down.
Appendix L: Transcript Coding: Initial Coding

1086 Brendan: Family Interview Date 24/05/14
Interviewer (I); William Father (R1); Kate, Mother (R2); Brendan (R3)

R1: I think he's actually better than what they expected, yeah.

R2: Yeah, because they usually say after - by two years they're going to be as good as they're going to be. But Brendan did keep improving in certain things, so - and I think it was just because he had always said that he was going to get back to as good as he could be. He's very determined.

I: So that combination of his determination with that support that you guys were able to...

R2: Yeah.

I: Now I'm interested in - you said something like it was hard but you just have to do - you have to find the strength. How do you find the strength? How - what's that process of finding the strength?

William: You've got to come to grips with what's happened and just live with it.

Kate: You've got to say to yourself, well this is it. We've got to pull together and do the best that we can. It was hard because you felt you were having to share - we were having to share ourselves between us all that can get very hard.

R1: Because the daughter, she sometimes felt a bit left out because we were concentrating on Brendan.

I: How old was she then? Is she younger than...

R1: No, she's older.

R2: She was 20 when Brendan had his accident, but not that we meant to, but then she spoke to us because we've always said that if you've got something to say, we talk about it as a family. She did say, there were sometimes there I felt a little bit left out. We said, well look, we never meant for that to be that way, but as - I think...

R1: We were very protective of Brendan after the accident. To let him go and do anything by himself and things like that - because his temperament changed, his mood had changed. If he'd gone out and said something that he wouldn't normally have said, someone might take it the wrong way and hit him. We still worry about things like that now, but at his age he's

Expressing pride in outcome
Brendan did better than expected-exceeded expectations
“He’s very determined”

“you’ve got to come to grips with what’s happened”

Communication
Pulling together: You've got to say to yourself, well this is it. We've got to pull together and do the best that we can.

Sharing ourselves- family dynamics

Communication: if you’ve got something to say, we talk about it as a family.

Protective

Brendan changed
Appendix M: Case Analysis Memo

Neville’s experience

Taking control was a necessary course of action in order for Jo to function and continue to support the children, however it may have been to the detriment of Neville, whose emotional needs may have been overlooked. It was only through the course of the interview that Neville expressed his ongoing challenges with feeling depressed and frustrated and worries over his future health. These concerns were the same as he had expressed in study 1, and Jo was surprised to hear him say this. Neville expressed that he goes through stages where some weeks he feels good, some days he feels terrible. Headaches makes him feel why me. Sometimes he wishes he could go back in time and accident didn’t happen, and that he would be happier and more content with life than he actually is. He says he’s a lot better now, but has taken him a lot longer to accept what’s happened to him. He says that deep down hasn’t accepted it. Neville has not had any support with these concerns, largely because he hasn’t communicated them to any-one. Neville spoke about experiencing frustration in study 1, and when asked if he had strategies to manage this he replied “no not really, I just try and switch off” (Neville, 24/10/02). In the absence of any-one asking him how he was feeling, or any information about brain injury Neville responded by shutting, down and not communicating.

Response to challenges (what they did)

New role for Jo

Neville’s pre-injury role as partner and father changes a result Jo assumed responsibility for running the household by herself which created considerable pressure and uncertainty for her. This was particularly the case for the family’s finances, as Neville had previously controlled those matters.
Neville and Jo talk about Jo being the “brains of the family” (Neville, 2014), and how Jo had to take on the responsibilities for finances, decision-making and parenting. Jo explains that the role changes that occurred at the time of the accident became permanent.

*I then had to become the mother and the father, so to speak, I was everything. I'm still very much like that and Neville relies very much on me doing that too* (Jo, spouse, 2014).

*I just sort of slipped into the role and it stayed that way kind of thing* (Jo, spouse, 2014).

**Jo taking control**

It’s interesting that Jo uses the language of “I” and “me” rather than “us” “we” when talking about how they managed. “Then Centrelink, because Neville was no longer working and I had two dependents, they were supporting me then. So they supported me every fortnight” (Jo, spouse). I get the impression that she really felt like she had lost her husband, and it was really all up to her now to look after the kids, albeit with support.

Jo focussed on minimising any trauma the children might suffer by staying strong herself, and keeping the family together and functioning.
Appendix N: Comparative Analysis Memo

Thinking about the difference between Alison; Brendan; Ronald and Nathan

Seems like Alison & Brendan don’t cause their families problems now- unlike Ronald and Nathan. The nature of the injuries obviously plays a part- part with Nathan, I can’t see how it could have been different/ but for Ronald- if he had the same support as Brendan/ Alison- could have been different. Nathan’s story is more about how families can experience services as useless.

