

ANGLIA RUSKIN UNIVERSITY

FACULTY OF SCIENCE AND ENGINEERING

THE IMPACT OF COPING, FAMILY CHANGES AND LOSS ON  
ADJUSTING TO LIFE AFTER ACQUIRED BRAIN INJURY

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# ABSTRACT

FACULTY OF SCIENCE AND ENGINEERING

DOCTOR OF PHILOSOPHY

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Acquired brain injury (ABI) can be a life-changing condition, potentially resulting in emotional, cognitive, physical, and/or behavioural changes. For families, the impact of such changes can be devastating. Current rehabilitation focuses on the person with the injury, with support for relatives often a secondary consideration. There remains a need to understand how best families can be supported to adjust to life after ABI.

To investigate potential areas of importance which may aid adjustment to living with the impact of ABI, 21 individuals with ABI and 19 family members took part in semistructured interviews exploring the following research questions: a) does ABI change families and if so, do family changes impact on adjustment and does this differ for the individual with ABI and relatives?, b) what is the experience of coping with ABI like for individuals with ABI and their relatives, and does this change over time?, c) do individuals with ABI and their relatives use different coping styles for ABI related stress, and how do the effects of the ABI interact with this coping?, and d) what is the experience of loss after ABI and do these feelings relate to subsequent experiences of adjustment? Qualitative data was analysed using thematic analysis, with two exemplary dyadic case studies analysed using interpretative phenomenological analysis.

Main results indicated that ABI impacts in specific ways dependent on participant type. Pre-existing coping strategies can be compromised, and new ways of overcoming challenges need to be established. Injury related loss is a multifaceted concept that can present differently for individuals with ABI opposed to relatives. Despite significant adversity, most participants were able to identify positives and felt adjusted to their situation.

Further suggestions for research in this area are presented to help improve understanding of adjustment to life after ABI, and support challenges faced in the areas of coping, family change and loss.

Key words: acquired brain injury, family, adjustment, coping, loss.

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## Posters, presentations and publications

- Buckland, S., Kaminskiy, E., & Bright, P. (2020). Individual and family experiences of loss after acquired brain injury: A multi-method investigation. *Neuropsychological Rehabilitation*, 1-21. Abstract available in Appendix 9.
- Buckland, S. (June, 2019). *It depends who you ask: Insights from dyadic relationships and mixed methods into concepts of loss after acquired brain injury*. Oral presentation given at the Neuropsychological Rehabilitation special interest group of the World Federation of Neuropsychological Rehabilitation 16<sup>th</sup> annual conference, Granada, Spain.
- Buckland, S. (January, 2019). *All is not lost: A mixed methods enquiry into the relative's experiences of loss, role changes, and adjustment after acquired brain injury (ABI)*. Oral presentation given at the Faculty of Science and Engineering 8<sup>th</sup> annual research conference, Cambridge, UK.
- Buckland, S. (November, 2018). *The relatives' experience of loss and adjustment after acquired brain injury (ABI): A mixed methods study*. Poster presentation at the United Kingdom Acquired Brain Injury Forum (UKABIF) 10<sup>th</sup> annual conference, London, UK.
- Buckland, S. (Sept, 2018). *The relatives' experience of loss and adjustment after acquired brain injury (ABI): A mixed methods study*. Oral presentation given at the British Psychological Society East of England branch 2<sup>nd</sup> annual research conference, Norwich, UK.
- Buckland, S. (July 2018). *All is not lost: A mixed methods enquiry into the relative's experiences of loss, role changes, and adjustment after acquired brain injury (ABI)*. Poster presentation at the Anglia Ruskin University doctoral school conference, Chelmsford, UK.
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group of the World Federation of Neuropsychological Rehabilitation 15<sup>th</sup> annual conference, Prague, Czech Republic.

Buckland, S. (July, 2017). *The role of family adjustment in brain injury rehabilitation*. Poster presentation at the Anglia Ruskin University doctoral school conference, Cambridge, UK.

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## **Chapter 1. Introduction**

### **1.1 Motivation and outline of research**

Acquired brain injury (ABI) is a prevalent health condition that can affect anyone at any time. Statistics from an extensive report by Headway – the brain injury association (2018) show hospital admissions have increased by 10% since 2005 with approximately 350,000 people admitted to UK hospitals each year. People can sustain an ABI through a variety of causes such as a vascular event (for example stroke, haemorrhage or aneurysm), traumatic event (such as a road traffic accident, assault or fall), or infection (such as encephalitis or meningitis). These examples are not exhaustive, and people could be left with a brain injury through more unusual avenues, for example by losing oxygen to the brain from suffering a heart attack, or through significantly low blood sugar levels (hypoglycaemia). Men are 1.5 times more likely to sustain a traumatic brain injury (TBI) than are women, but female TBI admissions have risen by 23% over the past 15 years, and the prevalence of stroke admissions has increased by 10% over the same time period (Headway – the brain injury association, 2018).

Medical advances mean more people are surviving ABI than ever before, but the availability and consistency of rehabilitation services for these individuals is lacking (Menon & Bryant, 2019). A recent audit of rehabilitation services estimated the weekly saving of care costs for patients who received sufficient rehabilitation after their ABI to be an average of £536 per week (National Clinical Audit of Specialist Rehabilitation for Patients with Complex Needs following Major Injury, 2019). However, only 40% of the patients included in the audit received such rehabilitation, with a current shortfall of around 330 rehabilitation beds.

The All- Party Parliamentary Group on Acquired Brain Injury (APPG on ABI, 2018)

has been raising the issue of the variability in the quality of rehabilitation service access since 2017, which has culminated in a report aimed at driving change in ABI rehabilitation and raising awareness at a parliamentary level for those affected. As well as the increasing prevalence of ABI, the complex needs of individuals with ABI and their families and lack of rehabilitation services has motivated this research and made it an important addition to the current literature.

As a way of supporting people to cope with the challenges of ABI, researchers have turned their efforts to the identification of factors which contribute to good psychosocial functioning post-injury. The term ‘psychosocial’ has a long and complicated history but has now come to be known as a description of the interplay between psychology and sociology (see Hayward, 2012, for a full history). The term recognises that individuals do not live independently of their surroundings, and there are factors in the environment which affect one’s psychological wellbeing, and vice versa (Lent, 2004). Psychosocial adjustment can be thought of as “the psychosocial accommodation of a person to a life-altering event or transition” (Anderson, Keith, & Novak, 2002). Psychosocial outcomes have therefore been the measure for many researchers of how someone is adjusting to life with ABI. Examples of such outcomes are levels of depression, satisfaction with quality of life, community integration, and self- esteem to name but a few (Lent, 2004). Moreover, psychosocial outcomes are of importance as they are seen to persist even after significant cognitive and physical recoveries are made (Honan et al., 2019; Morton & Wehman, 1995).

Numerous factors could be responsible for how individuals with ABI achieve psychosocial adjustment to living with their disability. Historically, deficits caused by the injury have been investigated, with a disproportionate amount of the literature concerning traumatic brain injury (TBI) samples (Antonak, Livneh, & Antonak, 1993; Frencham, Fox, &



Maybery, 2005). How much cognitive, physical and behavioural deficits impact on the adjustment process has been questioned, but there is much conflicting evidence as to what is important and what isn't. For example, it has been found that the severity of the injury and impairments has an effect on psychosocial adjustment to living with an ABI (Tate & Broe, 1999), but it has also been found that depressive symptoms are more important than neurological ones at predicting psychosocial outcomes (Ownsworth and Flemming, 2005).

More recent efforts have considered feelings of identity change and loss relating to how the injury has affected an individual (Gracey, Longworth, & Psaila, 2015; Ownsworth, 2014; Carroll & Coetzer, 2011). There is a shift of focus from the injury itself, to the person with the injury. It has become clear that the severity of an injury and the severity of its consequences do not have a linear relationship with how someone come to terms with the injury as a result (Blais & Boisvert, 2005; Gracey et al., 2008).

Although this shift in focus has led to the gathering of new information in the field of ABI adjustment, it has also highlighted how little is known about this complex area. The individuality of ABI means generalisation is difficult, and what helps one person may not be of help to another. There has been a metaphorical opening of a can of worms. We don't know, for instance, if the way someone chooses to cope with the injury has a direct impact on their psychosocial outcomes (Adams, & Dahdah, 2016; Donnellan, Hevey, Hickey, & O'Neill, 2006). Moreover, it is often recognised that the family plays an integral role in an individual's recovery from ABI, but to what extent this influences outcomes, and what factors of family functioning are most influential is not understood (Tarter, 1990; Gan, & Schuller, 2002). However complex the landscape, the amalgamation of research efforts towards this common goal is bringing us closer to refining services and interventions that help the adjustment process, to in turn support the more traditional rehabilitation programmes

(Bergersen, Halvorsen, Tryti, Taylor, & Olsen, 2017; Radomski, Anheluk, Bartzen, & Zola, 2016).

In an attempt to answer some of the main points raised, the following research questions were devised:

1. Does ABI change families and if so, do family changes impact on adjustment and does this differ for the individual with ABI and relatives?
2. What is the experience of coping with ABI like for individuals with ABI and their relatives, and does this change over time?
3. Do individuals with ABI and their relatives use different coping styles for ABI related stress, and how do the effects of the ABI interact with this coping?
4. What is the experience of loss after ABI and do these feelings relate to subsequent experiences of adjustment?

This project concerns three main areas concerning adjustment: coping, family change, and loss. Chapter 2 of the thesis outlines the current literature of interest covering these three main areas and will describe what has already been established and what areas still require further investigation. Chapter 3 details the methodology used, participant sample and philosophical standpoint of this project. Chapter 4 presents the results of the thematic analysis of semi-structured interviews and the implications of the findings among current literature. Chapter 5 outlines 2 dyadic case studies which will look at individual families in greater depth using interpretative phenomenological analysis (IPA). Finally, Chapter 6 will open up debate about the use of quantitative measures in the field of ABI family adjustment, and the experiences encountered during the course of this project which raise concerns for standardised approaches. A critique of three quantitative measures will also be presented, along with conclusions about their use in clinical populations.

## **1.2 Journey from proposal to final research design**

The initial inspiration for this study came from over ten years of experience working in the field of brain injury rehabilitation. I had heard from colleagues across this time, and seen in the literature I was reading, that brain injury is thought of to have a family-wide impact. None more so than the work of Brooks (1991), who coined the term ‘head-injured family’. However, it appeared to me that this was a phrase that was used, but not necessarily acted upon or evidenced in services available to people after ABI. Even my own place of employment, Headway Cambridgeshire, focused the majority of its valuable resource on those who have the injury. It was evident that much was still to be done before family members had available to them sufficient support to cope with having a relative with an ABI.

In my working life I had encountered many barriers to supporting families. It was not as simple as arranging a peer support group and waiting for everyone to turn up, share their problems and feel better about their lot. For one, finding a time that was convenient for family members who frequently juggled work, children and caring commitments was the biggest challenge of all. In-house market research at Headway Cambridgeshire had failed to find a time and place that would suit any reasonable number of relatives at one time. Moreover, this notion of peer support concerned me. Would a person need to be a carer to be invited? Would they need to live with the person with ABI or was loving them sufficient? The parameters of the ‘peer’ support were undefined. I decided to embark on a mission to understand how to best help family members cope with their situation in an accessible way. I had seen an article by Anson and Ponsford (2006b) about a coping skills intervention for individuals with ABI and started to consider whether providing some kind of training in coping skills would extend to family members too.

From this initial spark aimed at gaining an understanding of how best to encourage family members to cope, I felt that surely their increased coping efficacy would have benefits for the individual with ABI and thus improve their outcomes too. Consequently, the working title for my study of ‘the role of family adjustment in brain injury rehabilitation’ was created.

Whilst I was starting to craft my research idea, I was also delivering vocational skills training to groups of individuals with ABI. Increasingly I was finding the focus of these sessions would turn from the practical skills training activities, and onto discussions about ‘struggling to come to terms’ with changes and ‘I’m not the person I was’. Even though these individuals with ABI had so much to give, their potential was stifled by a harbouring of the past. I became intrigued by this image of an injury occurring and that individual turning around and facing backwards, living a life of attempting to be someone they no longer were. It was this evident struggle with identity that led me to the book ‘self- identity after brain injury’ by Tamara Ownsworth (2014). Inspired by this, I added an autobiographical memory (AM) test to my research inventory. It appeared that an aspect that hadn’t been considered in this field was that of autobiographical memory. If this is compromised in some way for people, would it hinder or enhance the adjustment process? It could be that if a person didn’t have a strong sense of who they were before their injury, it might actually help them move on to living as the person they now had become. All my ideas were swimming around and finally I had my proposal.

I chose to use a mixed methods design because I wanted to study these areas in depth as well as breadth. I felt the use of standardised measures would allow for more generalisability of the results and comparison with existing literature. However, the uniqueness and variability of ABI lent itself to a qualitative element to allow the individual stories to come through. I devised a convergent QUANqual mixed methods study (Cresswell,

2015), which meant the data would be collected concurrently and there would be an emphasis on the importance of the quantitative data over the qualitative. Individuals with ABI and one of their family members would complete the quantitative measures, with individuals with ABI completing the AM interview, and family members completing a semi-structured interview about their experience. I intended to use Interpretative Phenomenological Analysis (IPA) to analyse the interview transcript. This was thought to be the best approach to allow the individual as well as lived experience of each participant to come through (Alase, 2017).

Initial recruitment of participants was fairly steady, even with the restriction from the ethics committee that I could not approach participants directly. This restriction was applied due to my job role at Headway Cambridgeshire potentially creating a position of power. Once I had completed 17 interviews I ran some preliminary tests on the emerging data. What became very evident was that the AM scores were not falling within the range for impaired AM and there was no relationship between these and the rest of the data. I decided to discontinue the AM interview, and intend to revisit this aspect at a later stage with a specific sample of patients who have impaired autobiographical memory.

The withdrawal of the AM interview meant that I had capacity within my study to extend the semi-structured interview to individuals with ABI and not just family members. As this would mean I would now be able to cross-examine the responses to the same questions for both groups, and use a much larger sample size than originally intended for the interviews, I decided to change my analysis technique from IPA to a general thematic analysis. At this point too, as recruitment had slowed significantly, I decided to extend the recruitment to any adult with ABI and any family member of an adult with ABI, and not just those who made dyadic pairs. I would now effectively study three groups: individuals with ABI, relatives of individuals with ABI, and those that made dyadic pairs. This made a

marked improvement on recruitment and increased my participant group sizes, particularly for individuals with ABI who had previously declined because they did not want their family members to take part. Family members remained difficult to recruit. Main barriers to this were a lack of available time of the family members to give to the study, and a lack of preexisting relationships between myself and family members.

As recruitment became increasingly problematic, I decided to challenge the ethics restriction of relying on gatekeepers to invite participants for interview. I was granted this change in return for giving potential participants a two-week cooling off period and making it explicit that the study was separate from Headway Cambridgeshire services.

Whilst continuing to problem solve the slow recruitment, I started to look more closely at the data I was collecting. To fulfil an abstract for a conference I analysed the interviews I had completed and started to see some interesting themes emerge among the questions relating to loss. It was clear that there were certain types of loss felt and that these differed for individuals with ABI and their relatives. It was also becoming apparent that I may not reach a sufficient sample size to draw confident conclusions from my quantitative data. Based on the richness of the qualitative data against the weakness of my sample size for statistical analysis, I decided to change my design to a full qualitative study. An in-depth analysis of the complications of using standardised measures in the field of family adjustment research can be found in chapter 6.

Once my design was finalised, I was able to focus on recruitment and reach a respectable number for a qualitative study. Listening to the experiences of individuals with ABI and their family members was an honour I will not forget. The trust displayed and openness given was humbling. I would always conclude my interviews by thanking the participants, but more often than not they would thank me back, saying the opportunity to

feel like they were doing something useful with their experience was a privilege. It appeared that a common motivator for people taking part was to gain a sense of giving something back to the ABI community that had helped them through. It appears we all had a common goal of wanting things to be better.

### **1.3 Defining ABI**

Literature searches using ABI related terms will return a majority of studies concerned with TBI populations. The literature is saturated with research for this patient group, with comparisons of mild, moderate and severe traumatic injury available (for examples see Rakers, 2018; Wallace, Mathias, & Ward, 2018; Wardlaw, Hicks, Sherer, & Ponsford, 2018). Beyond this, a second sub-group of stroke populations appears of interest (Palmer & Glass, 2003; Sarre et al., 2014.) There are a small number of studies using specific groups such as encephalitis patients (Dewar & Gracey, 2007) or those with disorders of consciousness (Cruzado, & Elvira de la Morena, 2013). Finally, a very limited number of studies are available which include any person with an acquired brain injury, regardless of method of acquisition (Gan, Campbell, Gemeinhardt, & McFadden, 2006). It is understandable that researchers would want to control for injury cause, given the range of variability already found in ABI populations (Rabinowitz & Levin, 2014; Rao & Lyketsos, 2000). However, the study here attempts to address adjustment to ABI as a whole, rather than a certain type of injury. This is for two reasons. Firstly, it is intended the findings of the research can be applied to ABI services of any type so as not to exclude people based on the nature of their injury. Secondly, through years of experience, it appears more advantageous for individuals with ABI to consider the effects of their injury rather than the cause of it. The group work I have experienced has shown little indication that people, on the whole, feel more or less peer support with those that had a similar type of injury. It is more the effects of the injury that

bonds them. Therefore, as the study here is concerned with adjustment to the effects of the injury, rather than the processing of the injury event or cause itself, all ABIs are included in this research.

#### **1.4 Unique aspects of this study**

There are three main aspects of this study which provide a contribution to knowledge in this field. The first significant contribution comes from the use of dyadic analysis. There has been some use of this technique before (such as Cole & Jordan, 1989 and Dickstein et al., 1998), but it has been very limited in the field of brain injury and has not fully explored relationships between individuals with ABI and their family members. One study by Wade et al. (2003) looked at parent-adolescent interactions after TBI, but they focused on group differences between these participant types rather than highlighting unique aspects of the parent-adolescent relationship. Some studies have used marital dyads to investigate changes experienced by spouses of individuals with ABI (Bracy & Douglas, 2005; O’Keeffe, Dunne, Nolan, Cogley, & Davenport, 2020), but have not discussed experiences which affect their adjustment to these relationship changes. To my knowledge, this is the first study to compare both people in the dyadic relationship to make deductions about the impact of ABI at both an individual and family level and consider how such impacts contribute to the adjustment process.

The second contribution made by this study is the development of a relatives’ version of the Brain Injury Grief Inventory (BIGI; Coetzer, Vaughan, & Ruddle, 2011). Currently this is a questionnaire used for patients to measure feelings of loss and adjustment after brain injury. For this study I created a relatives’ version, so the same questions regarding loss and adjustment could be asked but from a relative’s perspective. This would mean direct comparisons could be made between the participant groups, both on a group level and a dyad



level. This revision to the BIGI was endorsed by Rudi Coetzer, who also felt it was the first time this had been done with the BIGI. This data was subsequently omitted from the study as the methodology changed (see page 8 for full explanation of the development of the study methodology). Although the data collected from the relatives' BIGI was omitted from the analysis, the experience of using the measure alongside the original patient version has allowed for a unique insight into the different perspectives of loss and adjustment after ABI, which are discussed in chapter 6.

The third contribution to knowledge comes from the consolidation of three key areas of ABI research into one study. The areas of coping, family changes and loss have all been studied separately in relation to adjustment, but this is the first study to bring them together and investigate changes to experiences concerning the three constructs. As listed in the publications section on page viii, the study has already contributed to the area of loss and adjustment with a publication in the peer-reviewed journal *Neuropsychological Rehabilitation* which highlights the differences between group-level and dyadic feelings of loss (Buckland, S., Kaminskiy, E., & Bright, P., 2020).

## **Chapter 2. Literature Review**

This chapter will outline key areas of interest within the three main topics covered in this study. Firstly, traditional theories of coping will be presented and critiqued in the context of coping with ABI. Secondly, research which has focused on family changes after ABI will be discussed which highlights the impact ABI can have on family members, and the variety of ways in which they can be changed as a unit. Lastly, a review of research concerned with loss after ABI is presented which reveals the paucity of studies in this area which focus beyond the individual with ABI to include family members. Areas which require further investigation are highlighted along with the challenges of studying the complexities of family systems.

### **2.1 Coping**

#### **2.1.1 What is coping?**

It is important to define what is exactly being referred to when using the term ‘coping’ as it involves many complex functions that are still not fully understood and there are a number of conceptual nuances to be considered (Carver, 2019; Pearlin & Schooler, 1978). Empirically, coping can be split into two main themes: a behavioural response versus a cognitive appraisal.

As a behavioural response, coping can be considered an action which is directed at a given problem (Lundqvist & Ahlström, 2006). From this view coping is an active process which may or may not result in successful depletion of the stressor. Coping only occurs when one is actively taking action against the stressor and is not sitting passively accepting its effects. With this view, only actions which seek to control the stressor are considered acts of coping. Letting out negative emotions or denying what is happening are not classed as coping

behaviours because they do not seek to eliminate the cause of the stress (Ray, Lindop & Gibson, 1982).

From a cognitive appraisal point of view, coping occurs when a person perceives the demands of the stressor to outweigh their resources and a coping strategy is selected as a result of this appraisal (Lazarus & Folkman, 1984). This process precedes the coping behaviour to be employed and aims to either problem solve the situation at hand or deal with the emotional state elicited by the stressor. An individual's appraisal is the core concept here and influences how that person will attempt to cope with the stressor. A key difference between this approach and the behaviour response approach, is that the person can internalise their coping strategy and it does not have to result in a behaviour which tackles the stressor itself. For instance, denial, alcohol use, and wishful thinking are all considered ways of coping with a stressor, even though they will not change the stressor itself (Folkman & Moskowitz, 2004).

### **2.1.2 Dispositional coping**

Dispositional coping styles can be thought of as representative of how someone generally responds to stress and burden. That is, it is the belief that people tend to have a relatively stable 'style' by which they react to situations and stressors. This approach is strongly linked to personality and the idea that our innate personality traits will inform much of how we respond (Watson & Hubbard, 1996). A dispositional coping view subscribes to the notion that, although these traits can fluctuate, there is a way people generally will respond to stress and burden throughout their lives. Certain types of style are associated with certain types of personality trait. For example, people who score highly on neuroticism are found to be more confrontational and blame themselves a lot in stressful situations, whereas conscientious individuals use very empathetic styles and will experience less self-blame

(DeLongis & Holtzman, 2005). Moreover, those who are very extravert in nature and are open to new experiences tend to be able to adapt their coping style to the demands of the situation and utilise a variety of strategies. There are, however, difficulties with this theoretical approach as people are made up of a variety of personality dimensions or traits and do not fall neatly into one 'type'. The influence of the other personality traits on the one considered as dominant or under investigation is hard to determine and often overlooked, rendering the correlation of one personality trait as a predictor of an outcome variable problematic. Extensive research in the field of personality has revealed the complexity of interactions between separate personality traits, such as the Big Five model (McCrae & John, 1992), Myers-Briggs type indicator (Myers, 1962), and Cloninger's (1993) psychobiological model. For a review of personality traits see DeNeve, & Cooper (1998), who performed a metaanalysis of 137 distinct personality traits and found nine of these traits were associated with subjective well-being alone.

What does appear to be consistent though is the trait of neuroticism relating to a greater tendency to choose maladaptive coping strategies which often exacerbate the stressor, whereas other personality traits have a greater ability to bend and flex from stressor to stressor with more positive outcomes (DeLongis and Holtzman, 2005; O'Brien & DeLongis, 1996). Ultimately this area remains under-researched and still not fully understood.

A dispositional approach to coping is seen as advantageous because it indicates a more longitudinal view of a person's behaviour rather than a snapshot from (usually) a very severe stressor which may have induced more extreme coping activity. A disadvantage of this approach is that it does not give a real time depiction of how someone has responded to something stressful and coping styles may get 'watered down' (DeLongis and Holtzman, 2005). If someone is trying to analyse a specific type of stress response – for example to

receiving a diagnosis of a terminal illness or experiencing a traumatic event – then the dispositional approach is not so strong. Research using dispositional measures has not been able to ‘predict’ how someone will respond to stressors in the future (Coyne & Racioppo, 2000). Also, by asking people to think generally about their coping there is no reference point from which to reflect. Moreover, what is to say participants are not using references by which to respond which could fluctuate depending on the question being answered? It has been found that, particularly when factoring in personality traits, people respond differently depending on the demands of the stressor. For example, people who are considered extravert may use more confrontational coping styles when dealing with marital conflict than when they are dealing with a child’s challenging behaviour (Lee-Baggley, Preece, & DeLongis, 2004).

### **2.1.3 Situational coping**

Situational coping is based on the theory that people respond according to the situation or particular stressor being faced. This approach can be beneficial because it shows how someone has reacted to a particular situation of interest, such as receiving a cancer diagnosis (Stanton & Snider, 1993) or witnessing a terrorist act (Gil & Caspi, 2006). However, this viewpoint is limited because it is a snapshot of how someone reacted to something quite unique and does not provide information about how someone acts in response to chronic stressors or less obvious everyday occurrences. How representative is a response to a one-off, complex or extreme event and what can it actually tell us about the influence this coping has on adjustment to living post the event? Indeed, Ray, Lindop and Gibson (1982) go as far as to say that acknowledging the stressor itself is of little use as coping is so dependent on the appraisal of the situation, which is formed from our past experiences and personality, that the type of stressor is seen as irrelevant.

It has also been found that people are not accurate reporters of their own responses to specific stressful events when reporting retrospectively. A study by Stone et al. (1998) found a third of participants failed to recall coping efforts that they had recorded 'in the moment' two days before. Furthermore, a third of participants reported using coping strategies when asked two days later that they had failed to record on the day they should have occurred. In a similar study, Todd, Tennen, Carney, Armeli, & Affleck (2004) found slightly more consistent results than Stone et al., but still much discrepancy between baseline measures of dispositional coping and daily coping reports recorded over 30 days. This suggests people have the ability to either over or under report coping efforts even when asked about their behaviours just two days later. When you consider that some participants in this study could be recalling coping responses to brain injuries that have happened some thirty plus years earlier it becomes hard to take retrospective coping reports as factually based evidence of behaviours at the time.

Further complications arise when general inferences are drawn from studies using a situational approach. For instance, participants are commonly asked to describe their coping strategy for a stressful event within the past week (such as Lundqvist, & Ahlström, 2006), or month (such as Turner-Cobb et al., 2010). The types of event people may draw on could vary significantly, eliciting a variety of strategies based on the demands of the stressor. Researchers then draw conclusions from their findings as to the efficacy of the coping styles when the stressors are not common. The widely cited coping research by Lazarus and Folkman (1984) is built on such a method. When creating their predecessor to the Ways of Coping Questionnaire, the Ways of Coping Checklist (WCC, Folkman & Lazarus, 1980), Lazarus and Folkman asked 100 middle-aged adults to comment on how they coped with stressful events that had occurred during the past year. There were 1,332 events reported and

they ranged significantly in severity, from household maintenance to bereavement (Lazarus and Folkman, 1984). The variety of events the couples could have been basing their answers on is undisclosed and furthermore no attempt was made to control for severity of stress or importance to the individual. The participants could have been referring to coping with an admission of infidelity or a neglect of a household chore. It is possible that the severity of stress, significance of the stress to the person and resulting coping style could be very different. However, this does not seem to stop researchers drawing population wide conclusions as to which styles are advantageous, which protect against stress, or which relate to psychosocial factors such as community integration, wellbeing, and adjustment (For relevant examples of these in the literature see Felton & Reveson, 1984; Kendall & Terry, 2009; Lazarus, 1974; and Oddy, Humphrey, & Uttley, 1978).

#### **2.1.4 Stance of the current study**

The current study adheres to the conceptual theory of dispositional coping. This is because the nature of dealing with a chronic condition such as ABI and the multitude of potential strains that can come as a consequence – many of which may be subtle and hard to distinguish – suits the dispositional approach for long-term coping. Living with and adjusting to brain injury is not about dealing with the one off event that caused the injury in isolation. It is about finding a way to withstand the shifting nature of rehabilitation and changing landscape of prognosis that is of interest here. Ideally this study would consider both dispositional *and* situational coping (as recommended by Moos & Holahan, 2003) but due to the discrepancy in time since injury, ranging from as little as 2 years to as historic as 40 years, it was felt the variability in recall would leave too much uncertainty and cloud the results. As the emphasis for this study is on adjustment to living life with the challenges of brain injury, it was decided that a focus on general ‘go to’ styles would be most telling as to

how people are getting through day to day struggles, and how these styles might differ from ABI specific stressors.

### **2.1.5 Coping theories**

It is difficult to discuss coping without including stress. The two terms logically pair well for research purposes. The term ‘stress’ was taken from physics, where it was used to describe a substance’s ability to withstand external force (Hobföll, 1989). Early researchers focused on biological sources of stress, such as the General Adaptation Syndrome (GAS; Selye, 1950), and then later psychoanalytical ones which focused on ego-defence such as the work by Menninger (1954), Haan (1969) and Vaillant (1977). It wasn’t until the ground breaking work of Richard Lazarus and colleagues, beginning in the late 1960s, that the idea of cognitive influences on stress and coping were considered. Lazarus and Folkman (1984) brought to the forefront of coping theories the idea of ‘appraisal’. They all but discounted observable behavioural actions, seeing these as a consequence of how the person is perceiving the stressor, and brought the focus onto the cognitive assessment being made internally. Therefore, one is only coping when the situation has been appraised as exceeding personal resources and a choice of response is formulated as a consequence. Although widely received and still the most commonly cited coping theory today (Parker & Endler, 1992; Anderson, Simpson, Daher, & Matheson, 2015), Lazarus and colleagues did not go unchallenged. Some felt the theory was simplistic in its view and too reliant on cognition, discounting what people *do* in favour for what people *think* (Parker & Endler, 1992). Moreover, the authors categorised coping styles into just two groups: problem-focused and emotion-focused. Again, this was criticised for being too simplistic. It is telling though that some 40 years later this simple grouping has only received minor adjustments and many authors have merely offered their own variations on the original theme such as primary



control versus secondary control (Rothbaum, Weisz, & Snyder, 1982), mastery versus meaning (Taylor, 1983) and assimilative versus accommodative coping (Brandtstädter & Renner, 1990). An in-depth assimilation of the topology of coping terms can be found in Skinner, Edge, Altman and Sherwood (2003).

### **2.1.6 The Goodness -of -Fit hypothesis**

As part of their seminal work, Lazarus and Folkman (1984) also outlined the ‘goodness- of- fit’ hypothesis. This theory expanded on the basic ‘problem versus emotion’ coping styles, and suggested the appropriateness of the coping style chosen was dependant on the appraisal of the situation, along with the addition of a third coping style; meaning-focused coping. That is, should a stressor be appraised as controllable (such as multiple tasks needing to be completed, or training for a marathon) then a problem focused style would be most useful. However, if the stressor is appraised as uncontrollable (such as a health diagnosis) then an emotion-focused style would be better suited and thus yield better outcomes.

This hypothesis has been empirically tested numerous times since it was published, and typically the hypothesis has been supported, with problem-focused coping styles being found to enhance the outcomes of controllable stressors ( such as Roubinov, Turner & Williams, 2015) and emotion-focused styles complimenting uncontrollable stressors (such as Sargent & Manne, 2002). However, the strength of this connection is much more prominent for the problem- focused/ controllable connection than for the emotion- focused/ uncontrollable link. Park, Folkman and Bostrom (2001), found good support for the problemfocused/controllable hypothesis, a weak connection between emotion-focused styles and uncontrollable appraisals, and no support for meaning-focused coping styles, in a study with HIV+ men. One study which did not find support for the hypothesis is that by Kendall and

Terry (2008), who tested the goodness-of-fit of coping styles with a TBI sample. Neither emotion-focused nor problem-focused styles correlated with perceived controllability of stressors, but prolonged use of problem-focused styles was related to emotional distress.

In a more recent study, Finklestein – Fox, Park and Riley (2018) tested the goodnessof-fit hypothesis with mindful coping strategies in a longitudinal study. Participants kept diaries of coping appraisals and responses for one week. They found that mindful coping created a better ‘fit’ of coping strategy to the stressor, but that coping flexibility did not have an impact on coping outcomes. This does not support the Lazarus and Folkman model, with the core element being that those most skilled at matching their coping style to the stressor will fare best. This study also found no coping style to be particularly advantageous over another, but they did find that those who mis-attributed self-blame to uncontrollable stressors felt more negative as a result. This suggestion that self-blame is detrimental to the coping process has been supported by the findings of Ashworth and colleagues, whose work on compassion-focused therapy (CFT) has shown the ability to counteract self-critising thought patterns increases wellbeing post-ABI (Ashworth, 2014; Ashworth, Clarke, Jones, Jennings, & Longworth, 2015; Ashworth, Gracey, & Gilbert, 2011). Although not an attempt to influence specific coping responses, CFT aims to encourage the individual to re-think go-to styles of response to situations after brain injury which may be contributing to depression and anxiety. For example, a person may have a tendency to be critical of themselves due to the effects of their injury and see their challenges as failings that are attributed to the self, rather than the injury. So by re-evaluating these thought patterns and being more compassionate to oneself, the individual will use less self-blame which has been seen in the coping literature to lead to negative outcomes.

It could be that the weaker support for emotion-focused coping styles being important for coping appraisals is due to uncontrollable stressors eliciting negative consequences which far exceed those for controllable stressors. Uncontrollable stressors are mainly attributed to events such as significant health issues (i.e. a cancer diagnosis) which could leave the copers with elevated stress responses that are difficult to overcome regardless of coping style. Therefore, when outcomes measures such as depression and quality of life scales are used to judge the efficacy of coping, results fair worse in comparison to controllable stressors merely because the nature of the stressor is much more important and has more detrimental consequences for the individual concerned.

#### **2.1.7 Coping with ABI**

In the current population of interest, some researchers have started to try and link traditional and general coping theories to the brain injury community. One review of 14 studies of stroke patients found conflicting reports of the different ways people cope with the effects of their stroke, although problem focused styles were slightly more dominant (Donnellan, Hevey, Hickey, & O'Neill, 2006). No coping changes over time were found in these studies, although only five studies were longitudinal in design.

In TBI populations, it has been reported that most coping styles decrease in the first year post-injury (Gregório, Visser-Meily, Tan, Post, & van Heugten, 2011; Scheenan van der Horn, de Koning, van der Naalt, & Spikman, 2017) and there is a general trend seen of emotion-focused styles increasing and problem- focused styles decreasing in the first months after injury (Kendall, Shum, Lack, Bull, & Fee, 2001; Wolters, Stapert, Brands, & Van Heugten, 2010). Due to the association of emotion-focused coping styles with poor adjustment outcomes in TBI samples, it is recommended that people who use non-productive

styles should be identified as they are at risk of poor psychosocial functioning in the longterm (Gregório, Gould, Spitz, van Heugten, & Ponsford, 2014).

People's perceived belief that they have the ability to cope, known as self-efficacy, has been shown to play an important role in coping after ABI. Those who have high self-efficacy tend to select problem-focused coping styles which in turn yield better psychosocial outcomes for those individuals (Brands, Köhler, Stapert, Wade, & van Heugten, 2014). In comparison, those who report low self-efficacy more readily use emotion-focused styles and have poorer psychosocial functioning (Scheenen, van der Horn, de Koning, van der Naalt, J & Spikman, 2017). This has led to the suggestion that the choice of coping strategy can be dependent on one's belief that they can deal with the situation at hand (Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010).

Another variable that could be of importance to how people cope post-ABI is the flexibility of coping styles. That is, whether those who have the ability to draw on a wide repertoire of strategies and fit these to different stressors and situations experience better outcomes from their coping efforts. In general populations there is evidence to suggest this ability to discontinue a coping style which is proving ineffective and select a new one leads to better psychological wellbeing (Kato, 2012). Of the limited literature available with ABI populations, coping strategies have been found to be quite restricted after ABI, with a small variety of standard coping styles being regularly used for any type of stressor, regardless of severity or importance (Brands, Köhler, Stapert, Wade, & van Heugten, 2014). Furthermore, in a study involving people who have sustained a TBI, greater coping flexibility was not associated with better adjustment (Kendall, Shum, Lack, & Fee, 2001).

It has been found that the ability to use flexible, or adaptive, coping strategies, relies on cognitive functions which allow for the ability to respond to feedback about a situation

and differentiate between different aspects of the stressor to utilise the best strategy (Cheng and Cheung, 2005; Cheng, 2003). Given the impact ABI can have on the executive functions that underlie these coping strategies, it is worth further investigation to see if cognitive rehabilitation aimed at developing the executive skills needed to monitor and respond to stressors would increase the use of adaptive coping strategies, or whether the general literature findings do not relate to coping with ABI (Krpan, Levine, Struss, & Dawson, 2007).

In terms of evaluating interventions, some studies have demonstrated the benefits of peer support in community-based services. For example, one study in America found that a one-to-one peer support programme lasting approximately a year yielded positive outcomes for participants in areas of general quality of life, positive outlook, understanding of how to cope with the challenges of TBI, and a greater ability to cope with depressive symptoms (Hibbard et al., 2002). Another American study by Backhaus and colleagues found a peer support group as equally beneficial for TBI families as a cognitive-behavioural group intervention was (Backhaus, Ibarra, Parrott, & Malec, 2016). Although the needs of caregivers have been well documented (Baker, Barker, Sampson, & Martin, 2017), the utility of peer support for such caregivers has not been sufficiently explored. This is despite the identification by caregivers themselves of the value of peer support, which helps alleviate the emotional and social isolation they experience (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). Studies using peer support interventions as part of the rehabilitation process among UK populations is needed to establish if peer support presents a valuable coping resource for families which is currently untapped.

Researchers have started to consider whether coping with ABI could evoke specific coping styles that are different than the ways people cope with other health conditions. A

study by Brands and colleagues found coping with ABI and coping with multiple sclerosis to be similar, and in both groups emotion-focused coping was detrimental to quality of life (Brands, Bol, Stapert, Köhler & van Heugten, 2018). Similarly, Curran, Ponsford and Crowe (2000) did not find much difference between the coping strategies used by those who had sustained significant orthopaedic injuries and those who had a TBI.

Finally, as well as identifying maladaptive coping styles, we can learn from those who feel they are coping well with post-injury life. Nochi (2000) interviewed 10 people who had sustained a TBI but felt ‘at ease’ with their situation. A common theme between the participants was that they had re-evaluated their post-injury life, rather than just trying to accept it. The positives of caregiving have received considerably more attention in dementia research than ABI (Lloyd, Patterson, & Muers, 2016; Yang, Ran, & Luo, 2019), and the potential benefits of helping caregivers identify positives associated with caregiving is being revealed (Carbonneau, Caron, & Desrosiers, 2010). No such body of work with ABI populations is available. One review of the literature with stroke survivors identified 9 suitable studies from which to gain some information about positive representations of caregiving. They concluded that seeing progress in the person with ABI, stronger relationships, feeling appreciated, and having increased self-esteem were the main positive outcomes for caregivers of loved ones’ who had suffered stroke (Mackenzie, & Greenwood, 2012). The benefits of helping other family caregivers realise such positive aspects of caregiving remains unknown in the ABI literature.

Ultimately, there is a paucity of qualitative studies focusing on coping behaviours and adjustment to ABI. One example though is that of Shotton, Simpson and Smith (2007), who interviewed nine individuals with TBI about their coping and analysed their responses using IPA. The experiences of the participants of this study brought together the majority of the

areas of coping covered in this review to give a comprehensive view of how people cope in the early stages after injury. Flexible coping strategies, positive appraisals and feelings of being in control all contributed to positive adjustment to the early stages of TBI. Of the qualitative studies available, there is evidence that this methodology could be better suited to furthering the understanding of coping behaviours in relation to adjustment to ABI, as they allow for the addition of understanding how certain ways of coping have influenced the adjustment process for that person.

### **2.1.8 Coping in families**

The factors involved in good family coping are not yet well understood. Many researchers have focused on documenting the levels of stress and burden experienced as a result of a family member's caring role. For instance Jeffrey Kreutzer and colleagues have repeatedly reported elevated stress as a result of caregiving amongst family members as well as increased prevalence of depression and dissatisfaction with their situation (For example Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Kreutzer, Gervasio, & Camplair, 1994; Kreutzer, Marwitz, & Kepler, 1992). It appears that becoming a caregiver for a loved one with a brain injury can lead to stress, depression and social isolation and indeed this can be the case. Unfortunately, what is not being comparably investigated is the positive effects of caregiving on the family. There is a tremendous bias present towards highlighting the struggles of families (Perlesz, Kinsella, & Crowe, 1999). For instance, in the aforementioned studies by Kreutzer et al., whereby the elevated levels of stress in caregivers were highlighted compared to a control group, it was not discussed that only half the caregiver sample experienced elevated stress, and the finding that only a quarter of participants had elevated levels of depression was seen as a negative, without considering why the majority of this sample were not feeling this way (Kreutzer, Gervasio, & Camplair, 1994). Another example

is that of associations of coping styles within family systems after ABI, which reported 39% of the family caregivers' in the study had high levels of strain, and 38% reported low quality of life (Gregório, Stapert, Brands, & van Heugten, 2011). In the discussion though, there was no mention that the majority of the caregivers had not felt such a way, instead focusing on the negative impact ABI *can* have on families.

A good example of a more balanced representation can be found in Knight, Devereux, & Godfrey (1998) as participants were able to report equally on both the positive and negative aspects of being a caregiver for someone with an ABI. In this study, two-thirds of participants reported enjoying their caregiving duties and gaining a sense of satisfaction from their role. It is of note that the majority of the sample was made up of parents (56% of all family member types), so the results may be biased towards responses from relatives who have been used to caring for their loved one in the past and are taking back a role which is not particularly foreign to them (Kreutzer, Gervasio, & Camplair, 1994). However, this study also reported that parents felt more pessimism about their adult child's future than did spouses on a measure of caregiver burden.

The use of qualitative comments and questionnaires which allow for positive reports provide a much more comprehensive view of how families are responding to ABI. If researchers look for negatives and only give participants the opportunity to express those negatives then that is what will be found. The current study will address this issue by using a semi-structured interview which will allow for the expression of both positive and negative attributes of ABI to counteract this bias in the literature.

There has been much research into what factors might be most influential in determining how a family copes with their loved one's ABI. One variable of interest -injury severity- has not been found to influence coping (Anson & Ponsford, 2006a; Finset, &



Andersson, 2000) but more the meaning the injury has to the family is of importance. For example, if the injury is considered normative, such as a stroke in old age, then families cope with the effects of the injury better (Oddy, Humphrey, & Uttley, 1978). However, if the injury is perceived as a devastating tragedy then it has a greater impact on family coping (Carnes, & Quinn, 2005). This would fit with Lazarus and Folkman's theory that it is the perception of the stressor which plays an important role in coping, and it would be understandable that an unexpected event that feels unjust to a family would be harder to cope with than something which feels more a part of the natural course of life. Regardless of injury severity, families cope better with community-based support rather than residential based care (Verhaeghe, Defloor, & Grypdonck, 2005).

Along with injury severity, researchers have also considered the effects the injury has had on other variables of interest. Changes in the individual with ABI's behaviour, personality or emotions are consistently found to be the most difficult for family members to cope with (Kreutzer, Gervasio, & Camplair, 1994; Kreutzer, Marwitz, & Kepler, 1992; Verhaeghe, Defloor, & Grypdonck, 2005). One study used IPA on interview data from five marital couples and found spouses whose partner had experienced personality changes after their ABI changed the way they felt love for them (Bodley-Scott, & Riley, 2015). They reported difficulty loving the 'new' partner', yet they did not lose the love from the relationship, instead it changed to a caring love rather than a romantic one. Personality changes in individuals with ABI is reported to be particularly difficult for spouses, as the non-injured partner has to learn to accept a different person into their relationship than the one they married. However, parents have been shown to experience greater loss for their adult child with ABI than spouses do when personality changes are experienced (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). Regardless of relationship type, personality

changes in individuals with ABI leave families at risk of grieving for the loss of their loved one, leading to the presence of ‘ambiguous loss’ (described in detail in section 2.3.2).

The way a family copes has not only been said to have implications for the family, but can also have an effect on how the individual with ABI adjusts (Ell, 1996; Verhaeghe, Defloor, & Grypdonck, 2005), as well as their rehabilitation outcomes (Bond, Draeger, Mandleco, & Donnelly, 2003). As a result, family members have been identified as key to an individual’s long-term wellbeing after ABI (Anderson, Simpson, Daher, & Matheson, 2015). However, this impact of the family on individual outcomes was not corroborated by Gregório, Stapert, Brands, & Van Heugten, (2011). Their study found that the coping styles of the primary caregiver related to caregiver functioning, but not to the individual with ABI being cared for. They also found that caregivers using passive styles had lower family functioning, but caregivers using active coping did not have an effect on patient outcomes. They concluded that the coping styles of family caregivers are not sufficient to influence outcomes for the person with the ABI, it is individual coping styles that are of concern.

To conclude, coping behaviours appear to play a key role in adjustment to living with an ABI, but little is known about how ABI impacts on coping behaviours and how people cope over time. Coping remains one of the most researched variables in brain injury rehabilitation outcomes for both individuals with ABI and their family members (Blais & Boisvert, 2005). The investigation of coping has been included in this study to contribute to this field of literature and seek an insight into the meaning of coping behaviours for individuals who have been effected by, or are related to someone, with ABI.

## **2.2 Family Changes After ABI**

### **2.2.1 Definition of family**

The majority of ABI family research focuses on the main caregiver, or someone who has primary responsibility for the caring duties of the individual with ABI (Ponsford, Olver, Ponsford & Nelms, 2003). A limited number of studies have investigated more than one family member (such as Gan & Schuller, 2002 and Whiffin, Bailey, Ellis-Hill, Jarrett, & Hutchinson, 2015), but ordinarily inferences about family functioning or adjustment come from a main caregiver perspective. This study will not necessarily include the main caregiver but will get a family perspective from the patient and one close family member to make assumptions about the family influences on the patient's adjustment. It is of note that when investigated, there was no difference between the functioning of main caregivers and family members who were not main caregivers (Ponsford, Olver, Ponsford, & Nelms, 2003).

A common failing in the literature is a lack of definition as to what is meant by 'family' (Anderson, Simpson, Daher, & Matheson, 2015). When comparing across studies relating to family functioning, this could be a reflection of someone who lives in a vibrant six person household or someone who lives alone, meaning generalising research results to the wider ABI population is difficult. Moreover for some, a main caregiver may not be family at all. For this current study, family is referred to as those family members considered on a day to day basis, or those who may be involved when making family decisions. They do not have to be a caregiver for the individual with ABI. For people who live with family members, this definition would include the people living in the family home. For those who live alone, family is defined as those who would be considered when making family decisions, such as parents or adult siblings.

### **2.2.2 Impact of ABI on families**

The ways in which families have been impacted by having a relative with a brain injury has typically been conceptualised in the literature as their levels of reported stress and burden (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007; Kreutzer, Marwitz, & Kepler, 1992), along with how satisfied they may feel with their caregiving role (Knight, Devereux, & Godfrey, 1998), and severity of depression and anxiety (Ponsford, Olver, Ponsford & Nelms, 2003). Indeed, one review in 1999 identified 23 different measures used to assess psychosocial outcomes of primary caregivers (Perlesz, Kinsella, & Crowe, 1999).

Of the studies measuring the impact of ABI on families, there is a general consensus that ABI leaves families with higher levels of stress when compared to controls (Gan, Campbell, Gemeinhardt & McFadden, 2006). The variables responsible for this increased stress are less clear, and there are many conflicting reports in the literature. For example, it has been considered whether the severity of the individual's ABI is a factor in the burden felt by families. A study by Livingston, Brooks & Bond (1985) compared families affected by severe ABI and mild ABI. Between these groups, injury severity dictated greater distress and poorer functioning in social roles for family members who's loved one had sustained a more severe injury. However since this finding, contradictory evidence has been reported to suggest no such effect of injury severity on functioning and wellbeing (Carnes and Quinn, 2005), caregiver satisfaction (Knight, Devereux & Godfrey, 1998), and family functioning (Gan, Campell, Gemeinhardt & McFadden, 2006; Gan & Schuller, 2002; Wade, Drotar, Taylor & Stancin, 1995).

Rather than injury severity which is usually measured at the time of the injury through means such as the Glasgow Coma Scale or length of post traumatic amnesia (PTA) for traumatic injuries, many researchers have chosen to focus on the effects the injury has had on

the individual, and consider how this impacts on the family. Although some research has found no relationship between patient neurological impairments and family outcomes (Oddy, Humphrey, & Uttely, 1978), there is much more evidence to suggest this is a more accurate predictor of the impact on families than is injury severity. As also represented in the coping literature, patient impairments with social interactions, emotional disturbances, and behavioural changes have been consistently seen to cause more stress amongst family members (for example Tarter, 1990; Carnes & Quinn, 2005; Chwalisz, 1992).

Another variable which bears inconsistent results is that of relationship status. It is not clear whether the type of relationship held between the family member and the individual with ABI impacts on outcomes for those people. Much research focuses on the relationships of parents versus spouses. Carnes and Quinn (2005) did not find any difference between these two groups of relatives when measuring family adaptation to ABI. This finding was also reported by Knight, Devereux & Godfrey (1998) although they did report the difference that parents feel more concern about the future of their injured child than spouses do for their partner. Being a spouse predicted depression in a study by Kreutzer, Gervasio & Camplair (1994), over and above other variables, and half of all marriages will end after a TBI is sustained by a spouse (Landau & Hissett, 2008). However, the majority of studies conclude relationship status is not a variable of importance when assessing the impact of ABI on families (Gan & Schuller, 2002; Livingston, Brooks & Bond, 1985; Ponsford, Olver, Ponsford, & Nelms, 2003).

### **2.2.3 Role changes after ABI**

Further to the research on relationship status, the impact of specific role changes could be an area of particular importance for families trying to adjust to life after ABI. Changes to the roles people have in their family unit can cause disruption to family functioning. As a consequence, family members can face 'identity confusion' as the normal boundaries of the family unit are

changed, and support is required to redefine roles to protect long-term wellbeing (Kreutzer, Mills, & Marwitz, 2016).

Even though the majority of research investigating relationship status found this not to be a factor in family adjustment outcomes (Ponsford, Olver, Ponsford, & Nelms, 2003), when identifying specific role changes, this is seen to be an area of particular strain for spouses.

Gosling, & Oddy, (1999) found that perceived role changes are more stressful for spouses than parents, deducing that this is because the relationship becomes imbalanced and the responsibility for decision making as a couple now falls solely to the uninjured partner. Similarly, Tyerman, & Booth, (2001) did not find parents and siblings experienced role changes, whereas the spouses in the sample did, although their parents and spouses did report similar levels of stress and burden. This could be suggestive of an additional factor that contributes to caregiver burden which is unique to spouses and should be considered in couples' therapy interventions. Tyerman & Booth (2001) warn though that the meaning of the roles to individual family members must be discovered first to avoid unintentionally causing a negative effect on the family functioning due to roles not having importance to individuals in the relationship.

Lastly, one study reported not only the negative impact of role changes, but also the positive ones that can be felt. In a study of individuals with TBI by Hallett, Zasler, Maurer, and Cash (1994), 60% of participants did not feel they had experienced a change in their family role since their injury. Of the 40% who felt a change, the majority of these changes resulted in a loss. These losses primarily related to work and leisure activities. However, this study also allowed for the expression of positive role changes, which were mainly felt in roles relating to the home and family environment.

The full impact of role changes within family units is not well researched, particularly for relationships beyond spouses and parents, but of the literature available it appears that spouses are at most risk of feeling increased strain due to the imbalance caused by the role changes in their marital relationship. The reports that relationship status does not relate to outcomes means the function role changes plays for spouses may be unique for them, but does not add to the impact of ABI as a whole. Whether this is because other relationship types have an equally prominent, yet different type of change which replaces this one is yet to be discovered.

#### **2.2.4 Issues with measuring the family impact**

To assess actual change within the family unit since a member sustained an ABI, most studies assess family functioning and attribute this to the impact of the injury using a crosssectional methodology looking at a single time-point (for a review see Perlesz, Kinsella, & Crowe, 1999). The problem with this is that it does not indicate change since the injury without considering how the family functioned before the injury occurred. For example, Macrodimitris & Endler (2001) in a study on coping with and adjustment to chronic illness, used outcome measures of depression and anxiety to assess levels of psychological adjustment to living with diabetes. However, there was no information on whether the participants suffered from anxiety and depression *before* their diagnosis. Similarly, Kosciulek (1994) used cross-sectional quantitative measures of how the family are functioning now to assume how they have adapted since the ABI occurred, with no measure of pre-injury functioning to compare to.

Some studies have attempted to address this issue. Using a measure of pre-injury relationship status, Carnes & Quinn (2005) asked participants to reflect on changes to their relationships since the injury occurred to see if pre-morbid relationship quality was a protective factor after ABI. They found that higher levels of pre-injury relationship quality

did not protect against family distress after injury, although it did relate to better family functioning. The authors acknowledge that this could be due to a greater loss felt by the disruption to a closer pre-injury relationship, and therefore the impact of the ABI causes more distress.

Another example of the implementation of good methodology to assess adjustment to ABI is seen in Curtiss, Klemz, & Vanderploeg (2000), who asked family members to reflect back on a stressful incident within six months prior to their loved one's injury, and then again at the time of interview, and compared the pre and post injury reports. Based on the responses given, 70% of families showed a negative change to their family structure when dealing with stressful events after the injury had occurred.

As with the coping literature, there is a bias in the family literature for highlighting the stress and burden on caregivers of individuals with ABI (Perlesz, Kinsella, & Crowe, 1999). This is not to say that families do not feel an impact from the ABI, but families who are responding positively and functioning well despite the ABI are not comparably represented and we could be learning from families who are adjusting well to living with ABI and supporting their loved ones' challenges.