Nathan- (16 ½ rebellious teen) It seems likely that Nathan was getting into a bit of teenage trouble before the accident (possibly at fault in the accident??), and this dynamic of challenging teenager has been perpetuated as a result of the injury. He hasn’t matured. It seems that this is a result of the injury. Injury invisible- difficult for family be people don’t realise- same for Ronald; Also the case with Neville & Daryl, but they are both less severe cognitive deficits, so can blend in

Ronald- (19) not 100% sure about pre- injury dynamics Seems he was in a relationship and about to get engaged feels like he slipped through the cracks somewhat, particularly bc his family language barriers. He didn’t get the help he needed to be more community engaged. There were definite behaviour problems, which family had to cope with, but this is a lot better now. He seems depressed and therefore given up on himself- overweight-bored; better intervention earlier could have really helped this family. From study 1 his couldn’t cope with how much his life changed- lost his girlfriends; friends; licence; couldn’t work- very depressed, and this is exactly the same 11 years later.

Brendan (19) Same age as Ronald, and also experienced anger/behavioural probs. These were handled well by his family, but were probably less extreme than Ronald. (Would Ronald’s behaviour would have been as bad if he wasn’t so frustrated & depressed). Points of difference with Ronald were- his friends stuck by him- he had continuity with his pre-injury life whereas for Ronald every-thing felt different;

Alison (20) already had close bond with M- only child, so M could devote all of her attention to Alison’s recovery. The fact that she was divorced was a plus, bc she didn’t have to negotiate changes in the relationship- did cause further rift with x-husband; Relationship with John, Alison was always injured. In early phase no competing demands of other family members, and L was always an achiever, driven, wanted to do well academic & sport- this continued. Combination of Alison’s personality & Mary’s capacity to understand what L needed to be the best she could. Federico & Ludmi lacked this capacity & didn’t know how to access support. But also Ronald’s behaviour and attitude (depressed/ angry/ unmotivated) made it very difficult for them. Alison lost friends and relationship, which was really difficult, but M knew how to support her emotionally; and L was able to focus on her recovery- she had goals and achievements.

Brendan and Alison share the determination to maximise their recovery- for Brendan he seemed determined to get back as much to his pre-injury physicality/identity; For Alison her
motivation was all about looking to the future, not the past- helped her to be able to do this, unlike Rich who grieved the loss of his former life to the point of depression/ hopelessness- there were barriers- no work/ no friends, that Brendan didn’t experience.

**Independence vs protection**

There have been multiple instances of families grappling with the tension between wanting the injured person to become more independent on one hand, but wanting to protect them from harm on the other. Families described harm in the sense of physical harm- injuring themselves again; emotional harm- pushing them beyond their limits resulting in loss of confidence; and vulnerability to being manipulated by others.

Mary seemed to instinctively know how to gradually increase Alison’s independence, happy for progress to be slow, but ever forward.

For June there was also the sense of protecting the public from Nathan.

My sense is that June’s perspective on this situation is valid, but hard to know with only her and Nathan’s input. A lot of Mother’s would like to keep control over their Son’s and protect them from drugs/ irresponsible behaviour/ unsuitable partners. Does his injury give her an excuse to keep him under her wing to the detriment of his independence and autonomy?? The whole interview process was controlled by her. Would be very good to be able to speak to Lynne

Similar problem with Ronald, where he lacks responsibility- These families stuck in situation with perpetual teenager.
Appendix O: Focussed Codes

- Getting back to normal
- The new normal
- Moving on
- Putting it behind us
- Family knows best
- Others don’t understand
- Taking one day at a time
- Resolve
- Compartmentalise
- Supress
- Avoid
- Humour
- Hope
- Determination
- Positivity
- Pride
- Compassion
- Gratitude
Appendix P: Procedural Memo

Memo 20.03.14: Changes in data collection protocol- Family interview

In reality I didn’t end up doing the interview in time periods- Before/ at time of interview/ years after. I tried in the first interview with N & J, but the genogram wasn’t conducive to discussion- not a good way to start the interview. Then it didn’t feel right to begin with- tell me about your family before the injury. The conversation flowed much more easily when I started very open- tell me about your experiences of TBI and then followed their lead.

I attempted to progress through time points in a linear fashion as per the life history interview method, but this is not how people spoke about their experiences. The time points jumped around between now and time of accident- often not much differentiation, and sometimes memory triggered and straight back to first few years. Richer data was obtained when I let people go where they wanted, and later I was able to sort out different time periods on the transcripts.

Changes to interview questions

After first few interviews I felt like I wasn’t getting all of what I needed- I’m getting the story of the injury/ experience of support- formal & informal/ a lot on early experiences/ carer perspective- carer resilience

Would like more on
- sense of family dynamics and how they changed
- What is the family story, rather than the individual story
- Much from the injured person’s perspective

Thinking on this before the IV2 with June & Johnathon I re-framed some of the questions, based on Charmaz’s questions in constructing grounded theory

Questions specifically for the injured person can help to show what role family played, and how the family responded.