In summary, it has been recognised for decades that ABI impacts beyond the individual with the injury, causing implications for the whole family unit and beyond (Brooks, 1991; Degeneffe, 2001; Verhaeghe, Defloor, & Grypdonck, 2005). Changes to families is therefore considered to be an important aspect in this study for understanding how people incorporate ABI challenges into their daily functioning and subsequently adjust to this new way of life.



## **2.3 Loss after ABI**

### **2.3.1 Grief versus loss**

Grief can be defined as a negative emotional reaction to a loss or change of some kind which also encompasses cognitive, functional and behavioural responses (Zisook & Shear, 2009). Commonly associated with the death of a loved one, Engel (1964) described in his seminal work a healing process when natural grief occurs which takes approximately a year to complete. This distinction is important to understanding the view of loss in this research. Grief and loss are undoubtedly intertwined (Howarth, 2011), but grief is considered here as an emotional reaction which is worked through by the individual to some kind of conclusion whereby it is not ‘held’ by the person. However ‘loss’ is considered within this thesis as a sense of change or difference which leaves a feeling of something missing or changed for that person. This is not so much a process or response, as with grief, but can be something recognised by a person which may never be resolved. Personal loss can be long lasting even when there appears to be a very good physical recovery from brain injury. Loss follows change, not just death, such as acquiring a disability (Coetzer, Ruddle, & Mulla, 2006). Some have even suggested that caregiver strain is a direct result of the loss felt after a loved one’s injury (Marwit & Kaye, 2006).

### **2.3.2 Loss after ABI**

For those who sustain an ABI, significant changes in identity and wellbeing can occur due to an altered sense of self. The person may no longer like the same foods, be able to take part in previously loved sports, or display the same temperament as before the injury. As described by Ownsworth (2014), the concept of self is complex. Our self refers to one’s enduring nature and spans a person’s past, present and future. Our sense of self encompasses our identity, which is thought of as our understanding of how we think, feel and behave in the context of our social groups, and distinguishes us from others. After someone experiences an

ABI, changes in how they think, feel and behave can disrupt their identity. Gracey et al. (2008) worked with a group of 30 individuals with ABI to investigate the construction of self and identity following changes brought on by their injury. Through the emergence of the theme 'self in the world', participants with ABI reported the loss of key activities that they once carried out that would have reinforced their usual pre-injury identity. The loss of meaningful activity was also reported by Turner, Ownsworth, Cornwell and Flemming (2009), whose study investigating experiences of transitioning from hospital to home highlighted the negative effect of lost activity for participants with ABI. The inability to carry out previous activities, such as driving or sports, and the barriers to replacing these with comparable meaningful activities, can have a detrimental impact on quality of life and feelings of satisfaction with one's self after a brain injury. Indeed, the detrimental effect of impaired self-awareness on psychological wellbeing after traumatic brain injury has also been documented by Coetzer (2004), whereby individuals with ABI can face repeated failures through the process of attempting to engage with pre-injury activities.

There are some studies which focus more directly on the concept of loss of self after ABI. A qualitative investigation by Nochi (1998) of 10 participants who had all experienced a traumatic brain injury (TBI) identified a main theme of 'loss of self' which took various forms. Loss of self could be viewed as a loss of knowledge for who they once were, which was brought on by the cognitive impact of their injury. It also took the form of loss of self associated with comparing the pre-injury self with the less desired post-injury self. This comparison also created loss through the expectations the individual with ABI felt were laid on them by people in their surroundings and notions of who they were supposed to be in their social context. Carroll and Coetzer (2011) also found a pre/post injury comparison of self to be detrimental to individuals with ABIs' sense of identity and that the recognition of losses as a result of the injury led to greater negative feeling associated with their situation. This

tendency to compare pre and post-injury self has not always enhanced feelings of loss though, as observed by Douglas (2013), and a detailed exploration of the differences between loss felt by individuals with ABI and the family around them has not, to date, been published.

However life has changed following ABI, the very fact it *has* changed can lead to a period of grieving for a former self and a prolonged period of ambiguous loss. As conceptualised by Boss (1999), ambiguous loss occurs when there is no resolution to a situation or normal focus for the loss (such as the death of a family member). Ambiguous loss has been documented in other groups such as dementia (Dupuis, 2002) and military deployment (Huebner, Mancini, Wilcox, Grass, & Grass, 2007), but has only recently started receiving attention in brain injury literature.

Research with those experiencing the acute stage of ABI with loved ones in neurocritical care report the presence of ambiguous loss in cases where impairment was permanent, and at the point at which the likely impact of ABI is first realised (Kean 2010). In studies of marital relationships, ambiguous loss is frequently reported when a spouse must adjust to living with a partner who has been changed by their injury, and the familiar marital relationship has also been changed as a consequence (Godwin, Chappell, & Kreutzer, 2014). It is not uncommon for loved ones to describe their relative with a brain injury as a different person, where they have mourned the death of who they knew before and had to come to terms with an altered relationship. As described by Godwin, Chappell, and Kreutzer (2014), married couples face a struggle to redefine their relationship in the absence of normal validations of relationship loss, such as death certificates or divorce decrees. Spouses can experience the loss of their partner without having these normative validations that aid acceptance when grieving. A detailed review of ambiguous loss theory in relation to traumatic brain injury (TBI) by Kreutzer, Mills and Marwitz (2016) highlighted how

ambiguous loss is especially pertinent for family members, more so than the injury survivor themselves. Most recently, Holloway, Orr and Clark-Wilson (2019) asked family members about their experiences of their loved ones' ABI and identified the theme of 'complicated grief', which described prevalent ambiguous loss among family members of individuals with ABI such as that described by Boss (1999).

The notion of a grieving period for the person with the ABI was documented by Persinger (1993), whereby cognitive deficits as a consequence of the injury were described as barriers to the normal grieving cycle, and should be considered as integral to supporting someone through the adjustment process. However, a sufficient understanding of how loss is experienced and what factors are most important for individuals with ABI and family members is still to be developed. In particular, the similarities or differences between families affected by the same injury has not been established. When considering family interventions, it is important to understand how family members are responding to ABI, both individually and as a unit so interventions can be implemented appropriately. Researchers and health professionals are starting to listen to the experiences of those who are adjusting well, rather than focusing on those who are not doing so well. This can help us link protective factors to coping with loss and understand how some people cope well with loss and others don't (Riley, 2009).

In summary, the way ABI has been seen to impact on families suggests loss could be an important factor in coming to terms with life after ABI. Whether this loss comes as a direct result of ABI limitations for those with the injury, or wider feelings of identity changes and relationship losses for family members, the concept of loss in ABI adjustment is currently under-researched and thus not sufficiently understood. Therefore, the inclusion of

loss as an area of focus in the interviews should provide valuable insights into how people experience this after ABI.

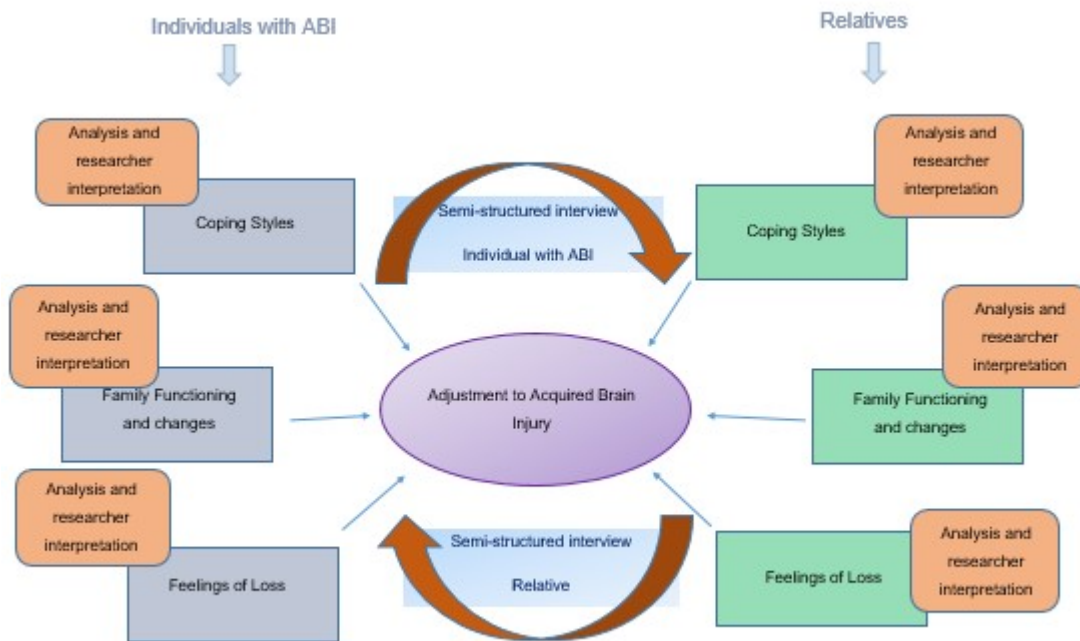
In summary, this literature review has highlighted a variety of gaps in current knowledge about how ABI impacts on families and their subsequent adjustment to the resulting challenges. Coping research using qualitative methods is lacking and may help with understanding the motivations behind coping behaviours and the function they have for individuals coping with life after ABI. How families adjust to the changes they face as a unit after ABI is not fully understood, and experiences of loss are currently focused on the individual with ABI and does not fully consider the experiences of those around them. Although research has been focused on family, rather than individual, outcomes for some years, the complexities of this field of study mean there is still a lot to be discovered.

## Chapter 3. Method

### 3.1 Design

*Triangulation and conceptual framework* This is a qualitative study using semi-structured interviews to gain data regarding family adjustment to ABI. Methodological triangulation has been employed as depicted in figure 1. The perspectives of individuals with ABI and relatives of individuals with ABI have been brought together to investigate the concept of adjustment to brain injury. The researcher interpretation is acknowledged as an integral part of this triangulation, providing a third perspective on family adjustment, along with the use of two different forms of qualitative analysis of the same transcripts (thematic analysis and interpretative phenomenological analysis).

The conceptual framework has incorporated elements of both inductive and deductive enquiry. Deductive elements refer to the selection of three key areas of research relating to coping, family change and loss. These areas have been pre-determined as topics of interest to cover in the interview based on current prominence in the field of ABI adjustment (Coetzer, 2013; Maggio et al., 2018; Mueller et al., 2018). However, the study has remained primarily inductive in that no assumptions about the meaning or importance of these areas for the participants has been made, and open-ended interview questions have been carefully constructed to allow for a variety of responses to be elicited. Moreover, a specific question relating to adjustment has been included in the interview which makes no assumption of what contributes to the adjustment process, with participants having the opportunity to elaborate on areas of importance outside of the three main research topics.



*Figure 1: research design depicting methodological triangulation and conceptual framework*

The reporting of the method used in this study, including the design and procedure, has been prepared in accordance with the 32 items of the Consolidation Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury, & Craig, 2007). This checklist ensures qualitative studies are reported in a comprehensive and explicit way to allow for transparent dissemination of the research quality.

**3.2 Aim of study** The aim of this project is to understand the importance of the subjective experience. The interview gives participants the opportunity to tell their story in their own words. Interview questions are open-ended and do not assume a position (i.e., bias-free so as not to lead participants to answer in a particular way). This allows for elaboration of the key concepts under investigation (coping, family change and loss) and for individual responses to emerge that may not be represented otherwise.

The aims of the study are captured in the following four research questions:

1. Does ABI change families and if so, do family changes impact on adjustment and does this differ for the individual with ABI and relatives?
2. What is the experience of coping with ABI like for individuals with ABI and their relatives, and does this change over time?
3. Do individuals with ABI and their relatives use different coping styles for ABI related stress, and how do the effects of the ABI interact with this coping?
4. What is the experience of loss after ABI and do these feelings relate to subsequent experiences of adjustment?

Ethical approval was granted by the research ethics committee at Anglia Ruskin University, Cambridge, and the study was conducted in accordance with the tenets of the Declaration of Helsinki.

### **3. 3 Philosophical standpoint**

The philosophical standpoint taken for this research is that of a constructivist - interpretivist epistemology. A constructivist-interpretivist stance postulates that one's reality is viewed through their own personal lens which is created by past experiences, beliefs and biases. It is this belief that has led to the interviews being integral for the understanding of lived experiences post-injury (Tuli, 2010). No two brain injuries are the same, so it is important to seek out individual perspectives on the impact they have. It is assumed that the perceived experience of that person is their reality. Akin to a constructivist-interpretivist stance, data analysis is an interpretation made by the researcher through their own lens and is open to reinterpretation and questioning. It is through multiple interviews and in-depth consideration of the resulting text that an understanding of the lived experience of family members and patients post ABI is sought.



Other philosophical stances were considered in the development of this project. For example, critical realism provides a philosophical stance which sits between positivism and interpretivism, and is seen by some researchers as a good compromise for the strengths and weaknesses of these two more extreme stances (Archer et al., 2019). However, a critical realist view does not allow for the reflexivity of the researcher to become integral to the analysis process. This study does not aim to seek an objective reality of adjustment to ABI, rather it is an attempt to gain more insight into experiences of coming to terms with this lifechanging event.

Although constructivist- interpretivist epistemology is suited to this research, there are some considerations that need to be remembered when interpreting the results of the interviews. The biggest consideration with this approach is that of researcher bias. Whilst it is believed and accepted that a researcher cannot fully separate themselves from bias to give a truly objective interpretation of the data, steps can be taken to enhance the ‘credibility, validity, dependability, and confirmability’ of the interpretations (Guba and Lincoln, 2001). Guidelines set out by Guba and Lincoln (2001), and outlined herein, help researchers check their interpretations and relationship with the data to create a scientific approach to the interpretation of people’s stories, whilst still remaining an integral part of the interpretation process.

*Credibility* Akin to the internal validity sought for quantitative measures, credibility relates to steps taken to remain impartial so interpretation has not been led by any personal objectives of the researcher. Gaining credibility for the study started with the use of a semistructured interview. A pre-determined set of questions meant each interviewee was responding to the same line of enquiry and had the same opportunities to express experiences on the research topics. The interview questions were checked and developed with a second

reviewer to avoid leading questions or insensitive ordering. Secondly, credibility of interpretations was also checked by a second rater who reviewed the initial coding for clarity and logical interpretation. The last stage of credibility checking involved that of participants. Two participants (one individual with ABI and one relative) offered their time to meet and discuss the interpretation of their interviews. These participants were chosen as people who would be able to engage with the process, were thought to be able to express any differences should they feel, and would not be adversely affected by discussing the interpretations. No changes were needed as a result of this process.

*Transferability* The next check subjected to the study was that of validity, or whether the reader has been given sufficient information about the participants and procedure to enable them to assess the credibility of the researcher. A full procedure has been provided in the method (page 38) and results section (page 53) of this thesis, including detailed coding, examples of interpretation, and full participant characteristics.

*Dependability* This is the necessity for the researcher to give sufficient information so a reader can make a judgement about the reliability of the researcher's interpretations. To fulfil this requirement, examples of the stages of coding have been given along with the final interpretations.

*Confirmability* This final point refers to reflexivity, or how the researcher is checking their interpretations and monitoring their bias. This was achieved through persistent and regular checking of the initial transcripts. Full analysis of the transcripts did not start until sufficient interviews had been completed to minimise the risk of the interviewer inadvertently using leading questions based on any emerging themes that may have been seen. Once initial codes were created, the transcripts were re-visited to check suitability and then adjustments

were made accordingly if anything was seeming to unjustly ‘fit’ the theme, rather than describe it.

### **3.4 Participants and setting**

Participants were registered clients of Headway Cambridgeshire (HWC), a charity helping brain injury survivors and their families cope with the challenges of life after ABI. All participants were eligible to contact their local Headway branch after the study if they required any follow on emotional support that was needed as a consequence of discussing their experiences. Comparisons of the socioeconomic status and general demographics of the current study sample with the general population of the county of Cambridgeshire can be found in Table 1 (p45), based on regional statistics from 2018 (Cambridgeshire insight, 2018).

Inclusion criteria for individuals with ABI were as follows:

- To be at least two years post-injury to allow for a normal course of grieving and adjustment to take place (Coetzer, 2013).
- To be considered to have capacity to understand and consent to the study.
- Be over the age of eighteen years at time of testing.
- Have a diagnosed acquired brain injury that was sustained after the age of 18 years to control for developmental disorders.

It transpired that after testing, one participant had sustained their injury at the age of sixteen years, meaning they did not meet the inclusion criteria of sustaining their injury after 18 years of age. It was decided after conversation with the lead supervisor, and in depth consideration of the data collected, to include this participant as the data was not showing any significant variations from other participants in terms of developmental disorders due to age

of acquisition. All other participants were over the age of eighteen years when they sustained their injury.

Table 1.

*Participant SES data compared to Cambridgeshire county population*

	Individuals with ABI	Relatives	Cambridgeshire county
Marital status (%)			
Married	52	84	49
Divorced	14	11	9
Single	33	5	33
Gender (%)			
Male	76	32	52
Female	24	68	48
Employment status (%)			
In employment	24	26	78
Part time employment	10	11	23
Full time employment	14	15	76
Education* (%)			
Degree or above	43	26	39
HE below degree	19	21	6
A- Level	5	11	22
GCSE A – C	23	26	20
Lower GCSE	5	0	7
No Qualifications	5	16	6

*Note.* \*or equivalent education level. HE = higher education.

For relatives, eligibility to take part was decided by the following inclusion criteria:

- There was a family connection, either familial or by marriage, to the individual with ABI
- They had been sufficiently involved with the individual with ABI both pre and post injury to be able to reflect on changes.
- Over the age of 18 years at time of test

All participants who volunteered were found to meet inclusion criteria and took part, although two of these participants had to have scheduled appointments to wait for the twoyear post injury threshold to be met. All participants were aware the first author was an employee of HWC and it was made clear that the research did not form part of their services and choosing or not choosing to take part did not impact on the HWC support they received. Approximately 38% of participants were met for the first time by the first author for the purposes of this research.

It was considered whether having a pre-existing relationship with the participants would be an issue. It could have been that those who knew the researcher better, and also knew they would regularly see them again whilst accessing HWC services, could lead to less openness, or more neutral responses which didn't fully expose the participant emotionally. Conversely, it could have been that a pre-existing relationship helped participants to be open, and that those who were met for the first time at interview would not display the same level of trust in their responses and would remain more guarded about their experiences. However, it did not appear to make a difference to the interviews if the participants had a pre-existing

relationship or not. No differences in openness of responses or richness of data were apparent. When participants were met for the first time there was a commonality shared based on the connection of HWC, which seemed to facilitate a warm and trusted response from the start. It was apparent that the ethical consideration of my powerful position as HWC staff was founded, but also respected, in that participants knew I was coming from a place of compassion with my research due to their experiences with the organisation as a whole. Of course, it could have been the fact they held HWC in such positive regard which led them to volunteer their time in the first place, even though a separation of the research from the charity was sought at all times.

**3.4.1 Participant Characteristics.** Demographic characteristics of the participants can be found in Table 2. Of the 40 participants completing the semi-structured interviews, 21 had sustained an ABI and 19 were relatives of someone who had sustained an ABI. From these participants, 17 dyadic pairs were present, that is, an individual with ABI had a family member also take part, thus reporting on the same injury experience. The causes of injury were predominantly traumatic injuries ( $n = 11$ ; 6 road traffic accidents, 4 falls, 1 assault) with the remainder covering vascular events ( $n = 7$ ; 5 stroke, 2 sub-arachnoid haemorrhages), tumours ( $n = 2$ ), and one case of hypoxia. Males made up 76% of the individual with ABI sample and 32% of the relatives' sample. This imbalance of participant gender is consistent with the population, with ABI predominately affecting males (Colantonio, 2016; Munivenkatappa, Agrawal, Shukla, Kumaraswamy, & Devi, 2016).

Table 2.

*Participant characteristics*

				Individuals with ABI	Relatives	Total/ combined
Marital status						
Married				11	16	27
Divorced				3	2	5
Single				7	1	8
Mean age at test				51.3	58.7	54.9
(SD)				(15.1)	(12.2)	(14.1)
Mean age at time of	45.1	51.1	48.1 injury			
(SD)			(14.7)	(10.6)	(14.1)	
Gender						
Male				16	6	22
Female				5	13	18
Mean months since	97	92	95 injury			
(SD)			(71)	(75)	(72)	
Employment status						
Retired				7	11	18
Part time employed				2	2	4
Full time employed				3	3	6

Unemployed	9	1	10
Self employed	0	2	2
Co-morbid health condition	7	4	11

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*Note.* Relatives' time since injury refers to their family members' with ABI. Relatives' age at injury refers to age when their family member sustained their ABI.

### 3. 5 Materials

A full list of interview questions and prompts used for the semi-structured interview can be found in Table 3. Please see Appendix 1 for the full interview schedule. Questions were created to cover the research questions set out in 1.1. Ordering always started with the intended first question, but the subsequent question ordering was not rigid due to the effort to keep the interview relaxed and informal for the participant. If it felt appropriate to change the ordering of the questions due to the participant's responses then this was done, with the schedule acting as a guide to keep the interview on track and make sure all questions were asked. The only difference in interview questions between participant type was to distinguish if the injury being referred to was sustained by the person being asked or if it was for a relative. For example, the wording 'your injury' was used for individuals with ABI, and the wording 'their injury' was used for relatives. Where possible the wording was kept neutral to apply as much consistency between interviews as possible, for example, using the term 'the injury' so it related to both participant types.

Table 3

*Interview questions and indicative prompts used in the semi-structured interview*



Question no.	Interview question	Follow or prompt if required
1	I would now like to ask you about your typical coping styles. Could you describe how you feel you generally cope with things that cause you stress?	Examples may be needed such as 'do you try to distract yourself' or 'tackle problems head on' etc
2	Would you view your coping style to be the same as before the injury?	
3	Has the injury changed anything for you as a family?	<p>What aspects of your life changed as a result of your injury? a) Could you tell me a bit more about that? b) Could you describe that in more detail?</p> <p>Could you expand on that point? Do you have any examples of this? Could you say something more about that? How did you react to that? Have you experienced this yourself?</p>
4	Do you feel you have changed the way you cope with any issues regarding the injury as time has gone on?	Could you explain how it has changed?
5	Would you say you cope with issues around the injury any differently from other forms of stress you encounter?	Could you explain why you think that is?
6	Would you consider that you and your family were in a good position to deal with the brain injury?	Could you tell me why you think that was?
7	To what degree do you feel you have an active choice over your/their brain injury support?	
8	Could you describe whether you have or have not experienced a sense of loss since the injury?	Have you felt you think about times before the injury and things you did then? a) What are the main areas of loss you have felt? b)
9	Have you ever found yourself dwelling on pre-injury life?	<p>Could you explain why you haven't felt loss?</p> <p>Why do you think that is? b)</p> <p>What helps you?</p>

- |    |  |  |
|----|--|--|
| 10 | Would you consider yourself to<br>adjusted to life as it is now                | Why do you feel that? Could you explain that have<br>a bit more? What would/does being adjusted after the brain<br>injury? look like to you? |
| 11 | How would you define adjustment?<br>What does 'being adjusted' mean to<br>you? |  |
| 12 | Is there anything else you would<br>like to add?                               |  |
- 

### 3.6 Procedure

Volunteer sampling was encouraged via poster, leaflet and email invitations which were circulated to aid recruitment of participants. The first author also gave talks about the research to clients of HWC who attended services there. Other staff members used some purposive sampling by inviting clients who they felt would be suitable to take part using the inclusion criteria as a guide. Once interest was shown, participants were given a participant information sheet (appendix 7) and a two-week cooling off period to ensure they wanted to take part and to give time for questions or concerns about participation to be addressed. All participants who volunteered were found to meet inclusion criteria and took part, although two of these participants had to have scheduled appointments to wait for the two-year post injury threshold to be met. The first author conducted all the interviews and had been employed by HWC for ten years supporting individuals with ABI and their families as well as experience of conducting qualitative interviews at post-graduate level, making her well placed to provide the skilled communication and sensitivity needed when conducting these interviews.

Interviews were recorded on a Dictaphone then later transcribed verbatim using standard conventions with the primary author and interviewee present only. Participants were interviewed separately from their family members to allow people to be free from answering

desirably about their experience due to a loved one being present. Data were mainly collected in two independent stages to manage fatigue and concentration and availability challenges. Participants could complete the quantitative and qualitative stages in any order, or within one interview if preferred. This meant that participants could subscribe to part of the research without having to commit to the full interview, and neither stage of the data collection was reliant on answers given from the preceding stage.

The interviewer did not annotate the transcripts with observations or keep field notes about the interviews to ensure later analysis remained centred around the raw interview data. Interviews typically lasted between 30 and 45 minutes and no repeat interviews were necessary due to sufficient and clear responses to the interview questions being obtained. If ambiguous answers were given these were dealt with in the interview with clarifying followup questions. Names were changed to protect the identities of the participants as well as those being discussed in the interviews and any defining characteristics (such as town of residence or number of children) were omitted during the transcription process.

### **3.7 Analysis**

Semi-structured interviews were analysed using Bryman's (2008) four stages of qualitative analysis, which uses a systematic framework to interpret the interview transcripts. Thematic diagrams of theme development are presented with the corresponding results. No software was used to code the data to allow the first author to remain fully emerged in the scripts and have a good oversight of the interviews.

The 4 stages of the coding process are described in Table 4 (page 53) along with the actions taken to adhere to this process. Data saturation was judged to have been reached when no new themes emerged. A selection of transcripts (3 individuals with ABI and 3 Relatives) were independently coded by a second rater and discussed with the first author to reach a

consensus on main themes. First and second stage coding conducted on the transcripts was also checked by a second rater for consistency, and one family member and one individual with ABI provided feedback on their coded manuscript via a discussion of the coding to check interpretation. Those invited to partake in member checking were purposively chosen due to their ability to engage with the process of checking the coding and minimal chance of emotional distress arising from reading through their transcribed speech. These participants were given time to read through their transcripts and comment on the coding and interpretation. No changes to coding were required as a result of this process. The participants who commented on their transcript coding both reported enjoying the process and felt the coding had reflected the intentions of their responses. The relative expressed that by discussing her experience and talking through the interpretation it had helped her process what had been a traumatic experience in her life.

It was decided that only two participants would be invited to take part in member checking for the following reasons. Firstly, time constraints on the research project meant it was considered more valuable to focus the limited time resource on recruiting as many new participants as possible, and subsequent data analysis. Secondly, a number of potential risks are present with member checking (Carlson, 2010). These risks include distress for the participant, either through being faced with their story ‘in black and white’, or being uncomfortable with the way they expressed themselves grammatically, or there could be a desire for the participant to change their original responses, which could lose important data that will no longer contribute to the themes. Not every participant would be suitable for member checking, and the more participants that took part in this process, the higher the risk of inducing one of the aforementioned risks with this approach. It is recognised that the selection of the two participants by the main researcher could be biased to those who were unlikely to disrupt the coding process and those who were felt wouldn’t raise too many

concerns about the interpretation. However, as a consistent framework for coding was applied to all transcripts, it is hoped that this bias is limited, and that the confirmation by the two participants who checked their transcript provides a good indication of the closeness of interpretation to script.

Table 4

*Description of the coding process for interview transcripts*

Coding stage	Aim of coding stage	Description of coding processes
Stage 1	To gain a first impression of the qualitative data and extract major themes	Reading of transcripts to get a general feel for the narratives. Initial note taking.
Stage 2	Identification of key words and further emergence in the data	Transcripts were re-read and annotated. Key words were highlighted
Stage 3	Refine codes and illuminate repetitions	Checking of coding. Grouping and reclassification of overlapping code names to create themes. Re-checking of transcripts against newly made themes to reflect on selection and interpretation of the coding.
Stage 4	To connect theory to the data in relation to the research questions	Themes interpreted in line with the research questions and existing literature

## Chapter 4. Results

### 4.1 Coping

The effects of ABI can have a life changing impact on the individuals who sustain them and also their families (Verhaeghe, Defloor, & Grypdonck, 2005). Specific coping strategies used to manage any additional stressors brought on by ABI is not fully understood. Moreover, the meaning of coping responses and how these have changed for people after an injury requires further understanding to see if there are detrimental, or indeed beneficial, ways to coping with ABI. Results herein relate to expressions from the interviews which related of coping and changes in coping behaviours. These questions aimed to answer research question two, *what is the experience of coping with ABI like for individuals with ABI and their relatives, and does this change over time?* And research question three, *do individuals with ABI and their relatives use different coping styles for ABI related stress, and how do the effects of the ABI interact with this coping?* Specific coping related questions were asked, namely “could you describe how you feel you generally cope with things that cause you stress?”, “would you view your coping style to be the same as before the injury?”, “do you feel you have changed the way you cope with any issues regarding the injury as time has gone on?”, and “would you say you cope with issues around the injury any differently from other forms of stress you encounter?” Figure 2 shows the development of coping themes through the thematic analysis process of the responses from participants that related to their coping behaviours. Three main themes were identified: *Coping change, specific coping with ABI stressors, and coping across time.*

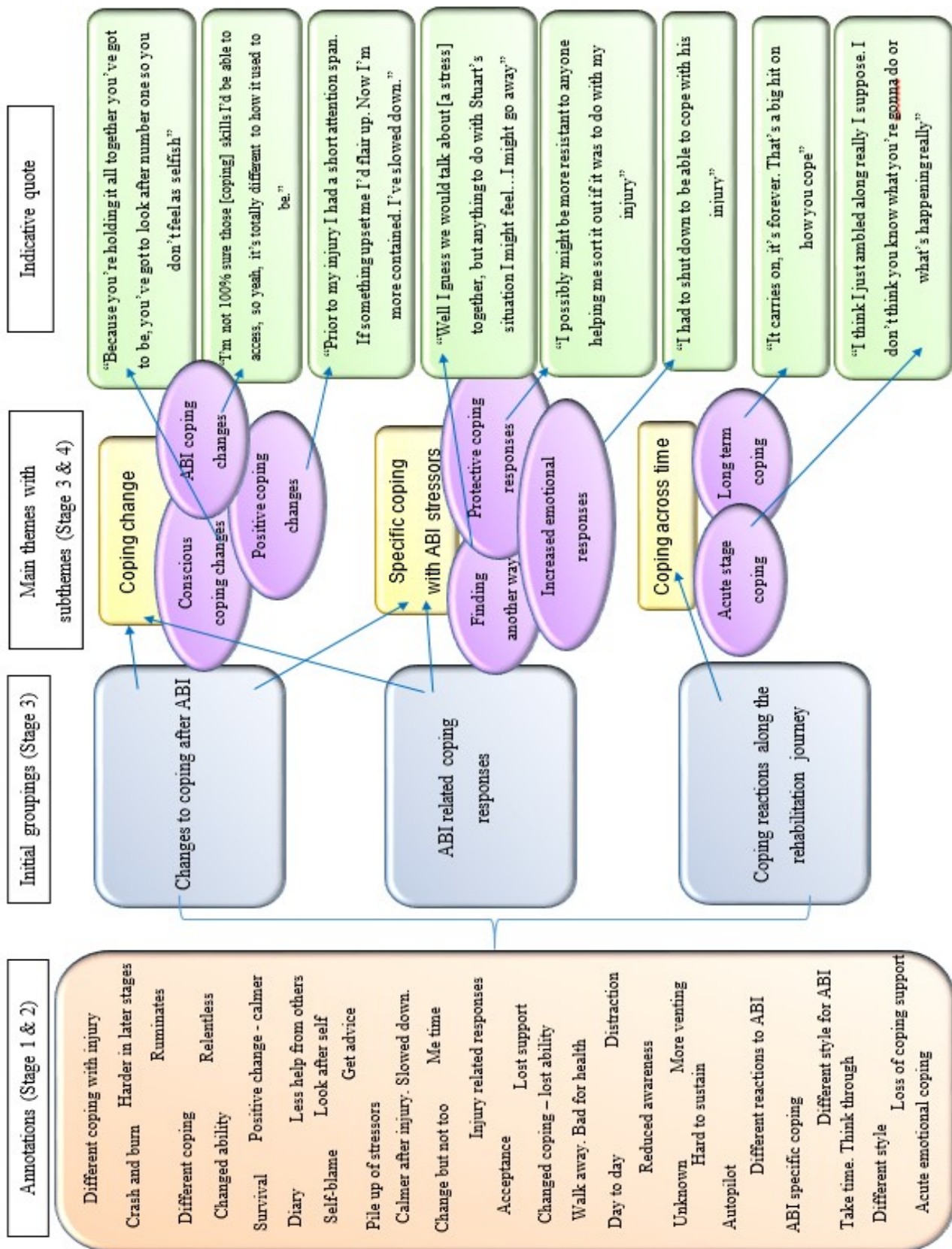


Figure 2: Thematic coding of coping data using the four stage framework of Bryman (2008)

#### 4.1.1 Theme 1 – Coping change

*“I don’t think I had a coping style before. I wouldn’t have said I had a coping strategy. I never really thought about it”*

It emerged across the interviews that many people experienced a change in the way they coped with stress as a result of the experience of the ABI. This was seen in 11 of the 19 relatives’ interviews and 8 of the 21 individuals with ABI interviews, meaning nearly half of all participants reported changes to their coping style as a direct result of the ABI experience, consequences, or event. Of those that did not feel a change, five could not be sure if they had experienced a change, and 16 did not feel a change at all.

Three subthemes emerged within the main theme of coping change: *Conscious coping changes*, *ABI coping changes* and *Better coping changes*.

*Conscious coping changes* These changes related to expressions of active coping strategies that people were now aware they used to cope with the challenges of ABI. This was dominant for relatives, who recognised that they had to be more strategic with self-care and stress management techniques as a result of the increased responsibility they felt since their loved one’s injury.

Here Debbie, whose husband has an ABI, explains how she never considered the need to actively manage stress before she was given the additional responsibility of caring for her husband, but now she has regular time-out to be more able to manage an increase in burden:

*“No I never did anything, no [stress relief]. I don’t think I’d bothered about me time because you sort of, the kids are only just going off your hands, I mean you’re last in the queue aren’t you? But now you know that, because you’re holding it all together you’ve got to be, you’ve*



*got to look after number one so you don't feel as selfish. I think perhaps before if you're thinking, you know, you shouldn't, but now I think oh yeah, put yourself first"*

Hazel also recognised that she now used more specific strategies to manage stress after her husband's injury:

*"I think I probably walk a lot more. I tend to try and walk and run a lot more than I used to..... but it, you know, feels like we both need more time out from each other. I need time out from him"*

Margaret, another spouse, echoes this feeling of going from a sense of getting on with life pre-injury to a shift towards acknowledging that coping efforts need to be made to be able to sustain the new way of life:

*"I don't think I had a coping style before. I wouldn't have said I had a coping strategy. I never really thought about it, it's not the sort of thing you think about, is it?"*

For relatives in this subtheme, coping strategies had become a way of life and were now recognised as essential for maintaining the ability to carry out additional responsibilities to compensate for the injury effects. All relatives who had adopted more conscious coping efforts were spouses who lived with their partner and expressed feelings of needing to employ these strategies as a way of coping with the additional demands the injury had brought to the household. Spouses that had perceived self-care routines as selfish and indulgent pre-injury now had a new found recognition for the need to preserve energy and emotional strength to carry out their caring duties and keep their new level of responsibility sustainable.

*ABI coping changes* This subtheme relates to changes in coping as a direct response brought on by impairments following ABI. For individuals with ABI, there was a lost confidence in

coping ability, or an acknowledgement that the injury effects played a direct role in their stress and subsequent coping efforts.

For Max, he recognised that the effects of his injury had created a different relationship between himself and stressful situations, and now he felt he was often the cause of stress:

*“I could always hold context, but I can’t anymore. My memory just doesn’t work like that...at work, problems would have been seen as challenges. They wouldn’t come about through miscommunication and people taking things the wrong way. Now I find the problem is me taking things the wrong way, so problems are different now.”*

Others also recognised that their injury had changed the way they felt about their coping ability, with some feeling a loss of confidence as a result of their injury deficits:

*“Yeah it’s changed [coping]. I always had a good coping strategy whereby, well in five minutes this situation will be over, so you just go and deal with it....I’m not 100% certain those skills that I had I would be able to access, so yeah, it’s totally different to how I used to be.”* Camilla, individual with ABI

*“I feel everything is more exaggerated. Probably I could deal with stress better, but now because it gets so bad for me I have to walk away otherwise I could feel really poorly.”*

Emma, individual with ABI

These experiences describe how the limitations in coping ability brought about by the ABI deficits then lead to a loss of confidence in their ability to cope. This in turn results in more avoidant coping strategies being used such as walking away from or avoiding potentially stressful encounters.

For relatives, this subtheme of ABI coping changes related to how they cope because of the way the injury had affected their loved one and the consequences to shared coping strategies previously relied on. This was only seen for relationships where family members lived together and it affected the use of family support that the relative used pre-injury. *“One thing [the injury] changed is just because obviously, before, I would go to John [Husband with ABI] but the actual support that I would get, it is different in some way....I don’t feel as confident in some if the decisions he would make, or his understanding.”* Katy, spouse

*“I think before his injury I used to talk to him [husband with ABI] about things.”* Liz, spouse

These spouses reveal how they have lost a previously used coping strategy due to their loved one no longer having the capacity to fulfil the role of a support partner. The marital bond has been changed in terms of the strength the couples used to draw from each other when faced with stressful encounters.

For some relatives, this feeling of a lost coping source comes from the perception that their loved one is no longer capable of fulfilling this supportive role as they once did. As a consequence, there was a feeling of wanting to protect their loved one from any additional stress themselves:

*“I think it’s changed slightly [coping style]. Maybe because before Camilla’s injury she was what I’d class as one of my best friends more than my sister. So I could always fall back on her advice and help. Whereas now, I don’t have that. She tries, she does, but she will be more likely to get stressed, so I don’t bring it home. So yeah, I’m more insular now.”* Olivia, sibling

This sense of the individual with ABI already having enough to cope with was also expressed by Tim when talking about coping with his own work and family stresses:

*“We have to plan a lot around it [ABI] which does put pressure on me in terms of trying to handle that and work which is quite difficult, but I don’t like to worry her about things like that so I try and deal with that...it makes her feel bad which you can’t do so you just try to avoid you know, do other things. You might mention some particular stressful thing at work or if the children have been quite hard work you’ll probably bring that up, but probably try to avoid discussing anything that causes stress because the injury, you know, it makes her feel bad.”* Tim, Husband

Katy also experienced this change in her natural coping strategy due to the limitations of her husband’s coping capacity after his injury:

*“Sometimes you just need someone else to talk about it and make sense of it all, but, it can be quite difficult sometimes when someone can’t really understand perspectives and things when you’re in a bit of an emotional state to then kind of have to be logical for them, when actually sometimes you need to be a little illogical...it’s hard when you’ve got to kind of not be able to just unload to someone because they’re gonna find it difficult.”*

For these relatives, they suffer a two-fold effect, whereby they have additional burden from taking on roles and duties that their loved one can no longer do, but also lose what would have been a readily available coping strategy in talking through life’s hassles with the person they live with. In order to protect the individual with ABI from feeling responsibility for this loss of support, relatives figure out different ways to cope with the problems they would have once halved with their loved one. Unfortunately, these different ways tend to be insular coping styles that load the responsibility heavily on the relative.

*Positive coping changes* The last subtheme to emerge was that of positive changes to coping with stress as a result of the ABI experience. This theme was mainly seen in relatives and

related to the recognition of new perspectives, and an increased resilience as a direct result of coping with the injury and the long-term effects experienced:

*“I’m much more patient than I have been before, because I have to be.”* Mandy, Wife

*“I think I’m more able to cope now than I would have been.”* Duncan, Father

*“I’m more tolerant, more tolerant. Tolerance has never been a big thing with me I might add.*

*No, I’m much more tolerant.”* Jeff, Husband

This sense of the injury experience giving strength and resilience to people, as well as better coping capacity is summed up by Patricia, whose son had an ABI:

*“Myself and my husband obviously did everything together and we do do everything together anyway, so I think that showed us our capabilities actually. That, you just don’t think you could cope with anything but when something like that happens you obviously can and you do, and then if someone else is going through something, maybe not similar, but it brings it back to you what Harry went through [son with ABI], and it makes you realise just how lucky we are that Harry is with us.”*

The accounts of positive coping changes show how relatives can find strength from their adversity, the recognition of which provides them with a new found resilience. Things that would have been sources of stress before the injury are dealt with more confidently, and they are more tolerant of things which don’t feel as concerning as they might have once done.

For one individual with ABI there was a positive response to coping now as a result of their injury experience. They felt the positive coping change for them had come from a different emotional response to stress, and the ABI rehabilitation they have received had helped them to slow down and consider things more:

*“Prior to my injury I had a short attention span. If something upset me I’d flair up. Now I’m more contained more, I’ve slowed down.”* John, individual with ABI

The paucity of reports of positive coping changes for individuals with ABI may be a reflection of a negative bias towards the challenges of their injury, which could feel more prevalent to them when considering coping behaviours. It could also be a reflection of how limitations brought about by the effects of the ABI (such as inflexible thinking, or problem solving deficits) may limit the individual with ABI from developing new ways of coping. The resilient feeling expressed by relatives was not equally expressed by individuals with ABI when asked about changes to their coping after their injury.

#### **4.1.2 Theme 2 – specific coping with ABI stressors**

*“It’s about your reactions to it. I suppose I’d just take more time to think about it, to deal with it in that way.”*

For some participants, if something stressful arose that was being caused because of the limitations from the ABI, then this elicited a different coping response than if it was a stressor unrelated to the injury. This was true for 7 individuals with ABI and 10 relatives, with 8 participants being unable to distinguish if they used different coping styles for ABI related issues (3 relatives and 5 individuals with ABI). This left 15 participants who felt their coping strategies did not differ for injury related stressors and unrelated stressors. The types of ABI specific coping was divided into three subthemes; *Finding another way*, *protective coping responses*, and *increased emotional responses*.

*Finding another way* This subtheme related to expressions of needing to find another way to deal with stress that was related to the ABI rather than an unrelated stress and was only expressed by relatives. This subtheme differs from the ABI coping changes subtheme seen in

theme 1 as these coping behaviours relate to specific responses to stressors brought on by the ABI, rather than general coping styles. For these relatives, another form of coping was needed for ABI related stress due to not wanting to upset the individual with ABI, so therefore they did not consider the individual with ABI as a potential avenue of support. The relatives' coping was more measured as a result, or involved wider family members and friends, instead of the individual with ABI.

As was seen in the first theme, relatives often took a protective stance in their actions, and were sensitive to adding any additional strain to the individual with ABI:

*"I might not talk to Jerry [husband with ABI] about his injury. Sometimes I do, but you can't keep pointing out that they are wrong, they are different, because that just destroys his self-esteem."* Liz, Wife

Margaret also recognised that she would share problems with her husband, but only if they were unrelated to his injury:

*"Well I guess we would talk about [a stress] together, but anything to do with Stuart's situation I might feel...I might go away. But a family thing we would talk through together, so it wouldn't be the same."*

Alice expressed more consideration for reactions to stress around her husband's injury, whereby she would step back more to make sure her coping response wasn't harmful:

*"I guess I wouldn't [rush in], I wouldn't be so...it's about your reactions to it. I suppose I'd just take more time to think about it, to deal with it in that way."*

Coping for these relatives was not necessarily changed as a result of the injury, as seen in theme 1, but if they needed to cope with an injury-related stress it evoked a different reaction from stressors unrelated to the injury. Relatives had a heightened awareness of

stressors related to the ABI and how reacting to these might have a negative impact on their loved one.

*Protective coping responses* For some participants they recognised that when a stress was coming from something to do with the injury, this created a different response in them to stresses that would arise from non-injury related issues. This different response would aim to protect the self and others from the impact of the injury deficits. This subtheme was seen in both individuals with ABI and relatives. For example, Pete felt that if he had an issue relating to his injury he would be less inclined to reach out for help from others, brought on by a combination of not wanting to be beaten by the challenges of ABI and not wanting to burden others:

*“I possibly might be more resistant to anyone helping me sort it out if it was to do with my injury. It’s more a point of not wanting to impact further on things, probably too markedly.”*

This increased sense of pressure to cope with injury related issues without additional support was felt by others too:

*“I think it would probably make me more stressed because it’s hard getting people to understand”* Emma, individual with ABI

*“I suppose it must evoke a different response. I suppose when it’s affecting me directly it has an impact on my family and others, so it’s important I get it right.”* Phillip, individual with ABI

For these individuals with ABI they have an awareness of the injury effects and attempt to cope with these on their own, either because they do not want to further burden family members, or they do not think people will understand. They subsequently contemplate



their coping responses in the context of whether it will increase the burden on their loved ones or not.

For Shirley, she developed new coping mechanisms to cope with her son's injury which was disconnected from other forms of coping. Her revised way of coping served as a protective measure to enable her to be able to deal with the emotional strain of the situation she was in:

*"I think it does [evoke a different coping style] because with other forms of stress I don't turn my emotions off. With Andrew [son with ABI] I had to...I had to shut down to be able to cope with his injury, but with normal stress that goes on. It's in an emotional way than unemotional."* Shirley, mother

*Increased emotional responses* The subtheme of increased emotional responses relates to the way participants felt stressors which were created due to the ABI evoked a more emotional reaction in them than responses to other forms of stress. This suggests ABI related stressors may demand different coping strategies, or be more detrimental to the wellbeing of those who have these specific emotional responses.

For one individual with ABI, Nikki, the impact of her injury means she thinks through her social interactions that could be inappropriate due to her injury effects, but that this then leads to rumination and increased stress:

*"When I go out in the evenings, doing whatever with people who aren't my family, I will go out, enjoy the evening, but when I come home I will go to bed and then I will wake up the next day and do my best to drag my memories through everything that could possibly have happened the night before or anything I could have said that wasn't okay. I think if I said too much or if I offended anyone. If I find something I'll feel awful for the rest of the day....I*

*don't know if anxiety is classed as stress, but when I think about the emotional problems that have been caused I get really down."*

For relatives, stress caused by the injury created a more emotional response for them than if the stress had come from something else, and as a consequence they felt more isolated in their coping efforts. Jeff describes why brain injury related stress is harder to cope with than other forms of stress:

*"It's there all the time. It never goes away. Even when you have a good day it's always there, that niggling little bit at the back of your mind, whereas other things these days I'm fairly laid back and don't bother me too much.....You're a bit on your own. I don't think anyone really knows, the fact the problem is there and the problem is never going to go away, and for that reason alone you can't really do anything."* Jeff, Husband

Neil describes how the emotional reactions to injury-related issues create maladaptive coping strategies and put strain on the relationship with his daughter:

*"The thing with the brain injury is you sort of know how the person would have been if it wasn't for the brain injury. And when you try to explain to that person that this isn't the right way they don't always realise that's not the right way, so they kick back at you until you lose it with them, because you are more frustrated with the situation than the person themselves."*

These accounts of specific responses to ABI stressors suggest that for some, they may not have experienced a general change in their coping behaviours, but when the stress involves the injury or injury effects, a different approach is required in the management of such stresses. For relatives, they may not use their loved one for coping support as they do not want to reveal the impact of the injury to the person who is creating the stress. Instead, coping with challenges from their loved one's injury is concealed from that person, meaning the individual with the ABI may not be aware of the true strain the family feels now the

injury is a part of life. For individuals with ABI, they may ruminate on their behaviours which creates a stress very specific to their injury. The emotional response is one of anxiety, feeling they cannot trust the way they function socially anymore, and are critical of their interactions with others as a result.

#### 4.1.3 Theme 3 – Coping across time

*“I remember thinking, you know at the time, if I can’t cope with it we’re all going under.”*

This final theme related to changes in coping style across the ABI journey. That is, differences seen for coping with the acute stage, the rehabilitation stage, and the chronic stage of the ABI pathway. For some participants, they did not feel they used any different ways to cope across this journey (7 individuals with ABI and 4 relatives), and for some they could not identify any coping changes when asked due to a lack of memory about coping with the acute stage (7 individuals with ABI and 5 relatives). For others, there were much clearer changes in the way they reacted to and dealt with the different aspects of the ABI event and subsequent consequences. This was reported by 7 individuals with ABI and 10 relatives. These time specific coping strategies could be separated into 2 subthemes: *Acute stage coping* and *longterm coping*

*Acute stage coping* For individuals with ABI, the very acute stage was often vague with a sense of not much active coping at all, and as they integrated into hospital life they started to realise the challenge their injury posed. Coping across time for individuals with ABI related to learning about their injury and focusing efforts on overcoming their new challenges. Here, Nikki describes how she felt she was functioning on instinct in the acute stage, but now this drive has gone as her journey has progressed:

*“I would say immediately post injury it was like my conscious brain stopped working and it was totally reliant on instinct....Like I fell out of bed and face planted the hospital floor because I was so desperate to walk to the bathroom and I was thinking ‘why can’t I do this?’ I didn’t even acknowledge the fact it was hard and I couldn’t do it, I just got on and did it...It’s like my instincts kicked in and said ‘we need to do this, get on with it’. Now however, the amount of times I look at myself and think I can’t be bothered.”*

This drive to improve in the early stages of injury was also seen by others, who describe a focus on tasks which would progress their rehabilitation and move them away from hospital as quickly as possible:

*“So what I did was just try and focus on doing anything I could to get better, and just focus on that. It was all encompassing really.”* Diane, individual with ABI

*“I mean in hospital it was almost like you tell yourself that you’re better. It’s if you believe you’re better then you’re better....if you put yourself in a negative mind set then you don’t really recover mentally, but if you think ‘yeah I’m fine, I’m fine, I’m back to normal’. I probably wasn’t. I probably left hospital quite early. I had focused my thoughts on getting out of that place”. Andrew, individual with ABI*

Some individuals with ABI remembered how detrimental their initial coping strategies were at trying to regain lost skills whilst in hospital, but that by gaining education around their injury deficits they learnt to work with them rather than against them:

*“Once you’re out of the acute stage and into the first part of recovery, I was just in crash and burn then.”* Says Philip, who was pushing himself so hard in the early stages of hospital recovery that he would develop spasms. He was referred to a sleep clinic who developed fatigue management strategies for him to follow in order to cope with the effects of his

injury. *“It did make all the difference and the consequence of that has been the most profound thing I’ve had to do as part of my recovery.”*

Gaining education about coping with brain injury also helped others with longer term coping after they had left hospital:

*“Finding out about the difference between sleep and rest, because I’d got a real bee in my bonnet about not sleeping in the day time, and I was making myself over tired, and then you [Headway] spent that time explaining about how it’s not about physically sleeping, and that mindfulness, and that made a big difference to me...I kind of flew then.”* Camilla, individual with ABI

*“It’s a journey. I think at the start of my journey I didn’t really know who I was. It’s a slow process but trying to use those coping strategies, I suppose to get away from stress, because I just can’t cope with it.”* Emma, individual with ABI

For relatives, coping changes across the journey related more to dealing with the initial shock of the injury event, followed by coping with the longer term challenges of the ABI effects. In the acute stage, a feeling of being on an automatic drive was common, with the addition of practical strategies to deal with the emotional stress and unfamiliar environment of the hospital:

*“You just accept it and get on with it, and you just do it I think.”* Barry, husband

*“So at the beginning you are literally going from moment to moment. I wrote lots of lists. I had tiny scraps of paper with all things crammed on. I even had things like ‘eat’ on my list, stuff like that. Literally just to try and get through the day.”* Hazel, wife

*“I think in the early stages I just turned my emotions off. I remember being quite robotic about it all and I turned my emotions towards other relationships like my parents, just to be able to cope with what I was going through really.” Shirley, mother*

*“I think you just go onto autopilot really, and because I haven’t got family around I did have to get into a routine. I didn’t have any choice other than to get on with it.” Katy, wife.*

This feeling of having no choice and holding the family together in the early days was echoed by another spouse:

*“I remember thinking, you know at the time, if I can’t cope with it we’re all going under. And I just sort of took a deep breath and just got on with it. There were times I remember sitting in the dark in the kitchen at night time, cold in the night, just crying about it.” Liz, wife*

Some relatives used more distraction based and practical strategies to cope with the initial emotions of the acute stage:

*“I would go to the day room and I was cleaning the microwave, cleaning the sink, cleaning the cupboards. I just had to be busy. And I kept a diary. I had a folder and it was a way of controlling where everyone was, who was at work, who did that....and that was a kind of security, you know?” Faye, mother*

*“My way was always look to the next step...we were always asking “what’s the next stage? Where do we go? So it’s determination and always asking what’s happening, not now, it’s what’s happening next. So forward thinking, that’s how we coped with it.” Neil, father*

*Long term coping* As the journey from hospital to home progressed, some participants were able to recognise that coping behaviours were required to change to accommodate the different demands of each stage. For some, they even felt the hardest challenge was learning to cope with the long-term management of life with ABI, as families started to re-integrate

into everyday life away from the hospital environment. Coping behaviours shifted as the journey progressed from the acute stage to longer term, and how relatives particularly could recall how reactions to their loved ones' ABI had changed across that time. Neil describes how it can be hard to remain patient to the ABI effects in the long term phase after the injury:

*"When the accident first happened you put everything down to the injury, so you're forgiving shall we say? But as time goes on you become less and less forgiving, because you are now sort of, is it the injury? Or is it just her? So you still have sympathy for the injury and for the person involved, but you become less and less forgiving of it."* Neil, father

Shirley said she switched off her emotions in the acute stage, but that as her son's recovery progressed her coping changed to one of emotional expression and peer support:

*"I think when Andrew was in recovery though, when he was in rehabilitation, he would get quite short with me, and I felt at that stage I was very emotional and I felt very hurt. I remember talking to another lady I'd met in intensive care whose son had been in there and I remember sobbing and sobbing on the phone"*

When Shirley's son was discharged from hospital and went back to his home, she was able to distance herself from the injury and use routine to find a normality in which to cope:

*"When Andrew left hospital I was able to go back to work and try and get on with my own life and try not to think too deeply about what he was dealing with...I tried to get back to some normal sort of life again."*

Others talked about the shift from the initial struggles to living long term with someone with an ABI, and how they had to adapt to their new family environment:

*"In many ways it was a lot easier when he was very incapacitated and couldn't do very much in the early days, you know, for it was easier to do the dealing with things and sharing*

*responsibility because he didn't take any responsibility then. So yeah it's actually this sort of, moving it back to more of sharing, and I think I am a bit of a control freak so it's quite difficult for me as well."* Mandy, wife

*"I think initially I suppose I wanted to cope the way I had previously coped, by thinking, by discussing things and going to him [Husband with ABI] with the problem. But slowly you realise you have to change the way you cope with stuff."* Katy, wife

*"It starts to normalise to a degree. I sort of reverted to the way I once lived and he didn't, so you know, sometimes I find it quite difficult, but it's getting better."* Joanna, wife

This realisation of having to reassess coping strategies in the long-term due to the reality of how life had changed was also expressed by individuals with ABI:

*"I think whereas before, the first 18 months, I would have coped with stuff in the way, 'okay this is for the short-term', just sort of deal with it. If it happens and knocks you back a bit it doesn't matter, what doesn't kill you makes you stronger. Whereas now, I know that's not the case. What I've got is where I am and where I'm gonna be. Have I changed the way I cope with things? I guess I don't cope with it in such a positive way as I would have done. I guess I try and cope with something that doesn't feel natural to me. It's not who I was for the last 43 years sort of thing. So from that point of view it's changed."* Pete, individual with ABI

As with the more acute stage, gaining education about coping with brain injury also helped others with the longer term management of the ABI effects after they had left hospital:

*"Finding out about the difference between sleep and rest, because I'd got a real bee in my bonnet about not sleeping in the day time, and I was making myself over tired, and then you [Headway] spent that time explaining about how it's not about physically sleeping, and that mindfulness, and that made a big difference to me...I kind of flew then."* Camilla, individual with ABI



*“It’s a journey. I think at the start of my journey I didn’t really know who I was. It’s a slow process but trying to use those coping strategies, I suppose to get away from stress, because I just can’t cope with it.”* Emma, individual with ABI

These reports of coping behaviours and how they changed along the rehabilitation pathway show how some people adapt coping behaviours along with the changing presentation of ABI life. For relatives, they were able to recognise their utilisation of unique coping strategies to deal with the initial trauma of the injury event, yet have needed to develop different ways of coping in the chronic phase due to the persistent nature of ABI coping. For some, they found the acute stage easier to cope with than the longer term stage, when the reality of ‘this is how it is now’ begins.

For individuals with ABI, coping with the transitions from early injury rehabilitation to long-term management was eased by gaining information around how to manage their ABI limitations effectively. Those who could re-evaluate how they viewed their changed circumstance to accommodate their injury appeared to feel more in control of their injury limitations and presented as coping more confidently with these challenges once they had educated themselves on relevant techniques.

#### **4.1.4 Discussion of thematic analysis for coping**

Specific changes to coping behaviours after ABI have not been investigated extensively in the literature. Research to date has been concerned with the relationships between the types of coping effort (namely emotion focused versus problem focused) and psychosocial outcomes such as quality of life and community reintegration (such as Karlovits, & McColl, 1999; Tomberg, Toomela, Pulver, & Tikk, 2005). The results of this section of the study show how coping behaviours can be changed after ABI for both the

person with the injury and their family members. Furthermore, these changes can be forced by the specific challenges resulting from the injury neuro-sequelae.

Theme 1 represented ‘coping changes’ and highlighted the impact ABI can have on a person’s usual way of coping with stress. Sometimes these changes were brought on by the experience of the ABI itself, and sometimes it was because of the limitations brought about by the injury, creating either positive or negative changes to tried and tested strategies the participant used previously. Currently minimal literature exists which examines the actual change in coping as a consequence of ABI. Theme 1 suggests this is an area worthy of further investigation due to the way ABI can interfere with a person’s previously used coping strategies. These new limitations to pre-used coping behaviours can be brought on by specific ABI deficits (such as a reduced ability to problem solve), or as a reaction to living in the aftermath of a traumatic event. Research efforts would be warranted so we can understand the impact of these coping changes and whether individuals with ABI would benefit from support to develop new strategies which take into account the way their injury has affected the accessibility of previous coping behaviours.

A subtheme which occurred in theme 1 was that of ‘positive coping changes’. It could be interpreted that for many participants their coping ability has actually been enhanced as a result of the injury. Predominantly an outcome for relatives, a number of participants felt more confident in their coping ability as a result of surviving the trauma of the ABI event. A sense of being able to deal with any life eventuality was harnessed in these participants, and the lessons learned as a family resulted in a stronger, more resilient unit. The act of taking on more self-care practices left spouses, in particular, better equipped to deal with day-to-day pressures and persistent caring duties. This resilient feeling may in turn produce more effective copers due to their increased self-efficacy towards coping, as it has been found

previously that greater self-efficacy is linked with more desirable coping outcomes (Brands, Köhler, Stapert, Wade, & van Heugten, 2014).

The subtheme of ABI coping changes highlights the impact of ABI on how someone may choose to cope post-injury. Coping changes relating to the ABI were only seen for relatives who lived with the individual with ABI. This was primarily spouses with one sibling who live with the individual with ABI in a similar domestic set up to a marital one. They shared household tasks and were each other's main source of day-to-day support. It has been suggested multiple times in the literature that spouses experience more strain after ABI than do those in other types of familial relationship (Burridge, Williams, Yates, Harris, & Ward, 2007; Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011), and that spouses in particular are at risk of losing their main source of emotional support when their partner has an ABI (Gervasio & Kreutzer, 1997). It may be, however, that it is the function of this relationship that is more important. It has been suggested that parents fair better when expected to take back a caring role for their child, even when these duties had been relinquished (Kreutzer, Gervasio, & Camplair, 1994) and that this explains the increased burden reported in many studies comparing the relationship status of carers (Elbaum, 2019). For other relationship types, it may be the change in the expectations created when the relationship was established that it would have a level of equality, rather than something unique to spouses. As this was only prominent in co-habiting relationships, it is worth investigating the impact of coping changes for relationships which are expected to be more balanced than child/parent ones, such as sibling and tertiary relationships, e.g., cousins. By understanding the causes of the increased stress seen in spouses we can make sure less common co-habiting family set-ups are not neglected just because they are not seen as presenting the same risks as marital ones.

Theme 2 highlighted the specific coping reactions that are unique to stressors which are related to the ABI, both for those with the injury and their relatives. Using specific coping strategies for ABI stressors may be representative of ‘fitting’ the coping style to the situation, as described by Lazarus and Folkman (1984). When participants reported realigning management techniques for their ABI effects with a newly learned style they felt positive outcomes from this. These findings support those of Kato (2012), who found the ability to stop one ineffective coping strategy in place of selecting a more effective one was associated with better outcomes on wellbeing.

The positive consequences to long-term coping seen by individuals with ABI who could integrate self-management techniques of ABI deficits into their routine is in line with experiences reported elsewhere in the literature showing better adjustment outcomes are present when individuals can change and adapt to the different challenges along their rehabilitation pathway (Shotton, Simpson, & Smith, 2007). More research is needed to decipher if the ability to change coping styles is more important than the style itself. For example, if an individual with ABI is accustomed to using an active coping style such as problem solving, but post-injury had encountered issues with executive functioning, the ability to adjust to a new coping strategy that is accessible to that individual could be more important than whether the strategy is emotion or problem focused.

Theme 3, *coping changes across time*, showed how peoples coping behaviours can change across the rehabilitation pathway, with different styles being used during different stages of this journey. These findings do not support those which have suggested people do not change their coping strategies across time (Donnellan, Hevey, Hicky, & O’Neill, 2006). It has been seen that stress increases after the first three months after injury (McKinlay, Brooks, Bond, Martinage, & Marshall, 1981), and these results suggest it could be due to the

‘autopilot’ system of coping coming to an end as the initial trauma is processed, and the realisation of life changes becomes apparent. For some participants, coping with the chronic stage was more difficult than the acute trauma due to the enduring nature of day-to-day struggles. These reports are in line with others in the literature which show the impact of ABI endures long after someone is discharged from hospital (Andelic et al., 2018; Wood, & Rutterford, 2006). As interventions for individuals with ABI and their families tend to focus on early parts of the ABI pathway, families are at risk of a long-term neglect of the support they need to manage a life after ABI.

#### **4.2 Family changes**

The research concerning the impact of ABI on families has often revolved around how much stress and burden main caregivers have been placed under (Kreutzer, Marwitz, & Kepler, 1992; Ponsford, Olver, Ponsford & Nelms, 2003). The present research aimed to ask members about how their family may or may not have been changed by the injury and allow for both positive and negative aspects to be expressed. Due to the literature documenting the impact ABI can have on families, it was expected that changes to the family unit would be reported, with an aim to answer research question one: *does ABI change families and if so, do family changes impact on adjustment and does this differ for the individual with ABI and relatives?* The key issues relating to what these changes were, what they meant to the family, and how they differed for individuals with ABI and non-injured family members were explored. During the semi-structured interview, participants were asked “Has the injury changed anything for you as a family?” If required they were asked to provide more details on points they raised or to try to think of any specific aspects that were relevant for them. Here follows the themes which emerged across the interviews.

Three main themes are presented from the interview data for both individuals with ABI and their relatives: *relationship changes*, *functioning changes* and *role changes*. Figure 3 shows the progression of these themes from initial annotations to final coding. Of the 40 interviews, only five said they did not feel there had been a change to the family as a result of the ABI (2 relatives and 3 individuals with ABI). It is important to note that although quotes have been used to capture the essence of the family change, this does not aim to imply the relationships have either faltered or excelled in comparison to each other. Rather, the expressions of the participants is specifically about family changes expressed and may appear positive or negative for that person, but the relationship or family may hold other positive or negative attributes which were not discussed here which are independent of the ABI and may mediate some of the specific ABI changes which have taken place.

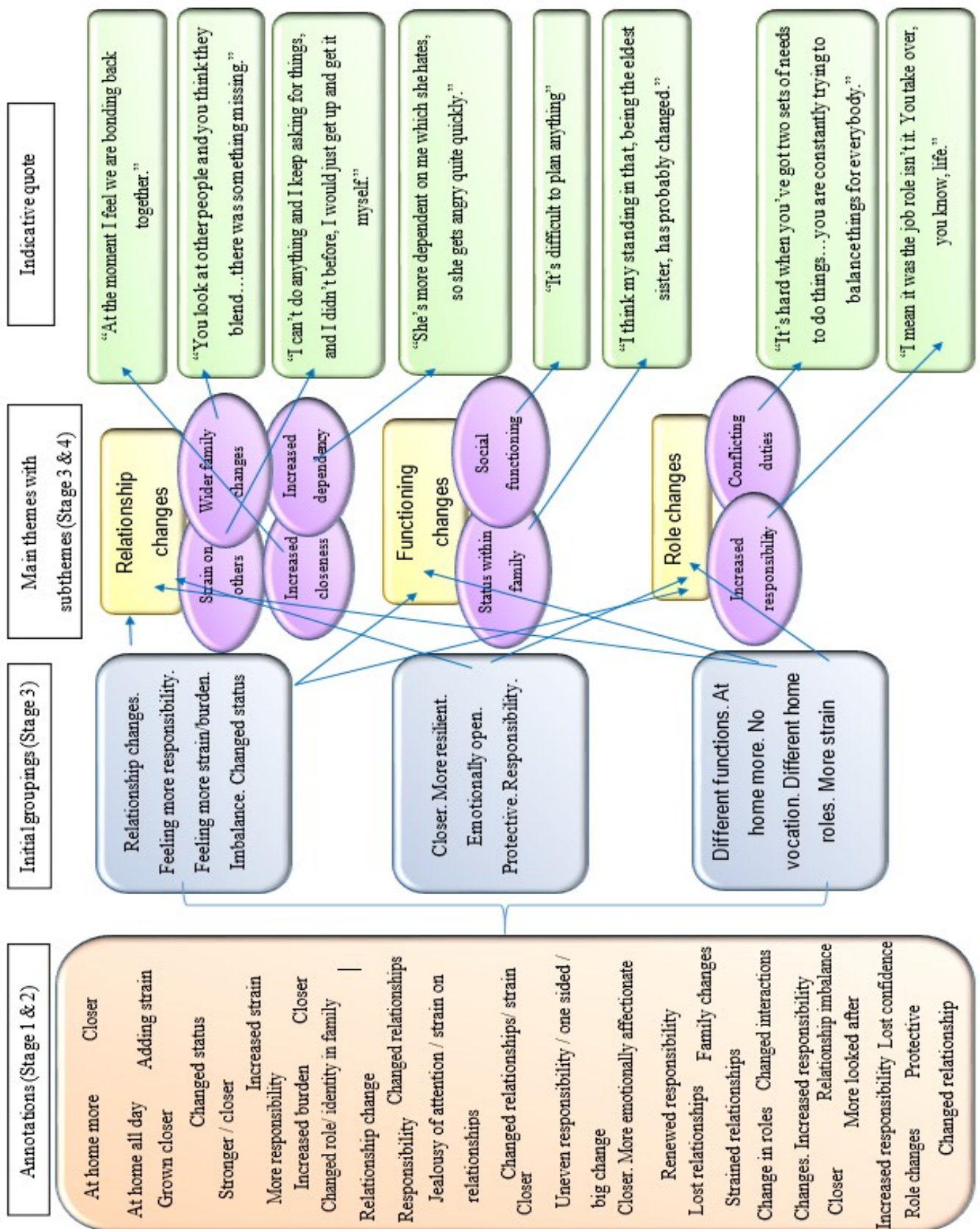


Figure 3: Thematic coding of family change data using the four stage framework of Bryman (2008)

Herein the results have been separated by participant (Individual with ABI versus Relative) to highlight the differences between the reports of family changes between the two groups. As outlined in the analysis process, initial thematic analysis did not separate the interviews by participant type so as not to assume differences between the groups. However, as the themes emerged it was clear that for some aspects of family changes there was a distinct difference between whether the person had sustained the injury or whether they were related to them. Therefore, it has been presented as such here to allow these differences to come through.

#### **4.2.1 Theme one – Relationship changes**

*“It’s completely changed my relationships with all my family members, individually”*

The theme of relationship changes refers to expressions of changes to specific or family wide relationships as a result of the brain injury event or its effects. This theme was created due to a shared ‘feeling’ between participants of how relationships between family members had been changed. For some it was an expression of how they felt they were viewed by other family members after the injury, whereas for others it related to different interactions that played out between members. This feeling of relationship change did not relate to any particular activities or processes, but more a sense that the relationship had changed in some way from the way it was before the injury occurred. This theme was present for 23 of the 40 interviewees (15 of the 21 individuals with ABI and 7 of the 19 relatives).

*Relationship changes – Experiences of individuals with ABI* Changes to specific relationships within the family unit were expressed by 14 of the 19 individuals with ABI. Two subthemes were further identified based on the expressions that related to this theme of relationship changes; *strain on others* and *increased closeness*. The expressions of individuals with ABI suggest that for the majority of these participants, the experience or



effects of their injury had extended beyond themselves as the patient to other family members, either directly or indirectly. These findings fit well with the seminal work of Brooks (1991) who brought about the concept of the ‘head-injured family’.

*Strain on others* This subtheme for individuals with ABI reports the acknowledgements of the impact the injury has had on people around them. For some, the change in relationship is seen as separate from themselves, almost an observation of how certain family members have reacted to the injury. For example, Liam doesn’t feel so much a change in feeling about his own relationship, but recognises there have been changes for his partner:

*“I think it is fine except Carly gets frustrated now because I can’t do anything and I keep asking for things, and I didn’t before. I would just get up and get them myself.”*

Anthony also recognised that his loved ones were interacting with him differently than he would expect them to had the injury not occurred. This change in relationship with his grown-up children felt like an unnatural addition to the way their family functioned:

*“My son’s, they’ve got a wary eye on me, which they didn’t have in the past, which is a bit wrong.”*

For other individuals with ABI, there was a sense that family members treated them differently post-injury, and interactions were more strained as a result:

*“It’s completely changed my relationships with all my family members, individually”* – Nikki

*“My husband loses his temper a lot”* – Jackie

*“My relationship with my dad and my step-mum, if anything I struggle a bit with frustration because I still have mood swings and anger outbursts. I’m quick to snap and I never would have done that previously.”* – Camilla

These changes to family relationships show how an individual with ABI's relationships can be affected even when they feel as though these changes do not come directly from themselves, but more from how others interact with them as a result of their injury. This was sometimes seen as a result of the increased burden put on some family members, with this burden being recognised by the individual with ABI. For others, it was due to how family members were regarding the individual with ABI's abilities after their injury, and that family members were more concerned for them as a result of the experience of going through ABI. This disconnected relationship change could be explained by the difference in experience that family members had of the injury event compared to those who have had the injury personally. This could be particularly prominent if the injury event had been traumatic, which might leave more of an impact on family members than it would for the patient themselves, as described here by Harry. He recalls how he was protected by the full trauma of his accident due to the severity of his injuries, whereas his family weren't:

*“Oh yeah they all see me differently. You can tell.... When we're here [place accident took place] and my dad's driving and stuff, he'll point out all the stuff he remembers when he rushed down like. You can tell, they're not going to forget about stuff like that. Like it was a lot worse for them than me, kind of thing. Because I was just sleeping through the traumatic stuff.”*

*Increased closeness* The second subtheme showed how not all relationships had been changed negatively by the injury. In fact, more individuals with ABI reported a positive impact on relationships as a result of the injury than did those who felt it had been more negative (8 positive expressions versus 7 negative). The positive feeling mainly came from a sense of being closer because of the injury. For some this was a closeness between themselves and a specific family member:

*“If anything me and my daughter are closer” – Barry*

*“My relationship with my sister has probably grown closer. We were always close anyway, but it’s probably made us closer” – Camilla*

*“Before we used to fight like cat and dog. Now she can’t do enough for me. I think that’s a positive” – Chris, talking about his sibling*

One spouse even attributed his injury to the rekindling of his lost marriage:

*“Prior to my injury [my relationship] wasn’t good. My wife split, gone our separate ways, going in different directions. Since my injury that’s kind of started to come back, which is good. I see it as a positive. If I didn’t have my injury we would have been divorced by now” – John*

For others the feeling of closeness was extended to the wider family rather than a specific dyadic relationship. These expressions were more general and referred to the family unit, and not just a co-habiting relation:

*“It’s probably brought us a lot closer together” – Jerry*

*“I get in contact with my family more. I didn’t really get into contact or anything [before injury], but then after uni I was like ‘I should of like, they’re my family like’, so I’ve got in contact with them a lot more recently.” – Harry*

*“I think we’ve become closer. We appreciate how different we all are.” – David*

Whether someone experiences specific relationship changes on a dyadic level, or whether they feel general family relationship changes could be due to how the interview question was interpreted. For some, responding to a question asking whether anything has changed for them as a family could prompt a general response as they were not asked to

reflect on specific dyadic relationships such as spouses or parents. However, other people may have focused on a prominent relationship to them, such as the person they live with.

Therefore, the reports of specific relationship changes versus general family unit relationship changes could be an area that warrants further investigation to ascertain the extent to which people feel relationship changes and what factors dictate the perspective of specific relationship changes to general ones. It could also be that those who expressed specific changes did so because these changes were more important to them and the consequences of these changes may have had a bigger effect on their day-to-day lives than general family relationship changes, or that the changed dyadic relationship was particularly important to them and therefore this became the focus of the response to the interview question.

*Relationship changes – Experiences of relatives* As with individuals with ABI, relatives also felt changes to specific relationships due to the injury, but the changes were expressed in different ways. Changes for relatives could be further categorised under three subthemes; *Increased dependency, wider family changes, and increased closeness.*

*Increased dependency* This subtheme relates to changes in relationships due to the effects of the ABI, and the consequences felt by this for the family member. The way relatives expressed these changes suggested an increase in dependency on them that created a more strained relationship between themselves and their loved one with ABI:

*“Camilla and mine’s relationship changed. She’s more dependent on me which she hates, so she gets angry quite quickly. I find I’m more tired as I don’t realise I’m doing things to compensate for her.”* – Olivia talking about her sibling relationship

*“You’ve got all the disadvantages of living on your own, and you’ve got all the disadvantages of being married if you like, but none of the advantages either way it seems.”* – Jeff talking about his marital relationship

Katy describes how the effects of her husband’s injury have resulted in a change to the sharing of responsibilities and decisions that they once faced together:

*“I feel more responsibility, and it’s quite difficult when you’re in an emotional place because your husband you want to be able to go to.”*

For these family members, the reality that they now had to consider their loved one’s ABI and support the deficits of it meant that they had a changed relationship with that person. There was an additional strain created by the relative having to either compensate for, or manage, the ABI effects and the different behaviours that brought to the relationship. The increased dependency of the individual with ABI created an imbalance in the relationships between them and their relative.

*Wider family changes* The first subtheme of increased dependency was primarily expressed as dyadic relationship changes. The increased dependency was felt personally rather than something shared as a family unit. However, the subtheme of wider family changes relates to expressions by relatives about family relationships beyond themselves and the individual with ABI. Barry describes how his wife’s injury changed the way she connected with her grandchildren:

*“They [grandchildren] are all good with her, they love her. But sometimes she doesn’t respond to them, and they find it strange...you see other people and you think, they blend, but she didn’t. She loved them and she’d hold them, but there was something missing. You know, that little bit.”*

The family reaction to the stress of the injury occurrence had caused fractures in the family unit independent of the individual with ABI:

*“I’ve had a big fall out with one of my brothers really because his attitude to my dad’s injury is completely different to mine... he just hasn’t bothered. He’s just carried on his selfish pursuit of his own attainments in life and he’s not, he’s just not that bothered, which is sad and I’m not like, I can’t forgive him, that’s not a very Christian thing to say but, forgive forget but, it has, yeah it has changed.”* – Tim, son of individual with ABI

*“We all got very stressed and fragmented really. I certainly don’t think it brought us together, you know, because we just couldn’t cope with it....And my husband and I got very distant. Whatever I did was wrong, whatever he did was wrong. We couldn’t be in the same room....yes I definitely think we just fragmented to be honest.”* – Faye, Mother of individual with ABI

These wider family effects show how the reactions of others to the individual with ABI can affect the relationships of those around them. There is an indirect connection between the injury and the family impact. The individual with ABI has impacted on family relationships even when the relationship is not with themselves, as it is in spite of their injury. The individual with ABI may even be unaware these relationship changes have taken place, meaning they do not experience the same family impact as their relatives do, and could be protected from the full extent of the injury impact as a result.

*Increased closeness* As with individuals with ABI, there were also positive relationship changes attributed to the injury, although these were not as common for relatives as for individuals with ABI (2 relatives versus 8 individuals with ABI) and both were from parental relationships rather than spouses. For Patricia, she could recognise a greater unity that the

family has through their shared experience of the injury, but also an appreciation of the time they get with Harry, who sustained the injury, as the outcome could have been so different for them:

*“It did, and does, and has made us all closer... as a family well, I think it brought us all closer together...and we are all very much aware of, we haven’t forgotten what happened to Harry....and when he’s with us it’s lovely.”* – Patricia, mother of individual with ABI

For Shirley, the increased closeness with her son comes from him being more emotionally open with her and her husband:

*“I’d always told Andrew I loved him, but he always responds now and tells me that he loves me, and that hadn’t, that wouldn’t have happened before. As an adult my husband would have found it hard to tell him that he loved him. I think he was able to show his emotions more after it.”* – Shirley, mother of individual with ABI

Shirley goes on to explain how her adult son had become quite separate from the family, but that the injury had brought them together:

*“Before the accident Andrew kept his friends very much to himself. He had a life in [his town], he had moved out, a life that we didn’t really know much about. But during his stay in hospital we got to see his friends and we loved them all, and I don’t know why he had kept them from us for so long because we found them very, very, supportive and it was great to spend time with them. But in that way, that was such a good thing that happened.”*

Increased closeness as a result of ABI is more likely to be felt by individuals with ABI than their relatives. For the mothers in this subtheme, it is interesting to see that they do not have to fulfil a carer’s role for their adult children. This may be why they can recognise

the positives that have come from their experience more, whereas family members whose relative with ABI is more dependent on them may feel this increased closeness as increased burden instead. For these mothers, seeing their adult child survive ABI and go on to live independent lives has created a gratitude for time spent with them, and cherished family interactions.

Within this theme there were four dyadic pairs present. That is, an individual with ABI expressed a relationship change and so did their relative. However, there were only two dyadic matches, whereby the two members of the dyad expressed the same kind of relationship change. These were both from a parent / son relationship, with one dyad expressing the ABI brought the family closer, and the other dyad expressing the family relationships had become more strained because of the ABI. For the other two dyads in this theme, the individual with ABI felt the relationship change had been positive, with an increased feeling of closeness to their relative. Whereas the relative in the dyad felt an increased strain from the caring duties that the relationship change had brought as a result of the ABI. Therefore, although relationship changes can be expressed within the same family as a result of ABI, the connotations of these changes remain very individual. If individuals with ABI experiences are presented in comparison to their relatives on a group level, the specific dynamics of individual relationships are lost as the experiences of the individuals making up the dyads are more often than not in contrast with each other.

#### **4.2.2 Theme two – Functioning changes**

*“The fundamental difference is that I’m much more active and much more flexible about the times I’m able to enjoy time with my family.”*

This theme relates to changes within how the family unit functions and behaves as a result of the injury. This may have been changes to activities undertaken, a change to how the



family functions socially or domestically, or how family members are viewed within the family unit. These were expressed as both negative changes and positive changes for both relatives and individuals with ABI and were expressed in 13 of the 40 interviews (6 of the 21 individuals with ABI and 7 of the 19 relatives).

*Functioning changes – Experiences of individuals with ABI* For individuals with ABI, functioning changes mainly related to how they felt they were viewed within the family unit, or the role they felt they played in how the family worked. The two subthemes of *status within the family* and *social functioning* were identified.

*Status within the family* For these individuals with ABI, there was a feeling that the role they played in the family unit had been changed and the family functions that they helped facilitate pre-injury had been affected as a result. For Camilla, she felt her very ‘rank’ in the family had been changed because of her injury, and that the relationships with her siblings had not been affected equally. The relationship with her younger sister had become stronger and she was appreciative of the support her sister gave:

*“I’m the eldest of three. I think my standing in that, being the eldest sister, has probably changed. My relationship with my youngest sister probably has grown closer. I would say that I rely on her a lot more. She would argue and say she doesn’t do half the things that I think that she does, but, we were always close anyway it’s probably made us closer.”*

However, Camilla did not feel appreciative of her other sister who dealt with her injury related challenges in a more derogatory fashion. Although not explicitly said, it could be telling of a sibling relationship that was not as well-bonded pre-injury as that which she shared with her youngest sister:

*“I think I need to perhaps tackle the relationship that I have with my middle sister a bit. She treats me as somebody who’s still, I think I’m clawing, I’m starting to claw my independence back a bit, whereas she’s still trying to, she’s still treating me that I’ve got, that I can’t do things, and is very quick to take over things and that, and is quick to explain to people when I’m out and about that I have an issue, that I have a health problem, whereas, I would perhaps if I was on my own attempt to deal with it a different way, or gloss over it or, muddle through a bit more. She is a bit more ‘oh she’s had a head injury’ sort of thing or ‘she’s a bit slower’ or, she’s quite abrupt about it. Which I didn’t, perhaps didn’t bother me perhaps a year or six months ago because it wasn’t that, but now it’s starting to grate a little bit.”*

Other individuals with ABI had recognised that they used to play an integral role in orchestrating specific aspects of family life, but post-injury this was no longer the case so family functioning had been affected as a result:

*“For the family I was the social secretary, so everything we’d do would stem from me....So the kids and family, we probably did get quite insular really, and we didn’t do as much.”*

Diane

*“I was very much the alpha male before. I used to handle all the official work. I hide away in fact from official as much as possible. Which was difficult at first because it was so much against my nature.” – Carl*

*Social functioning* These expressions by individuals with ABI related to changes to the way they experienced family life after their injury. For example, Chris did not identify changes within the relationships with his parents as such, but felt the way they treated him had impacted on what he would choose to do:

*“I mean if I went out the door without telling my mum and dad, and they wanted to know where I’m going and why, and so I just don’t bother, don’t bother with the hassle, but that’s life. That’s how it is now.”*

For Chris, he was resigned to living in a way which satisfied the needs of his parents to feel he was safe. Even though he lived independently he still considered them in his day-to-day life. He further explains how this consideration comes from the recognition that his parents have been through a traumatic time and that he feels his injury was his own fault:

*“Now, I know that everything I do has to go through my parents to say, I have to get their permission to do more or less anything. And they will say yes it’s good, or no it’s not, and if it’s not I won’t do it. But I know even now, because they’ve been through such a fright as well, because they’ve seen me in hospital and whatever, I know that the worst thing that I would have to do would be to frighten them again if you like. And I know everything I do has to go through them because even now I have to phone them when I get home every night, and if I don’t phone them then they’ll phone me by six o’clock or whatever, and I know that I give them such a fright.”*

For Max, he felt his balance of activities had altered and he did not provide the same value to the family as he once did. Organising social time with his wife was difficult due to the effects of his injury and the loss of his career meant he didn’t feel he contributed as much to family conversations:

*“I suppose you get used to going to work, coming home, they are two very, very definite slices of the day. Whereas now I only have one slice. I don’t have anything to talk about. I get tired suddenly, so making plans is a little bit here and there you know? It does put strain on the family. And when Hazel goes out and works, and I do bits of gardening but they’re local*

*and they're low key, I don't have anything to talk about. I struggle with going out, I get tired suddenly, so making plans is a little bit here and there you know, hit and miss. ” – Max*

For one individual with ABI, the impact of the injury resulted in positive social functioning changes, with a mindful perspective and more quality family time being available due to a forced early retirement from his career:

*“I'm at home, that's fundamentally different and so I've changed my outlook on life since my injury and what's really, really important is my family and friendship groups. I actually spend as much time as I can with them. The fundamental difference is that I'm much more active and much more flexible about the times I'm able to enjoy time with my family.” –*

Philip

*Functioning changes – Experiences of relatives* Family members on the whole felt functioning changes had been negative after the injury. This negativity came from a feeling of the family not behaving in the way it used to as a consequence of the effects of the ABI needing to be considered and that they were more socially restricted after the injury. As was seen with individuals with ABI, the challenges the injury effects brought to the family sometimes stifled normal family practices. Some relatives were able to identify how they felt differently about how they functioned socially as a direct result of the injury effects:

*“It's quite difficult to plan things because I never know quite how he's going to be at social events....I find it quite stressful. He'll say 'oh yeah we'll do things' but in the back of my head I'm thinking, you know, he might not be up for it or we'll get somewhere and he won't be able to cope with it, you know,” – Hazel, Wife*

*“We were quite social, we'd go out quite a lot, but Jerry gets tired, we don't go out in the evenings now...In some ways I feel we missed out a chunk of our lives.” – Liz, wife*

Other relatives felt they could not function with as much freedom as they would like due to the caring responsibilities now put upon the family. They had compromised on how they wanted to live their lives as the ABI had to be considered in their future plans. For these relatives, there was a sense of a part of family life that was now missing:

*“For us, it was losing what we thought was gonna be an easy part of our life now, you know. That if we wanted to go away for a few days we could just do it. We didn’t have to think we would need to be around for the family.” – Rosa*

*“Me and my wife, we don’t get a break anymore, because she’s at home all the time. You’re confined to come back at a time, because you know she’s on her own.” – Neil*

As with individuals with ABI, only one relative felt a positive functioning change as a result of the injury. This relative was the dyad of Philip, the individual with ABI who also felt a positive functioning change, and his wife Debbie. The injury had resulted in Phillip taking early retirement, which meant an increase in social time for the family:

*“Priorities have changed. Whereas work was a priority, now having quality time together is a priority. That’s better.” – Debbie, wife of Philip*

Others recognised that decisions about their own life no longer concerned just themselves, but their relative with ABI too:

*“I’ve got to focus on getting my dad better. Even in the future, wherever I wanna move to or whatever I wanna do in life, I know I want to...Dad will have to be with me.”- Tim*

Only two dyadic pairings were present in the functioning changes theme, but both of those matched in terms of how they were expressing these changes. Both dyads were spouses and both expressions referred to changes in how time was spent as a family. One dyad felt

this was a negative change, as the effects of the ABI meant social planning was difficult and unpredictable. The other dyad, however, felt the injury had allowed for new perspectives to be found as a family, and quality time together was now a priority.

Although functioning changes were expressed in 13 interviews, it does not appear that these functioning changes are felt for every member of the family concerned. On the whole though, functioning changes were felt negatively by most participants and could signify an area of importance for the individual who is feeling these changes, who may feel additional isolation or burden as a result of the strain not being shared or acknowledged amongst other family members.

#### **4.2.3 Theme three – Role changes**

*“Well I feel for me I’ve taken on more or less everything.”*

The third theme related to a change in role for people within a specific relationship or as part of the family unit. This was seen in 9 of the 40 interviews (3 of the 21 individuals with ABI and 6 of the 19 relatives).

*Role changes – Experiences of individuals with ABI* The family changes for individuals with ABI which related to role changes were not about a role change for themselves, but more a recognition of the role change for their relative. This was only expressed by spouses and was not always seen as detrimental to the family, with some spouses feeling the change had benefits:

*“He’s taken on some of the roles I used to do, so that’s changed. I used to become a bit in control of everything, other than what he did at work, and then I had to accept I couldn’t do everything, and he took over some of the things, so that’s stayed the same actually, so that’s changed still. Which I think is actually a good thing.” – Diane*

Individuals with ABI that felt these role changes had been able to acknowledge that their relative had taken on aspects of family life that were once their responsibility. For some this meant re-establishing new responsibilities within the home due to their changed circumstance:

*“I don’t work anymore so I’m at home all day, which means I take on certain things, more so than I would have done before, but that’s neither here nor there. Sometimes Alice has had to step up to things that she wouldn’t have wanted to do before, like all the driving. It changes the dynamics because I think you build your relationship based on your strengths and weaknesses that you are when you meet, and these, and some of the things that I was and how I like to do things and how we function we can’t do anymore.” – Pete*

*“Well from day one my Wife’s had to take on a completely new life, and she did very well.” – Anthony*

For these individuals with ABI, their loved ones had taken on different or additional roles within the home and this was acknowledged. It was not expressed as a bad thing for them and was felt with appreciation and acceptance for the way things had to be.

*Role changes – Experiences for relatives* Whereas individuals with ABI recognised and appreciated the role changes for their relatives, for relatives themselves they felt the additional strain and responsibility that taking on these roles had brought. This main theme could be divided into two subthemes: *Increased responsibilities* and *conflicting duties*.

*Increased responsibilities* All role changes which resulted in an increase in burden were felt within spousal relationships, rather than parental or sibling ones, highlighting how the usual expectation of marital partnerships had been disrupted by ABI:

*“Well I feel for me I’ve taken on more or less everything.” – Margaret*

*“Simon was the main bread winner, and I don’t really see how that’s gonna pan out cause I don’t really see him being able to go back and be doing, what he was doing. So at the moment I’m the main bread winner.” - Hazel*

*“Tasks we would have split between us more, Pete will be doing more because he’s at home during the day. And there’s some things I’m doing more of because it’s harder for Pete to do them, like the driving.” - Alice*

*“I’ve taken over all the organising, all the family things I organise. I used to do a reasonable amount, but now I do everything.” – Mandy*

*“He used to take the children doing that [sports clubs], so that fell on me to take them to various places. I have to drive everywhere.” – Liz*

For one husband, the impact of his wife’s imposed role change had implications for the whole family unit. He could recognise that his wife had undergone a vast role change and that had consequences for her emotionally:

*“Diane’s obviously a stay at home mum now, which I think she doesn’t find particularly rewarding. She went from having an important highly skilled job to essentially domestic worker, which I think gets her cross now and again. Me and the kids bear the brunt of that now and again.” – Owen, husband*

The expressions of these spouses show how role changes for relatives is of primary concern for spouses rather than parents or siblings. This is in line with other findings that show spouses are uniquely affected by role changes (Zeigler, 1999). The discrepancy between how these changes are perceived by the spouse with ABI compared to the uninjured partner requires further investigation to discover the importance of this difference on a



relationship level. It could be that highlighting this discrepancy as part of family therapy could prevent long-term suffering for relatives who take on additional burden in the relationship and conceal this from their partner. Supporting better communication to bring the experience of role changes within marital relationships in line for both parties could harmonise the coupling. However, without further research there is a risk of creating a greater rift, should the experiences of the strained family member be revealed to a vulnerable individual with ABI, who thereafter might feel guilt, responsibility, or anger at the way their spouse feels about their role change. By understanding more about the importance of role changes in marital relationships we can provide the most sensitive and supportive interventions when required.

*Conflicting duties* This subtheme relates to expressions by relatives about the difficulties they faced managing multiple family responsibilities. There was a sense of feeling the pressure of holding the family together through times of crisis and how the stress of the ABI was exacerbated by the competing needs of other family members. Katy describes how the addition of a young child and lack of her own parental support had led to increased strain within the family unit:

*“It’s hard when you’ve got two sets of needs to do things because you’ve got one set of needs that kind of can’t grasp the other set of needs and vice versa. You want to relax but it’s hard because you are constantly trying to balance things for everyone. So yeah, it is harder to do things as a family.”*

This conflict in needs of family dependents was most evident for Katy during the acute stage of her husband’s injury:

*“It was hard because I did have Sam [son] and Sam was starting school, so I had to think of him in the grand scheme of it, and because I haven’t got family who live around I did have to get into a routine...I was in a position where I had to do it that way. I didn’t have the option to go in and say I’m gonna sit by your bed 24 hours a day, because there was never the option for that....and actually at that time I also had a son that needed to be cared and looked after so I just had to get in a routine and get on with it.”*

This feeling of responsibility for others whilst trying to cope with her husband’s injury was felt during the acute stage for Liz, who also had children to consider:

*“Trying to keep the children, who all reacted in different ways, some were quite sort of accepting of it, some others had their own issues through it. And trying to just keep them on an even keel, and cope with Jerry [husband with ABI], yes I think it probably was the closest that I’ve ever come to a mental breakdown.”*

These accounts highlight the importance of the wider family support network required for managing the conflicting demands of family life. The impact of the ABI can create strains on other family relationships which then require their own attention and resolution. Such experiences are indicative of the importance of family interventions which seek to look beyond the impact of primary or intimate relationships, and consider the ripple effect the reactions of those who are still dependent on the primary caregiver can have in terms of these conflicting duties and additional stresses.

Of the dyads present, there was only one pairing where both family members expressed the same theme, which was a spousal relationship. This may be indicative of how personal role changes are felt, a feeling which does not always seem apparent to other family members. The dyad who shared this theme also matched, with an almost identical response to

how the family had been changed after the ABI. Both described changes to household tasks as a result of the individual with ABI no longer working, but with the relative having to take on some additional tasks as a result of the challenges the ABI had brought. Neither described these changes in roles as particularly positive or negative, rather as just how things were for them now. It is interesting that for this dyad, they expressed being flexible with their roles and not having clearly defined expectations before the injury, as described here by Alice, the relative in the dyad:

*“Well I suppose some things have changed simply because Pete [husband with ABI] is at home most of the time, so something’s that we might have split, tasks and so on, would have been split between the two of us more, Pete will be doing because he’s at home during the day, and there’s some things I’m doing more of because it’s harder for Pete to do them, like the driving. So there’s been a little bit of, I won’t say role reversal because we weren’t particularly ‘he does this and I do that’ before, but there has been a bit of a change there, certainly.”*

The way Alice and Pete have established new roles based on the circumstances of their family life after the ABI has meant they have continued to function with the expected partnership of a marital relationship. Relationship imbalances between spouses after ABI have been reported to be an area which results in marital strain (Marsh, Kersel, Havill. & Sleigh, 1998), so interventions which support families to establish ways to re-gain a more shared responsibility of tasks based on ability and capacity could help mediate this factor and contribute to more harmonious family functioning.

#### **4.2.4 Discussion of thematic analysis of family changes**

The results presented in this section relate to the interview responses pertaining to family changes as a result of ABI. Theme 1 focused on relationship changes, with these kinds

of family changes being evident for both participant types. The difference seen between the groups was how individuals with ABI interpreted the support they received from their loved ones as positive, with a feeling of closeness and gratitude brought on by the new caring relationship. For relatives though, the increased support they had to give the individual with ABI was felt as strain, with a new imbalance in a relationship that previously harboured reciprocal support systems. These types of different expressions were seen in another study measuring marital satisfaction after head injury, with wives reporting significantly lower satisfaction with their marriage than their injured husbands' (Gosling & Oddy, 1999).

Theme 2 showed functioning changes for individuals with ABI were predominantly negative in expression, whereas their relationship changes in theme 1 were more often positively expressed. This may be indicative of the gratitude felt for their loved one in recognition of the caring duties they have taken on after the injury. The positive relationship changes related to feeling closer to family members and could be a result of an increased connection with that family member, imposed by the injury and its effects, which may not have been there before, or was not acknowledged so mindfully.

Relatives expressed more negative functioning changes predominantly around a feeling of increased responsibility of having to consider the individual with ABI in plans for themselves as well as the family unit. The main challenges for relatives regarding family functioning changes were those which related to emotional, behavioural or social changes. ABI limitations which affected how the person functioned either emotionally in the family or when encountering social situations outside of the family caused the most pressure on relatives. This supports other research which advocates that challenges with these areas result in the most strain on families, above those relating to other injury deficits such as physical disabilities (Tarter, 1990; Carnes & Quinn, 2005; Chwalisz, 1992). It could be that family

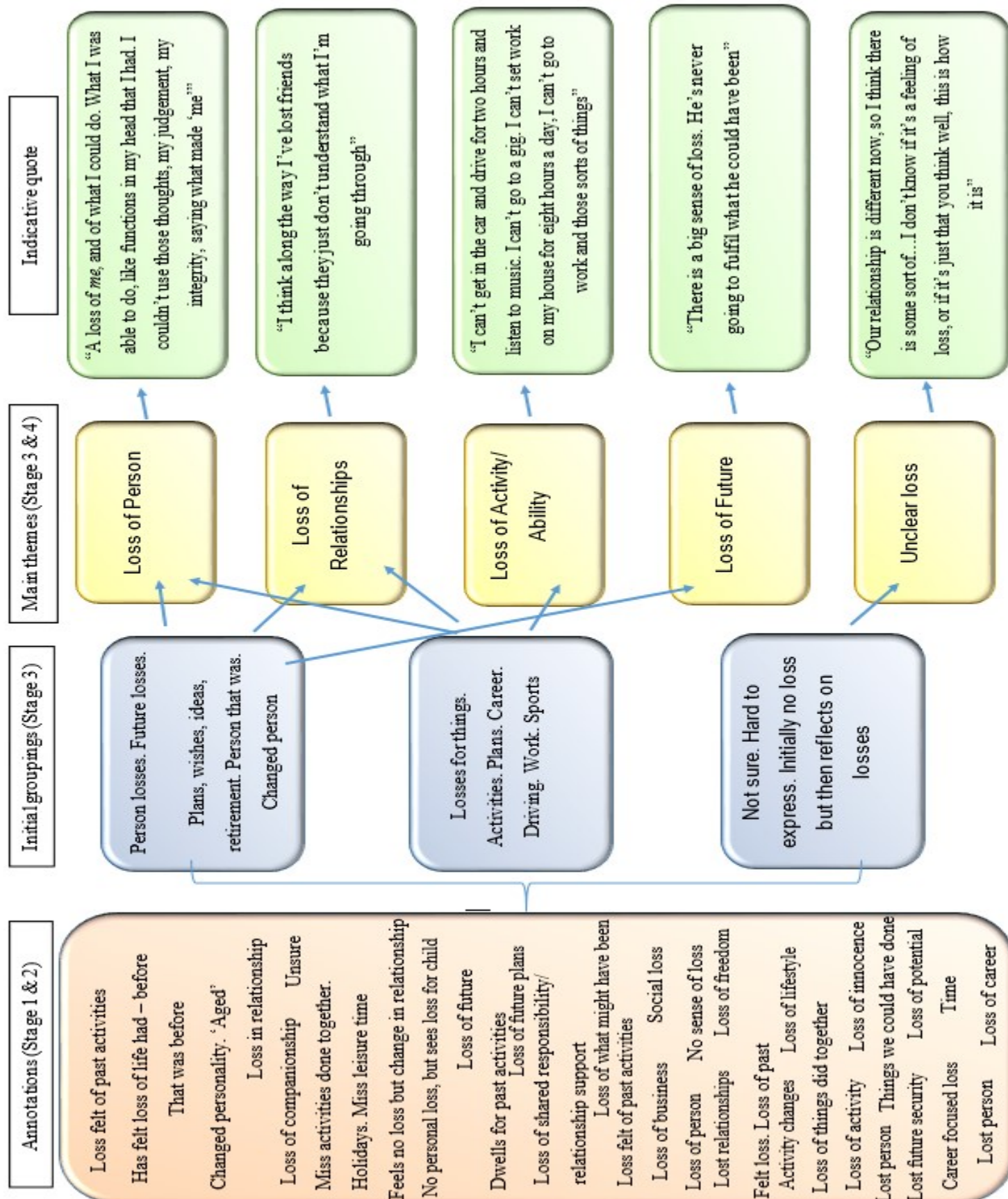
interventions that are focused on inter-relational communications and tools to enhance planning of social activities would increase positive functioning outcomes. This would be an area of interest for future research to investigate, ideally with a pilot intervention.

Theme 3 described how members of family units experienced role changes after ABI. For the relatives in this theme, only spousal relationships were affected, and the changes were not expressed in a positive way. This could suggest that the unique partnership made with a marital relationship finds it harder to accommodate a shift in balance when one party cannot carry out their expected roles anymore, and it subsequently falls to the uninjured spouse to take on these duties, as well as any additional caring responsibilities brought on by the ABI. These findings support those that advocate that there are specific difficulties experienced by spouses after ABI which are more detrimental to this type of relationship than others (Gervasio, & Kreutzer, 1997; O’Keeffe, Dunne, Nolan, Cogley, & Davenport, 2020). Not every spouse reported negative role changes, and it would be useful to understand if this is due to the way the relationship functioned pre-injury (for example if it was more weighted to one person having more responsibility anyway), or whether there is something about the type of role change that is of importance. By further investigating the significance of role changes, interventions for couple’s therapy will be better informed.

#### **4.3 Loss after ABI**

In an attempt to answer research question four (*what are the experiences of loss after ABI and do these feelings relate to subsequent experiences of adjustment?*) the responses here relate to the question “could you describe whether you have or have not experienced a sense of loss since the injury?” Figure 4 shows the process from annotations and notes to final themes for responses relating to loss. Of the forty interviews, thirty-seven participants expressed a form of loss relating to the injury. Of these, thirty expressed a clear and

identifiable loss that was present and enduring, whereas seven of the interviews did not express living with loss per se but could identify losses resulting from the impact of the injury.



*Figure 4:* Thematic coding of loss data using the four stage framework of Bryman (2008) The proportion of individuals with ABI and relatives reporting loss or unclear loss was nearly identical in the participant groups (91% of individuals with ABI versus 95% of relatives). Two individuals with ABI clearly stated no loss, with one relative clearly stating no loss. Five main loss themes emerged from the semi-structured interview data: loss of person, loss of relationships, loss of activity/ability, loss of future and unclear loss.

#### **4.3.1 Theme 1 – Loss of person.**

*“I was just left as this personality free blob”*

This related to a loss of the person who ‘was’ before the injury. These participants expressed a disruption to their core sense of self. This could be profound, even when resulting changes could be interpreted positively. This was evident in eleven of the interviews and expressed more with relatives than individuals with ABI (7/16 relatives to 4/14 individuals with ABI). For the most part, these losses are ambiguous in nature as they transcend the changes in identity experienced after ABI, and relate more to the grieving for the psychological aspect of the person left in the physical body.

For individuals with ABI, loss for the person was persistent and profound. Initial changes in the sense of person were all-encompassing and affected wellbeing even as cognitive and physical challenges improved through rehabilitation. The feeling of not being as they were was evident and predominantly negative.

*“A loss of ‘me’, and what I could do, and who I was...things were a bit skewed for a while. Knowing where my future was, where my direction was, knowing my plan....saying what made ‘me’, felt like it had gone, and I didn’t know who I was anymore” ..... “I miss who I*



*used to be and I miss how I could just turn my hand to anything without really thinking about it, you know...I used to do that and I used to be that...and now it's an effort to do anything really"* – Diane, individual with ABI

For some relationships the observed change in the individual with ABI had left profound ambiguous loss, as Neil expresses about his daughter's injury. His ambiguous loss is clearly evident in that he is experiencing a grief for the psychological loss of the daughter he had, even though she has not been lost physically, as described by Boss (1999):

*"There is a family loss there. Even though we've got the same body, we've just got a different person that lives in it. We've lost a daughter and gained another one, even though it's the same person."*

This was expressed by another parent, Rosa, along with the complexity of ambiguous loss in brain injury populations:

*"Well the loss of Stuart that was, to the Stuart that is now. In a lot of serious illnesses you don't lose the person, and as they get better they start losing the illness that they've got, but it just seems that with brain injury, if it's affected the person who's got it, they are different."*

Even though the loss of person was the most profoundly expressed of all the losses, people still showed an ability to see positives that have come from dealing with and withstanding this level of loss. Although there has been a change, there is acceptance of the new person and a co-existence of affection for their loved one with sadness for what has disappeared. Feelings of loss for the person were still being experienced, even when the new person was accepted and loved. This positive perspective was reported by both individuals with ABI and relatives.

John felt his perspective on life had been changed after his injury for the better and he had an improved work/life balance as a consequence. Even though he was happy with his post-injury self, he still felt a loss from the change:

*“It’s a balancing act. Yes I do feel loss because I’m not the same person I was since I had my injury, but I do feel that I’m a better person....it’s positives and negatives but it’s a balancing act”*

Liz experiences a clear loss for the changes to her husband after his injury, although she can accept and live with the husband she has now:

*“And I think suddenly it hits you. You haven’t had time to grieve, because you have lost somebody. You have lost that person. And people used to say ‘oh you’ve got him back’, and I used to want to say ‘I have somebody that looks like him but it’s not the person that went out that morning’. I mean Jerry is very different now to what he was, but that doesn’t mean it’s a bad thing. ”*

Some found confidence in the resilience gained from surviving their experience and could take strength from acknowledging that surviving the brain injury trauma added something unique to their lives:

*“I had a brain injury and it affected me in lots of ways... I was just left as this personality free blob....I’m not saying I’m different or special than anybody else, but I feel these things happened and here I am. I did that” – Nikki, individual with ABI*

*“I wouldn’t change it. I wouldn’t go back and not have it happen again, for there were lots of positives that came out of it.” –Shirley, mother*

A positive gratitude helped some live with their changed loved ones:

*“They are different. I can’t say it’s a bad difference in Stuart, in fact some of it is quite nice how he is, but that is the bit, we’ve lost the Stuart we had forever now, but we love the Stuart we’ve got.”* – Rosa, mother

These stories show how, even if people have adjusted well to the changes, either within themselves or in their loved one, there can still be loss present. In addition to the above individual representations, there were nine interviews that formed part of a dyad, but only two dyads ‘matched’. That is, only two individuals with ABI felt loss in a similar way to their relative. Relatives made up six of these interviews, with individuals with ABI expressing this loss in three interviews. It emerged that, out of nine dyadic relationships, only twice did a dyadic pairing feel the same loss of person. These dyads both expressed ambiguous loss, with a clear feeling of a different person living inside the same body postinjury.

As reported, this theme was more frequently expressed among relatives, with almost half of all relative interviewees reporting a loss of person. The dominance of this theme in relatives suggests it is harder for an ‘onlooker’ to witness the changes in a person and respond positively to this, which may be harder to comprehend due to them not being experienced personally. In contrast, the changes in person for the one that has been ‘changed’ intrinsically by the injury are not felt as a loss as such. It may be that the focus for the individual with ABI is more on external reminders of their injury, such as reduced ability to play a favoured sport or a loss of independence, rather than an experience of emotional lability or personality changes.

It is also a consideration that this type of loss is not felt as strongly among individuals with ABI due to impaired insight into the way they have changed after their injury.

Individuals with ABI may simply have reduced awareness of the way they have changed as a person and therefore this type of loss is felt more profoundly for relatives as a result.

#### **4.3.2 Theme 2 – Loss of relationships.**

*“I’m not close to anybody anymore. Well I don’t feel as if I am.”*

Losses occurred from changes to groups of relationships, such as social connections or friendship groups, or from more acute changes within specific family relationships. This theme was expressed by ten out of thirty interviewees reporting loss, and it was more present for individuals with ABI than relatives (6/14 individuals with ABI to 4/16 relatives). Losses were evident if relationships were felt to have been lost as a result of the injury, or to have changed from how they used to be.

The loss of friendships led to negative feelings about people and a harbouring of resentment. This type of loss was expressed as a feeling of being let down or abandoned at a vulnerable time. This was only reported in individuals with ABI’s interviews:

*“I mean the one time you needed, I needed them to be there, but they weren’t. Yeah that still, that still upsets me to this day.”* – Nikki, individual with ABI

*“I think along the way I have lost friends because they don’t understand what I am still going through.”* – Emma, individual with ABI

For some, the loss of friendship referred to the quality of their friendships, with a feeling there was a changed ability to connect on a deeper level:

*“Sometimes when I’m out for a drink and people deliberately come up to me, and that’s nice. But the fact that I’m treated as a, someone that had a stroke, they don’t hang around me. So yeah, that’s a loss.”* – Anthony, individual with ABI

*“I’m not close to anybody anymore. Well I don’t feel as if I am.”* – Barry, individual with ABI

For relatives the experience of relationship loss tended to relate to more intimate relationships and family connections which had changed rather than disappeared. Something about the way the relationships worked had been changed due to the injury. Although changes in the person could be interpreted positively in the previous theme, changes in the relationship were considered negative, largely down to an imbalance of responsibilities and loss of partnership that was once enjoyed. There is an increase in burden on the relative as a consequence of the ABI, and this is felt to be one-sided in the relationship. This type of loss was only described by spouses:

*“You’ve got all the disadvantages of living on your own, and you’ve got all the disadvantages of being married if you like, but none of the advantages either way it seems.”* - Jeff, husband

*“It’s a kind of loss of someone needs to be on the ball all the time and it would be nice just to think actually, I could just kind of not deal with this and someone would deal with it....so it’s almost loss of, I just feel more responsible, I can’t be as carefree as I used to be.”* Katy, wife

*“It’s a bit more like we’re friends in a way...you know it feels like we both need more time out from each other.”* - Hazel, wife

Of the ten interviews in this theme, six were from one half of a dyadic relationship, but none were felt on both sides of those relationships. No dyads reported a similar relationship loss, revealing how subjective this theme is. Just because one person in a relationship is feeling a change, it does not mean it is affecting the other party in the same way. This suggests changes in relationships are individually centred, even though there are two people in the relationship being discussed. When considering families as units, one

member may be living a strained experience that is not felt by others due to how they see their relationships have been changed within the family as a result of the injury. Individuals with ABI mainly experienced friendship losses, which could have a wider impact as a loss of social integration or wider support networks, putting additional pressure on the family to counteract these deficits. They spoke predominately about the reactions of their friends and peers, and less about changes in their romantic or familial relationships. In contrast, spouses of individuals with ABI, in particular, were predominantly concerned with the changes in their romantic relationship, which had led to an increased burden and sense of imbalance in what had previously been a more equal partnership pre-injury.

#### **4.3.3 Theme 3 – Loss of activity / ability.**

*“I used to play rugby, I could run a marathon, yet I can’t run now, I can hardly walk”*

This theme describes the feeling of a loss of a skill or activity that was once enjoyed or revered. The loss occurs due to the consequences brought on from the lack of skill or activity. For example, driving creates loss as it is felt as a loss of freedom and independence. Loss of skills equate to people experiencing a loss of confidence, competence and/or identity.

This theme was described in nine of the interviews and was predominantly an issue for individuals with ABI rather than relatives (7/14 individuals with ABI to 2/16 relatives). Individuals with ABI described this loss from a very personal perspective, whereas the loss of activity for relatives was about things enjoyed together with their loved one.

Physical changes that inhibit the ability to carry out previously enjoyed leisure activities can be a stark reminder of the effects of ABI. Jerry reflected on specific activities that he used to enjoy before his injury, with a clear feeling of then and now:

*“I used to play rugby, I could run a marathon, yet I can’t run now, I can hardly walk.”*

For others it was more of a general feeling of independence that had been lost due to a change in ability after their injury. It is not just the activity or ability that has been lost, but the wider lifestyle and impact on identity that loss brings:

*“I’ve lost my freedom. I can’t just get in the car and go off when I want to.”* – Carl, individual with ABI

*“It’s a bit self-centred, but it’s about things I’ve lost that I can no longer do. I can’t get in the car and drive for two hours and listen to music.”* – Pete, individual with ABI

*“Of course I feel loss. Not only do I not walk anymore, or even stand up, but my eyesight is rubbish. When it comes to reading things I can’t read unless it’s really big text.”* – Liam, individual with ABI

For relatives, the loss was more about changes to their lifestyle due to not being able to take part in regularly enjoyed activities together as before. The changes in their loved one has meant wider changes in the family lifestyle:

*“We can’t just go out anywhere. Whereas before we used to get in the car and go out for the day somewhere. That we really can’t do now...we can perhaps do a bit more with support for me, but the life we had is gone.”* - Margaret, wife

*“I suppose we’ve lost some things. We used to go to the football matches regularly.”* - Duncan, father

There was one dyadic match for this theme, although the type of activity lost was not the same. For the father in the dyad, the loss was attending football matches together, whereas for the son in the dyad the loss was for the ability to drive. Four other members of

dyads were present in this theme; three individuals with ABI and one relative, but none were dyadic pairs. It seems logical that this theme is presented as more individual because an ability or activity lost is often a personal one, although when expressing relationship changes, it would perhaps be understandable if there were more shared activities that were no longer attainable due to the effects of the injury.

#### **4.3.4 Theme 4 – Loss of future.**

*“You think ‘what if’”*

This theme related to a loss of what could have been and a feeling of unfulfilled potential. Of the six reports of this loss, it was predominantly represented by relatives, with only one individual with ABI experiencing this type of loss (5/14 relatives to 1/16 individuals with ABI).

For the individual with ABI experiencing this loss, it was clear the injury was seen to have held them back in many areas of life, and created a feeling of wondering, such as how things might have been different if the ABI had not occurred:

*“Well I look at them [friends] and their lives, where they are in their lives, well now they’ve got partners, marriage, children, careers. I mean my mate he lives in New York, and here I am, still stuck in Blighty.....I think if I hadn’t had my brain haemorrhage I would probably be a little bit more sorted in my career...because the thing that really held me back, it’s like having the reins on the kids so they don’t run away”* – Calvin, individual with ABI Calvin’s mother, Faye, also felt this loss for her son’s future:

*“Yeah it is a terrible loss. You think ‘what if? What if he hadn’t have had that? What would he be? What would he be like?’ He’s never going to fulfil what he could have been,”* Mainly,



uninjured spouses reported a loss of future plans and a change in the lifestyle that was meant to be for them as a couple:

*“It’s a loss of things we could have done when the children had grown up, that we can’t do.*

*It’s not gonna happen now, you know, then you see other people and...we can’t do that.” –*

Barry, husband

*“It’s a loss of what we’d planned together and just things not being how they were meant to be really.” –* Katy, wife

*“It’s regretting some of the possibilities, or the opportunities, that you might not now be able to take....it’s about maybe things we were planning to do actually, it’s not really gonna be achievable....anymore. So it’s a loss of potential rather than looking back at something perfect beforehand.” –* Alice, wife

As reported above, there was only one dyadic match for this category, with a son and mother both expressing very similar feelings for a loss of future and potential as a result of the ABI. Three more dyads were present for this theme, but only the relatives in the dyads felt this type of loss, with their corresponding individual with ABI not expressing the same feelings. As with loss of person it could be that the individual with ABI can either accept these changes more readily or has a changed priority to the present rather than harbouring a future plan that can no longer be fulfilled. For the relative, who maybe has not had the same level of support to cope with a changed future, and can be viewing the effects of the ABI in a wider context due to greater insight, this loss is more prevalent.

#### 4.3.5 Theme five – Unclear loss

In addition to the thirty interviews which defined at least one way in which loss was being felt, there were seven interviewees that found it hard to express their experience as loss.

The inclusion of these interviews is important to understanding how people may experience brain injury in terms other than loss, which may be equally as relevant as those expressing a clear definition of loss after ABI.

This theme appeared in seven interviews (5/14 individuals with ABI and 2/16 relatives). Unclear loss was present when the person did not connect with the concept of 'loss', but there was still a negative expression of the effects of the injury, and a longing for before the injury occurred.

For example, Max felt his injury had affected his sense of time in relation to before and after in terms of his injury timeline. As a result, he did not connect with 'loss' because he did not hold a time of being in mind to recognise it:

*"So no I don't have a sense of loss, but I do have a sense of not doing what I was that then gets applied to other things without me really knowing why...I could be specific about some 'thing' that I might attribute to the accident and my feelings around it. That might be anger, that might be sadness, that might be happiness, it might be bitterness. It's more normally bitterness and anger that will lead to sadness. But I don't know what loss was. Again, you'd have to put that on a particular timeline and I don't have that, so it's confusing."*

From the relative's perspective, the concept of loss was not always recognised if there was an acceptance for how things had changed:

*"Occasionally yeah, 'cause our relationship is different now, so I think there is some sort of,*

*I don't know if it's a feeling of loss or if it's just that you think well this is how it is. "* –

Mandy, wife

Debbie describes how the positives have helped to outweigh the negatives in terms of her husband's injury effects. There is a loss there, but it is not a lived loss within the relationship:

*"Not really. I know it sounds mean to say but I've had more of Philip since he had his injury than before because most of the time before he was a workaholic so he was there all the time, so although it wasn't a nice thing to happen, I've got more of him than I'd had before....well we used to like holidays, and you miss those because they were quite adventurous type things, which you would have done then."*

These expressions of unclear loss show how some participants are living with changes due to the ABI, but that in some cases the ability to appreciate the positives that have come with these changes can mediate the negative effect of the change itself. Also, it may be that these participants have reached a level of adjustment to their situation which means they can acknowledge losses, but that they are not felt in the same way as someone who is still coming to terms with accepting the consequences of the injury.

Not every person felt a type of loss from their experience. In fact, three of the participants (two individuals with ABI, one relative) did not report any feelings of loss from their experience, and could actually identify positives as a result of the changes they have faced:

*"I don't know I just feel the same, although there was some difficulties. But it wasn't like I couldn't carry on....well I guess my family, well they did, they must have supported me so well that I just felt like I could get on with it. And it's not like I was really that bad....If anything*

*it's made it better, because I actually try with stuff. I'm constantly trying. Before I was like, I didn't really care.*" – Harry, individual with ABI

*"In some ways I've experienced a gain...I appreciate what I've got."* – David, individual with ABI

*"I personally don't feel I've experienced a loss. Maybe at the time I did, in some strange way but I don't feel I've lost anything. Yeah okay he's not, he's got a brain injury now that he didn't before, that's his loss not mine. Yeah, I don't feel any, I personally don't feel any, that I have loss....We're just so grateful we've still got him. We're just so proud of how he's doing."* – Patricia, mother

When these participants who did not feel loss were asked what helped them feel the way they did, they all expressed a feeling of 'it could be worse' and showed a positive perspective on how much they could do despite the injury. A feeling of having made a good recovery, when at the outset things were much bleaker, was a contributing factor to feeling no loss as a consequence of the injury. Also, these three participants were no longer active clients involved in HWC services, therefore the feeling of not needing professional support anymore may provide a sense of normality and achievement which in turn mitigates any feeling of loss that may have once been present but is no longer identifiable.

#### **4.3.6 Discussion of thematic analysis findings for Loss**

Sections of the interview discussed experiences of loss after ABI, and subsequent analysis highlighted how these can differ between those who have incurred the ABI and those who are related to them. The occurrence of the five main themes of loss show how the person at the centre, i.e. the person with the brain injury, can be affected in similar yet separable ways to someone who is related to an individual with ABI. The use of dyadic analysis

showed that loss is experienced from a single perspective, independent of other people's experiences of loss, yet also dependent on how the brain injury has affected an individual.

The theme of 'loss of person' related to changes in the personality or the identity of the person with the ABI, either experienced personally or as an observer. Ambiguous loss was present in this theme, with the loss for the person being evident without the physical loss of that person. This observation indicates that ambiguous loss can begin at the acute stage of brain injury rehabilitation, as described by Kean (2010), but can also remain a profound focus of loss even years after the injury occurred, for both individuals with ABI and those related to them, as also reported by Holloway, Orr and Clark-Wilson (2019).

The theme 'loss of relationships' describes the way relationships are altered by the experience of ABI. Predominately for relatives, there is a shift in the equality of the relationship and a feeling of additional responsibility as a result. For individuals with ABI, this feels more evident among friendships, with a feeling of not having the same quantity or quality of social networks as before the ABI. The reasons for this difference in relationship focus is not clear. One possible explanation is that the relatives protect the individual with ABI from their feelings of negative relationship changes, and they are therefore not as apparent to the individual with ABI. Furthermore, as many individuals with ABI reported no longer taking part in the same vocational or recreational activities due to the effects of their injury, friendship groups may have more naturally declined for them, leaving a greater loss for the person with the ABI than for the relative. Given the observation that changes in relationships underpin a strong sense of loss for those affected, further research in this area is encouraged.

The theme 'loss of activity/ability' most commonly occurred for individuals with ABI and related closely to lost skills or activities due to the impact of the injury. For individuals

with ABI, the loss of an ability had wider reaching implications on their identity and sense of worth. The activity or ability per se was not the loss, but the feeling of somehow not being as capable or independent as they once were. For relatives the focus was on things that could no longer be enjoyed together with their loved one because of the effects of their ABI. This translated into changes to their lifestyle, with less spontaneity allowed for activities together now the ABI effects had to be considered. This loss of ability and activity had more of an impact on individuals with ABI, with relatives feeling they could accommodate the changes to their lifestyle more readily because they were not the main focus of day-to-day life. As the individuals with ABIs' loss was so personal, it may have been felt more deeply, whereas the loss for the relatives was more peripheral in comparison to other challenges they have had to accommodate. Although lost activity after ABI has previously been reported in the literature (Gracey et al., 2008; Turner, Ownsworth, Cornwell & Fleming, 2009), the inclusion of dyadic analysis indicates that the activities lost are personal and felt on an individual level, even when they were activities shared with family members. Just because one person feels the loss of a once shared activity does not necessarily mean this is still an area of importance for the other.

The theme 'loss of future' was much more of a concern for relatives than individuals with ABI. Relatives reflected on aspirations that their loved one would no longer fulfil, and they held this loss much more evidently than individuals with ABI. Spouses particularly felt that their own future, as well as that of their loved ones, had been changed due to the injury, and plans made together would no longer come to fruition. For these people, there was no preoccupation with the past and how life was before the injury, but a loss of the future planned together and the experiences that would now not be possible. The finding that this was predominantly expressed by spouses does not support the findings of other research which has found parents show an increased concern for the future of their adult children more

so than do spouses (Knight, Devereux, & Godfrey, 1998). This could be due to disproportionately more spouses taking part in this study compared to parents (14 spouses versus 6 parents), so this ratio should be interpreted with the necessary caution.

One explanation for the imbalance in feelings of this type of loss between individuals with ABI and relatives could be due to individuals with ABI focusing more on the day-to-day challenges that ABI brings, rather than looking too far ahead, whilst relatives are more able to consider how the plans for their futures together have been altered, as they are not personally experiencing the challenges of the ABI effects.

Another reason why some individuals with ABI do not experience as much loss of future could relate to the cognitive effects of brain injury and how this can impact on the ability to have foresight and think about things which have not yet happened. Imagining a future that could have been may simply not be a skill so readily available to individuals with ABI due to the complex executive processes involved. Evidence for the role of the frontal lobes in enabling a future perspective (e.g., Fellows and Farah, 2005) raises the likelihood that many individuals with ABI tend to live more in the moment as a consequence of frontal lobe damage. Future research is encouraged to explore the impact of executive (dys)function on feelings of loss for the future.

The final theme of ‘unclear loss’ demonstrated how some people expressed a loss of ability, relationship or activity, yet would not describe it as ‘loss’. For some, this appeared to be due to an ability to see positives over the negatives, which meant changes could be identified but not harboured after. For others, it could be that they have reached a stage of acceptance and adjusted to the changes which have taken place and may have in earlier stages resulted in a state of loss. This could have implications for the way interventions are offered to families after ABI, as they may not present with a need for support due to a disconnect

with the terminology being used. It should be considered that the emotional sequelae of ABI can be confusing and unclear for those involved, and traditional terms of loss and adjustment may not resonate with everyone.

A unique aspect of this research is the inclusion of dyadic relationships. The primary finding from analysing dyadic relationships is that even though the two people concerned are from the same family, they often reported different experiences of loss. For example, one person in the relationship can be feeling profound loss and expressing this negatively, whilst the other person does not necessarily consider such a feeling of loss in the same way. This observation suggests that even though Brooks' (1991) concept of the head-injured family has been useful at highlighting the wider impact of ABI, it does not necessarily follow that family members are experiencing a similar type of loss as those who have had the injury, and vice versa. It may be that individuals with ABI's experience is shaped by their rehabilitation journey, where focus is likely to have been on functional outcomes and personal goals, rather than protecting, strengthening or rebuilding family relationships.

Participants in thirty of forty interviews expressed at least one of the loss themes, but few incorporated more than one theme. The maximum number of themes present was two, with this occurring in only seven of the total forty interviews. This finding suggests that when loss is present, it is focused and prominent in the person's mind and could possibly overshadow any other less significant areas of loss that may, or may not, be present. Future research could use the themes that have emerged from these interviews to investigate if multiple loss themes are commonly present amongst those affected by ABI. It could be that the breadth of loss themes has been under reported due to the self-generating nature of the interview method. If people are given suggested prompts about different types of loss, they



may more readily subscribe to multiple loss themes rather than just the one that feels most pertinent at the time.

Loss appears to be connected with a person's perspective and expectations of life after ABI and can be present many years after the injury event itself. Knowledge that the passage of time alone may not be sufficient to heal loss experienced by families affected by ABI could prove crucial for rehabilitation and clinical management decisions. The normative grieving cycle associated with the physical loss of a family member (i.e., through bereavement) does not apply, so more targeted interventions to support the grieving process among those affected by ABI may be required.

#### **4.4 Adjusting to life after ABI**

The aforementioned three areas of interest describe how families can be changed after ABI. It has been seen how coping behaviours need to adapt to unfamiliar stressors, family members are required to adapt to different ways of functioning as a unit, and people can be left living with a number of different types of loss. Here, interview responses to the question "Would you consider yourself to have adjusted to life as it is now after the brain injury?" are presented to show ultimately how the participants felt despite how they may have responded to other aspects of their changed lives. The factors influencing adjustment are unlikely to be fully explained by feelings of coping, family change and loss alone. Moreover, the factors which could potentially be contributing to a person's feeling of adjustment will not be limited to these three areas. Therefore, participants were asked to explain why they either did or did not feel adjusted, and what contributed to this feeling. The responses could be categorised into three main themes: *adjusted to life after ABI*, *partially adjusted to life after ABI*, and *not adjusted to life after ABI*. The development of these themes are represented in figure 5. One participant did not respond to this question so was therefore omitted from the analysis.

Therefore, results here represent the responses from 39 participants (19 relatives and 20 individuals with ABI). Of these 39 interviews, 37 participants expressed feeling either completely adjusted to their life after the ABI, felt they were somewhat adjusted, or were in the process of adjusting. Only two participants reported not feeling adjusted to life after ABI when asked directly in the interview.

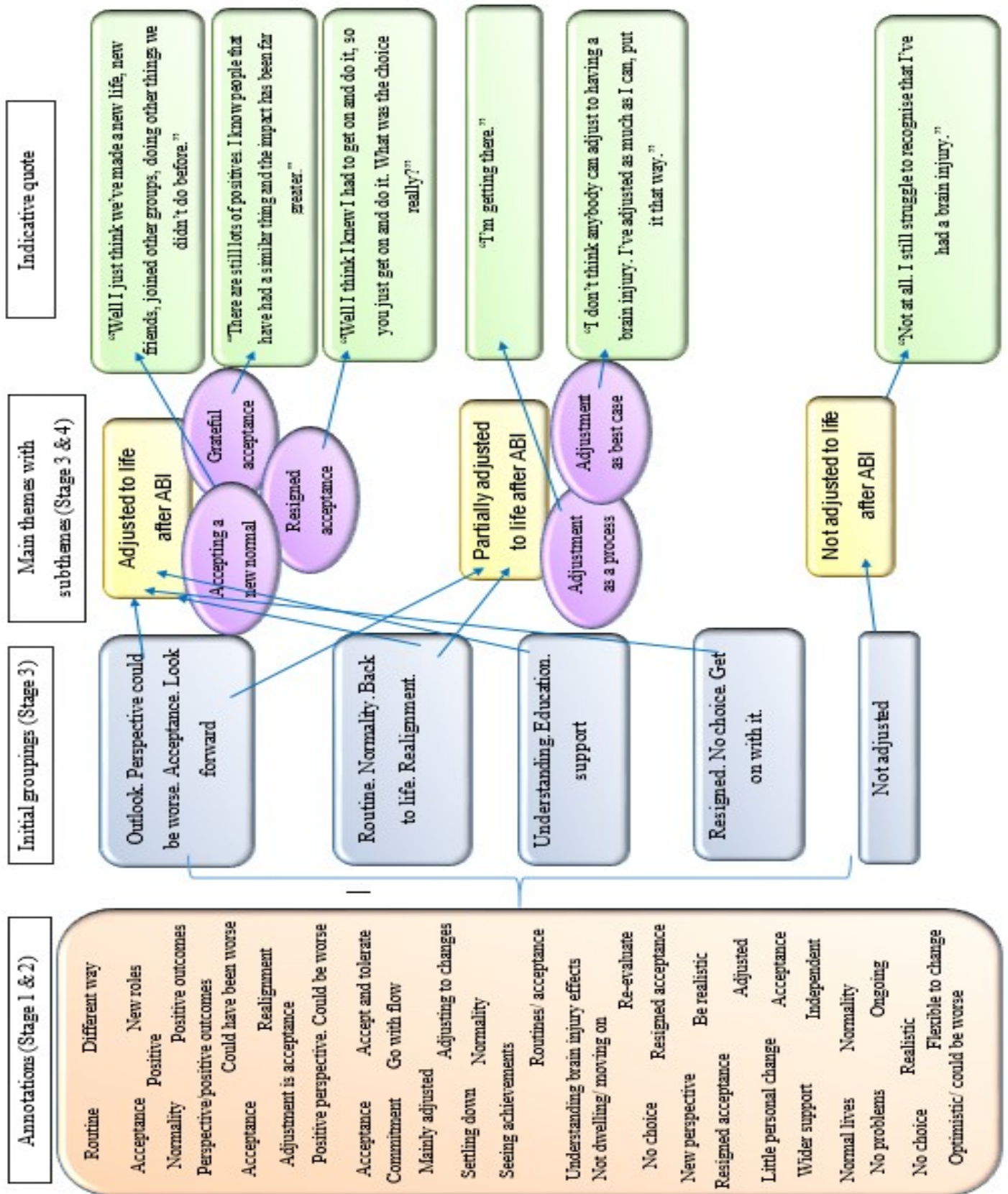


Figure 5. Development of adjustment themes using Bryman's (2004) four stage process.

#### 4.4.1 Theme 1 - Adjusted to life after ABI

*“I think being adjusted means that we are able to get on with our life”*

In response to the interview question, 29 participants were clear that they felt they were adjusted to life after the injury. This represented 16 relatives and 14 individuals with ABI. A commonality across this theme was one of acceptance. To participants who felt adjusted to life after ABI they had reached a feeling of acceptance for this life. The way this acceptance was portrayed elicited three subthemes: *Accepting a new normal, grateful acceptance, and resigned acceptance.*

*Accepting a new normal* For these participants, feeling adjusted to life after ABI meant establishing a new expectation of how things were going to be. Those who felt adjusted reported a realignment of their past goals and aspirations to accommodate the effects of the injury. Life has found a new normal, one which accommodates the ABI but does not revolve around it. For some spouses, this manifested as the successful transition to new family roles:

*“I suppose it’s accepting how things are and accepting sort of the modifications you have to make to how you do things.”* Alice, wife

*“It’s taking on things that you haven’t done in the past because you haven’t had to.”* Mandy, wife

For other spouses, they felt this new normal as a way of life and how they functioned as a couple now, rather than specific duties:

*“Well I just think we’ve made a new life, we’ve made new friends, joined other groups, doing other things we didn’t do before.....just accepting what’s happened and getting on with life really.”* Margaret, wife

*“Living with change, isn’t it really. Living with, or knowing, that you can’t just up sticks and do something spontaneous. You can’t be spontaneous now, because everything has to be planned. So I think that’s probably what adjustment is.”* Debbie, wife

For parents, the fact that they had not had to take on parenting roles again had helped them to feel adjusted to life after their adult child’s ABI. The individual with ABI had not been left dependent on them, so in terms of their own lives, they hadn’t had such a big impact from the injury:

*“I think being adjusted means that we are able to get on with our life....we’re not constantly worried about him....life can go on as normal, and it does.”* Patricia, mother

*“Well I say much hasn’t altered for us personally. We still do what we wanted to do and I mean it’s something that hopefully you just accept and carry on as normal.”* Duncan, father

For individuals with ABI, the ability to re-evaluate their life’s path and accept a new one contributed to their feeling of adjustment:

*“Routine. And also I think that as I don’t work I get more time to myself. So I think I’ve learnt more being like I am than if I was rushing about doing things.”* Liam, individual with ABI

*“Just learning to cope with what you’ve been through and just re-evaluate how you deal with new situations in life.”* Andrew, individual with ABI

*“I’ve come to terms with what has been a massive, I suppose if you have a cycle of life, mine had a big dent in it, and I fell in a chasm but I climbed out and now, now I’m on a different cycle, but I can see that in a very positive light going forward. Whereas in my very early stages of my rehabilitation I couldn’t.”* Phillip, individual with ABI

For these participants who had been able to accept a new life after ABI, the ability to acknowledge changes and take on new roles attributed to their adjustment. For individuals with ABI, the ability to look forward and think about how life was now, rather than looking to the past, played a beneficial role in helping them adjust to these changes. For relatives, a feeling of having a certain amount of 'life as normal' helped them feel adjusted. Being able to continue in some way as a family, without the ABI effects making too much of an impact, contributed to their feeling of being adjusted.

*Grateful acceptance* This subtheme relates to an acceptance of the ABI which stemmed from a positive perspective and feeling of gratitude. This type of acceptance was only seen with relatives, who expressed a strong feeling that life could be worse. They appreciated that the outcomes for their loved one with ABI had far exceeded their original prognosis:

*"I think because David is not very incapacitated. So the present and the future are looking okay....it's also adjusting is not dwelling on the past. It's gone. A positive attitude, having a glass half full rather than empty attitude makes a difference....I think some people are so much worse off than I am, so that makes things easier."* Mandy, wife

*"I'd say I always feel very lucky that he wasn't worse damaged."* Hazel, wife

For parents, the lack of dependence their adult child had on them contributed to their grateful acceptance. They represent what could be thought of as natural aspirations a parent may have for their child, and seeing them reach this potential despite their injury was helpful:

*"We haven't had to change our way of living or moving in with him or anything like that so, fortunately as I say he's been able to support himself in his own home."* Duncan, father

*“I think just to see him, getting on with life, working...he knows what he wants to do and he just keeps, he’s gonna get there, I know he’s gonna get there. I think just seeing him getting on with life. He’s getting on with it and he’s less of a worry, very much less of a worry than I thought he would be.”* Patricia, mother

For those who felt a grateful acceptance, adjustment had been reached through a positive perspective, with the acknowledgement that things could have been worse. Spouses recognised that for some the outcomes can be much worse than they had been left with, and for parents they cherished the achievements their adult child was still able to make on what feels like the normal trajectory of life.

*Resigned acceptance* For these participants, they felt adjusted to life after ABI, but it was a resigned adjustment, with expressions of having no other choice but to accept the situation they are in. This subtheme, like with *grateful acceptance*, was only seen with relatives:

*“Well, I think, well I knew I had to do it, so you just get on and do it. I guess not everybody can but, what was the choice really? Just getting on with it to be honest I think. Its Hobson’s choice ain’t it? What other choice is there?”* Barry, husband

*“I haven’t had a choice really. You have to. It doesn’t mean you don’t want things to be different but you have to be realistic.”* Katy, wife

*“I mean you accept it, you tolerate it, you put up with it. I mean after all’s said and done we’ve been together a fair few years.”* Jeff, husband

All participants who had a resigned acceptance were spouses, perhaps reflecting the commitment felt through their marriage and the partnership they had formed, but also highlighting that accepting the changes to their marriage was not easy. Even though

realistically they could separate from their spouse, this option was not considered due to the marital bond they shared. This was summed up by Mandy who, whilst talking about the support her husband now required from her as a result of his injury, became emotional and said:

*“Well I suppose it is a choice, because you can walk away [but] it’s for better or worse.”*

This subtheme highlights how some people learn to endure significant strain and change in their lives yet can find a way to accept this and adjust accordingly. The finding that this was only seen in marital relationships could be indicative of the fact these relationships are originally chosen, rather than bonded by birth. This appears to have led, for some, to a feeling of accepting their fate and remaining true to the commitment they made when they originally created the marital bond.

#### **4.4.2 Theme 2 - Partially adjusted to life after ABI**

This theme emerged due to some participants (5 individuals with ABI and 2 relatives) responding with less conviction than those in theme 1, explaining that they did not feel adjusted, but were not unadjusted to their life after ABI. Theme 2 could be separated into two subthemes: *Adjustment as a process* and *Adjustment as best case*.

*Adjustment as a process* For this subtheme, participants expressed being on a journey. They were not adjusted to their changed life, but recognised they were getting there and were starting to process the meaning the ABI had for them:

*“I think I’m starting to [adjust]. I think I’m starting to go on the right path as I’m starting to see the right [professional] people.”* Emma, individual with ABI



*“Probably more so than I have at any other time, yeah....I feel like we’ve got the balance right at the moment. I think everything’s starting to feel a bit more... I’m starting to feel a bit more positive about everything at the moment. So probably going through a good period, yeah.”* Camilla, individual with ABI

For these individuals with ABI, the feeling of starting to adjust was apparent due to feeling they were finally getting the appropriate services and clinical intervention they needed. There was a recognition that their life is starting to find its new normal, and the correct support from external services has helped bring about some acceptance of the impact of their ABI.

For Pete, he felt that the lack of finding his new normal combined with not fully incorporating the needed management strategies into his routine meant he still had a way to go before he felt fully adjusted to life after his ABI:

*“Ongoing.. I wouldn’t say I’ve adjusted to it, because if I’d adjusted to it I wouldn’t do half the shit I do, getting fatigued and stuff, and I still haven’t got the balance right. And I feel that part of the journey and the gains I thought you could make in those early years as much from adjusting and accepting where you are and working within those parameters but I wouldn’t say I’m quite there yet. Getting there. Getting there”* Pete, individual with ABI

The one relative in this subtheme, Shirley, was also recognising this sense of a new normal as an important part of the adjustment process:

*“I think I am adjusting to so many changes, not just Andrew’s accident, but I think I am adjusting now, things are settling down again into some sort of normality.”* Shirley, mother

Adjustment as a process represents how some people can acknowledge they are on a journey towards acceptance of the impact of ABI, and there is a collective feeling that this acceptance will come when life finds a rhythm where the ABI challenges are overcome.

*Adjustment as best case* Whereas some participants felt they were on the path to being fully adjusted but were still in the process, other participants felt they were somewhat adjusted, but that it was the best that could be hoped for given their circumstances. For example, Barry did not feel it was realistic to expect complete adjustment to an ABI:

*"I don't think anybody would adjust to having a brain injury. I've adjusted as much as I think I can, put it that way."* Barry, individual with ABI

One relative gave a similar account, feeling she has reached the best stage she can, given the impact the injury has had on her son's life:

*"For the most part, yeah. I mean because there is nothing I can do. You have to accept it. You have to accept it otherwise you're never gonna have any life again."* Faye, mother.

Faye's account is similar to those in theme 1 who felt a resigned acceptance, except Faye does not feel fully adjusted. There are aspects of her son's life which stop her making this successful transition, such as he hasn't been able to settle down with a partner or keep steady employment since his injury. It would be interesting to know if, should her son settle down and find a job, if this feeling of adjustment would change. With parents in theme 1 expressing that the achievement of normative life events such as employment and independent living had contributed to their feeling of adjustment, it would be worth further investigation to see if the realisation, or subsequent non-realisation of normative life goals, is an important aspect of parental adjustment.

One participant, Nikki, was able to give a thorough account of what adjusting to life with her brain injury felt like, and why it was difficult for her to say she was fully adjusted. Nikki felt she was adjusted “*to an extent*”, and described the adjustment process as this:

*“So you know in a job description, here’s a list of things you have to do, and we want you to do all these things in two weeks, and you think ‘yep, I can get all those things done in two weeks’, you’re adjusted to that job. Then you come in the next day and they say ‘we don’t need you on this job anymore, you’re going to finance’ or whatever, ‘here’s a list of things to do’. You’ve got no idea what you’re doing, you’ve never worked in finance before, and you battle, but you get through the list and you managed it in four months or whatever, and you’re like ‘okay that’s not a problem’, and you get another list and you have to do this list in two months because you learnt everything you learnt in the previous list. That is adjusted. And brain injury is exactly the same. You’ve got your requirements of life, and you’ve got every single one of them, and brain injury happens and fucks everything, and you’ve got a million things, and you can’t, you physically can’t. The thing is with life, everything on the list, it’s constantly changing, constantly developing, constantly becoming something new, requiring different things of you. Adjustment is being able to follow those changes, and change at the same time as those changes, in a complimentary way.”*

The accounts of participants who did not feel adjusted, but felt either partially there or on the way to becoming fully adjusted show how, even at least two years after an injury, people can still feel there is a process to take place to come to terms with their experience and the consequences it has had on their lives.

#### **4.4.3 Theme 3 - Not adjusted to life after ABI**

Only two participants expressed clearly that they were not adjusted to life after ABI. Although a small representation, it seemed appropriate to create a specific theme for these

participants due to the insights that can be gained from their explanations. One of the participants was an individual with ABI and one was a relative. What is striking about these two accounts is the presentation of anger towards the injury and the impact it has had on life.

Here, Max found it almost unfathomable that he could be adjusted to his injury:

*“No! [laughs] No, not at all. I still struggle to recognise that I have a brain injury....No I’m really at the bottom of the ladder on that one, and I can’t ever see me climbing a rung.”*

When Max was asked what being adjusted for him would represent, he said:

*“Being happy. Content maybe more than happiness. Saying ‘that’ll do’, and I’m not remotely. I am on many levels but I’m not happy.”*

Some of this discontent with his situation comes from his experience of his rehabilitation pathway. Max had been involved in a litigation claim relating to his injury and here he explains how the feeling of being ‘subjected’ to his rehab was detrimental to his recovery:

*“Everything [services] I felt subjected to....I have an awful lot of anger over what I went through, and I don’t know if it will ever go away....change the process so people are more self-accepting rather than being judged and assessed constantly in a way that’s not beneficial to that person. It’s shocking. It’s a shocking thing people go through, and under no circumstances should you force people into any kind of rehab that they’re not ready for.”*

It is clear that for Max, his experience of being involved in a legal process and how this affected his rehabilitation has left him with a measure of resentment which appears to be interfering with his ability to move on with his life now. For the relative in this theme, Neil,

he feels a resentment, but this emotion was directed at the injury itself and the changes he could see in his daughter:

*“I still feel that she’s more dependent on us than she should be. As I said we’ve tried to make her independent. We’re trying to force her to become independent....I think she’s still struggling with it...I [dwell on the past] all the time because of the way she is now and you know the way she is now is so different to the way that she was before the accident.”*

In a separate part of the interview, Neil had expressed that he did not feel depressed about his daughter’s injury, but angry, because he knew she was not the same as she would have been had she not had her accident. He went on to explain why he could not feel adjusted to life after the ABI yet:

*“I think adjustment is acceptance, and until such point you can completely and 100% accept this is the situation, this is the way it’s always gonna be, it’s very difficult to adjust to it. And I don’t think, well that’s difficult to say, at the moment, and in the near future, I very much doubt I will always accept it. The forward thinking of me has passed. I don’t, I can’t see how she’s ever going to improve.”*

Just as the adjusted parents’ attributed their feeling of adjustment to seeing their adult children on a ‘normal’ path of life which did not result in them re-establishing their parental duties, Neil has experienced an opposite effect, with his grown-up daughter remaining dependent on the family and needing to be considered again as a more child-like member. The fact his daughter was not following the expected trajectory of leaving home and living independently appears to have affected the adjustment process for Neil.

#### **4.4.4 Discussion of thematic analysis of adjustment to ABI**

Adjusting to life after ABI could be attributed to a multitude of variables concerning the unique aspects of the injury event, injury effects, and environment within which the consequences of the injury are felt. However, when asked directly about what helps people to feel the level of adjustment that they do, and free rein is given on this response, a more conservative amount of reasons for what is important to adjustment emerges. Specifically, those who felt fully adjusted to their life after the ABI had either re-aligned their expectations of their life trajectory to accommodate the ABI, had a perspective of ‘it could be worse’, or showed a defiant ‘just get on with it’ attitude. The expressions of these participants support the recent findings of Van Bost, Van Damme, & Crombez, (2019), who found that those who can identify and pursue new life goals after ABI report a better satisfaction with the quality of their life and better psychological wellbeing. The ability to be flexible with life goals also emerged through an earlier qualitative study with Chinese families by Man (2002) as a contributor to good adjustment after ABI. Also, the subtheme of a ‘new normal’ supports Nochi’s (2000) qualitative study whereby a common feeling amongst the ten family members who felt at ease with their life after their loved one’s ABI was the ability to re-evaluate their future with the ABI in it. For them, it wasn’t just about accepting the ABI, but readjusting their expectations of life to accommodate it. Therefore, it is worth further investigation to assess the impact life coaching or goal setting therapies could have for families to help them find a new normal which has sufficient value to them, rather than living with a resigned acceptance.

Another common factor which connected relatives who had adjusted was a feeling that the individual with ABI was either not dependent on them, or not as dependent as they could have been given the injury they had sustained. It has been seen before that the severity

of the injury does not contribute to family outcomes, but it is worthy of more investigation to ascertain how much this finding is influenced by the outcome versus the initial prognosis of the individual with ABI. For example, is it more important what actual deficits an individual has been left with, or is it more important that these deficits are not as detrimental as was first anticipated? Research investigating the discrepancy between potential outcomes versus actual outcomes would be a valuable addition to furthering our understanding of adjustment to ABI.

It could be that those who have experienced conversations about potentially losing their loved one, or their loved one being significantly incapacitated are more accepting of outcomes that appear more impactful than someone who has not experienced such extremes. Indeed, the difficulty diagnosing and treating more medically unobtrusive conditions such as postconcussion syndrome (Iverson, 2006; Rose, Fischer, & Heyer, 2015) have been shown to increase patient distress (Sterr, Herron, Hayward, & Montaldi, 2006). The use of the word ‘mild’ to describe one’s injury may be a detrimental term in helping that person process the impact of the injury effects on their life and subsequently adjust to them.

The two people who felt they were not adjusted at all both exhibited anger towards the injury for what it had meant to their lives. For the individual with ABI this anger was aimed at the litigation system they felt they had been subjected to. Although there are a number of studies looking at the way being involved in litigation might exacerbate or change a person’s ABI presentation (for example Feinstein, Ouchterlony, Somerville, & Jardine, 2001; Miller, 2001; Tsanadis et al., 2005), there is not sufficient research concerning the negative impact being involved in a litigation claim might have on psychosocial outcomes. One study which used involvement in litigation as a variable in outcomes four years after TBI found that those who had been involved in a litigation claim had a markedly worse outcome on measures of quality of life (Bayen et al, 2018). For the relative, this anger was at the

‘losing’ of their daughter and the gaining of someone who posed challenges to the family environment now. It is widely reported in the literature that personality changes create increased levels of distress over other types of change such as physical or cognitive ones (Perlesz, Kinsella, & Crowe, 1999). Although other participants recognised changes in behaviour, ability, or the ‘person’, Neil was the only one to feel so strongly about the change of personality in his daughter. It was evident this was his primary impression of the effects the ABI had left. This strong reaction from Neil, who is a parent, is in line with the results of the study by Kratz, Sander, Brickell, Lange, & Carlozzi (2017), whereby parents reported greater loss for their child ‘that was’, compared to spouses, when faced with personality changes. More specific ways to support families with personality changes in their loved ones is needed to help minimise this impact and subsequent emotional distress.

Those who do not feel adjusted to life after ABI may be under-represented in this study due to the self-selection process of participant recruitment. Those who are truly struggling with their situation may not have been inclined to volunteer to expose this through taking part in the research, therefore it is likely this study presents a sample biased towards those who are feeling more adjusted to their situation and are happier to share their experience as a consequence. The negative emotional affect of the two participants who did not feel adjusted supports the literature that advocates for the ability to show compassion and forgiveness to aid adjustment. For example, forgiveness has been seen to aid adjustment during the rehabilitation process, and self-compassion has been found to reduce feelings of self-criticism, anxiety and depression after ABI (Ashworth, Clarke, Jones, Jennings, & Longworth, 2015). For both Neil and Max, the emotional reaction to their ABI experience has resulted in part from a portion of blame to an external party. It has been seen in one study that those who apportion blame to an external party for their injury suffer with more depressive symptoms in the long-term than those who do not exhibit this external blame (Hart, Hanks,



Bogner, Millis, & Esselman, 2007). By being supported to develop a more forgiving narrative, along with practicing the fundamentals of compassion-focused therapies, people who struggle to adjust may be helped to find some peace. This area though, is currently not understood well enough to know if these kinds of interventions would be effective.

These results of the adjustment section of the interview show that, even after at least 2 years of living with ABI, there are varying degrees of adjustment which take place. It can take an extensive time to find a 'new normal', and adjustment can fluctuate along with the ups and downs of rehabilitation. Time since injury varied significantly for this study sample (from 2 years to just over 46 years). However, the mean time since injury for the participants who felt fully adjusted was 11.2 years, the mean time since injury for the participants who felt partially adjusted was 8.4 years, and the mean time since injury for the people who did not feel adjusted was 4.6 years. This suggests that adjusting to life after ABI takes a considerable amount of time, bringing into question studies which investigate factors contributing to adjustment when participants are much earlier in their rehabilitation journey. For example, many studies will use hospital –based samples when participants are at the very early stage of their recovery, such as Cairns and Quinn (2005; mean time since injury 57.5 days), Anson and Ponsford (2006b; mean time since injury 517 days) and Spitz, Schönberger, & Ponsford, (2013; 19.29 months post injury). It brings into question what is actually being measured when participants are so early in their ABI journey. It could be that rather than measuring adjustment, researchers are measuring the ability to cope with the fall-out of a traumatic event, the ability to process a life-change, or the flexibility to accept the effects of ABI. More understanding is required of the processes and different stages of adjustment before we correlate any given number of factors to this concept in an attempt to understand how to best support the individuals with ABI and their families. Moreover, we should be

considering at what stage people are at in their journey first, before trying to understand how they got there, as these results suggest the timescales of the adjustment process can vary considerably between individuals. Moreover, when comparisons of the factors which effect or contribute to adjustment are being compared across studies, these comparisons are flawed in that there is no way to tell at which stage the participants are at with their adjustment in terms of their process. Even within studies fall foul of this disparity, such as Bushnik et al., (2015) whose sample varied from 3 months to 9 years post injury, and Ownsworth and Fleming (2005) whose sample consisted of patients ranging from 6 months to 22 years post injury. Moreover, such patients may present on a scale as partially adjusted, which could for that person be positive as they are recognising they are on a journey to feeling total acceptance of their new life, or it could mean they feel that is the best it is going to be and they will never get to fully accept their situation. One person may present with a score which suggests they have adjusted to life after ABI, and this may be the case, as they have a gratitude for the outcomes achieved and a new normal has been found. For another person, they may present as adjusted to life after ABI, but feel resigned to accepting this life due to having no choice and feeling stuck with their lot. So two individuals could present at the same stage of adjustment, but it could have very different meanings for them.

#### **4.5 Summary of qualitative findings**

Taking the breadth of topics discussed in the interviews into consideration, it becomes evident that families, although functioning as units, do not experience ABI in a unified way. There are some similarities between the reports of individuals with ABI and the relatives of individuals with ABI, but there are more ways in which their experiences differ. These similarities and differences across the themes are separated here as a synopsis of the main

findings across these themes. The distribution of how participants responded to the interview questions is presented in Table 5 to enable comparisons of experiences to take place.

Table 5.

*Distribution of participant responses expressed in main themes*

Theme	Individuals with ABI <i>n</i> (%)	Relatives <i>n</i> (%)
<b><i>Coping</i></b>		
Theme 1: Coping change	8 (38)	11 (58)
Theme 2: Specific coping with ABI stressors	7 (33)	10 (53)
Theme 3: Coping across time	7 (33)	10 (53)
<b><i>Family Changes</i></b>		
Theme 1: Relationship changes	15 (71)	7 (37)
Theme 2: Functioning changes	6 (29)	7 (37)
Theme 3: Role changes	3 (14)	6 (32)
<b><i>Loss after ABI</i></b>		
Theme 1: Loss of person	4 (19)	7 (37)
Theme 2: Loss of relationship	6 (29)	4 (21)
Theme 3: Loss of activity/ability	7 (33)	2 (11)
Theme 4: Loss of future	1 (5)	2 (26)
Theme 5: Unclear loss	5 (24)	5 (11)
<b><i>Adjustment</i></b>		
Theme 1: Adjusted to life after ABI	14 (70)	16 (84)
Theme 2: Partially adjusted to life after ABI	5 (25)	2 (11)
Theme 3: Not adjusted to life after ABI	1 (5)	1 (5)

*Note.* Individuals with ABI sample size of 21 (20 for adjustment themes). Relatives' sample size of 19. Percentages are rounded to the nearest whole unit.

#### **4.5.1 Similarities between individuals with ABI and relatives**

Although people talked about the various difficulties ABI had brought to their lives and the strain this had put on family relationships, most people felt adjusted and had a positive outlook on general life with ABI. The biggest similarity seen across all participants was that of feeling adjusted to life after ABI. For both the individuals with ABI and relatives, 95% of both samples reported being either totally adjusted or partially adjusted to life after ABI. This finding suggests that even though experiences may differ greatly, and people can face a multitude of changes to their lives regardless of if they had sustained the injury or not, both parties are capable of remarkable resilience to living with these changes. It is therefore questionable when studies use depression scales as an indicator of adjustment, as families can present with a large degree of loss or show dissatisfaction with the family changes brought on by ABI, but may have found a way of living with these in the long term which allows for acceptance and the chance to move forward after any trauma of ABI event subsides. This does not mean we should leave families to live with their dissatisfaction and /or loss. Moreover, we should consider their individual narratives before assuming the family requires support. For instance, if a person feels adjusted to their life after ABI because they have found a 'new normal', but an intervention is suggested to encourage different family functioning due to dissatisfaction with new roles being identified, this new normal will be disrupted, and thus the feeling of adjustment is at risk of being lost. Successful adjustment processes could potentially be undone, leaving families to begin the process of finding their new normal again.

#### **4.5.2 Differences between individuals with ABI and relatives**

This study did not initially set out to separate the experiences of those with the injury from those related to them. However, across the process of analysis, it became clear that although very similar themes emerged for the participants as a whole, the meaning behind these themes differed by participant type.

For responses relating to coping behaviours, there was an equal distribution of individuals with ABI expressing responses to the three coping themes, with around a third represented in each theme. For relatives, just over half were represented in each coping theme. This suggests that each theme was equally represented for each participant type, but that each theme was reported by more relatives than individuals with ABI. The increased reporting for relatives in the coping section could be indicative of the limitations ABI can bring on self-awareness, reflection and expression for those who have sustained the injury. Individuals with ABI may simply not be as skilled at reflecting on their coping behaviours across a timeline and reporting these without much prompting. Participants were not given extensive examples during the interview in an attempt to avoid people being influenced by suggestions or led to a particular response through the type of questioning used. This may in turn have disadvantaged individuals with ABI from fully expressing the diversity of their coping behaviours and subsequent changes to it. The balance between encouraging experiences to be reported sufficiently whilst avoiding suggestive or leading questioning poses a challenge for qualitative researchers in the field of ABI adjustment. It may be that one interview is not sufficient, and that a staged approach will help create a more accurate picture of the changes experienced by individuals with ABI. For example, an initial set of semi-structured interviews could be conducted with a sample of individuals with ABI which inform a more structured set of interview questions from which the participants respond to in

a more prompted manner. The researcher can then compare the two interviews to interpret the responses and allow for the identification of desirable responses based on the type of questioning applied. Of course, the differences in the prominence of coping expressions in relatives versus individuals with ABI could be because relatives feel a greater impact from the ABI and report more changes as a result.

The most diverse differences were seen for the experiences of loss. Through the analysis, five themes emerged. However, the experiences of loss were very much dictated by participant type. Loss per se was reported quite equally by individuals with ABI and their relatives, but the type of the loss experienced was expressed differently. The ABI often has wide reaching implications, but the individuals with ABIs' experience and feelings of loss do not transfer to relatives just because they are related to each other. The experience of loss is highly subjective and not necessarily related to functional losses as a result of the ABI. For relatives the experience of loss is two-fold: a personal loss for themselves as well as losses for their loved one. The focus for individuals with ABI is more on personal loss. With rehabilitation interventions currently centred on the person who has acquired the injury, these results provide a motivation for addressing the complex dynamics of loss from the wider family perspective.

In summary, individuals with ABI and those who are close to them may not be affected by the injury in the same way. The analysis of the 40 experiences captured in this study show that family members require equal, if not additional, levels of support after their loved one sustains an ABI. Medically, the focus is on the person with the injury, but equal attention is needed for family members to enable the long-term impact of ABI to be supported. The analysis of three key areas considered to contribute to adjustment (coping styles, family functioning and feelings of loss) has shown that people can live through

considerable adversity and face daily challenges as a result of ABI, but that ultimately they can feel adjusted to these challenges and experience positive family changes, particularly for those who have sustained the injury.

Theoretically, emotion-focused and avoidant coping is not considered conducive to adjustment, but the experiences of participants in this study suggest different aspects of ABI coping require different coping responses, and that this is unlikely to impact on the feeling of adjustment. The two participants who did not feel adjusted were able to provide insights into the emotional connection towards the ABI aftermath, and how impactful this can be for the adjustment process. For the individual with ABI, their rehabilitation treatment was the source of their anger and subsequent inability to accept their ABI. The anger at their treatment remained the focus, rather than the coping with and subsequent readjustment to a new life which incorporated their ABI effects. For the relative who did not feel adjusted, they felt angry that their daughter had been changed by the ABI and they were now not living as independent a life as was expected. More research into the impact of anger and resentment on the adjustment process may be of more benefit than that concerned with the way people are choosing to cope with the challenges of ABI life.

## **Chapter 5. Dyadic case studies**

### **5.1 Introduction and rationale**

This chapter presents two exemplary case studies of dyads who took part in this study. Each case will be presented as an example of the different ways people can adjust to life after ABI, based on the interpretations of their experiences. These case studies have been purposively chosen due to how they represent coherent experiences of most, if not all of the main themes presented in chapter 4. The original transcripts were revisited and inspected for their suitability for representing dyadic case studies of different types of adjustment. Similarities and differences within dyads were noted, as well as how broadly they represented the thematic analysis themes from chapter 4. From this, four dyads were narrowed down, with two finally being eliminated based on the amount of replication they had with other transcripts, and the two most thematically rich dyads were chosen. The motivation for presenting these case studies is to further explore the lived experience of families after ABI in greater depth. Whereas the interviews were analysed using thematic analysis in chapter 4, interpretative phenomenological analysis (IPA) has been used for these case studies to allow for the lived experience to emerge (Alase, 2017). The full analysis of 40 transcripts was too vast to apply IPA techniques to and would produce highly individual results which would not be able to be generalised across the whole participant sample. However, the use of IPA on the following four transcripts gives greater insight into the wider themes found through thematic analysis.

### **5.2 Interpretive Phenomenological Analysis**

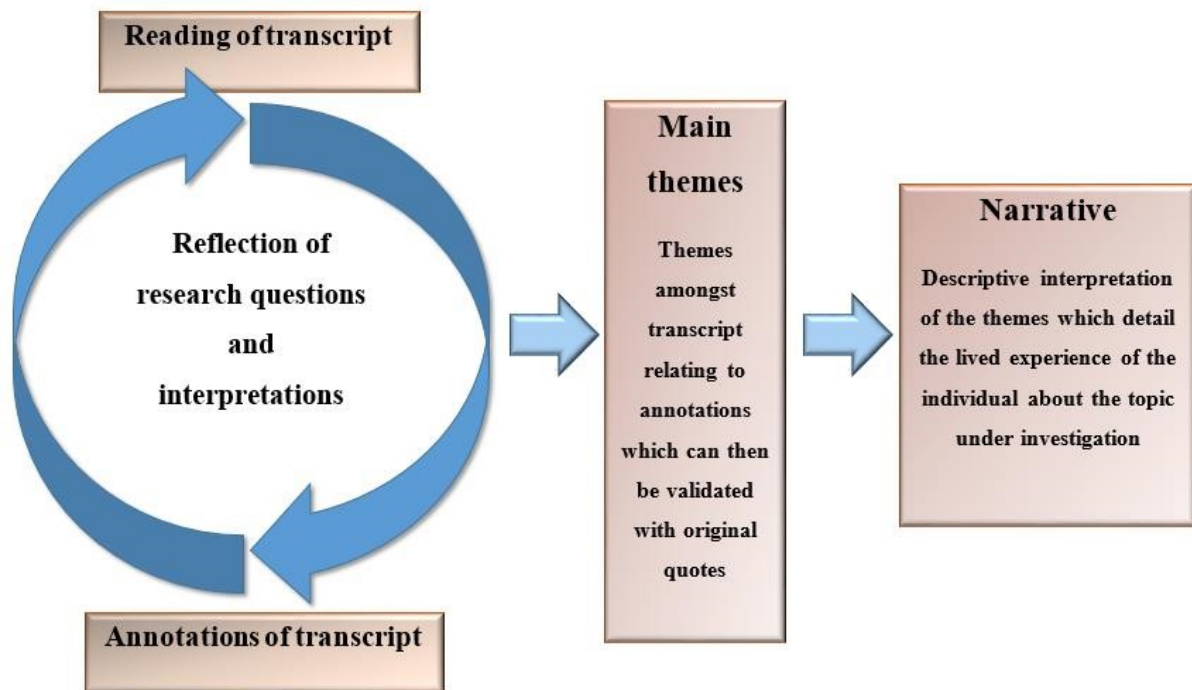
The aim of this section is to examine in-depth two dyadic cases of adjustment to ABI in an attempt to understand more about the complexities of family dynamics when one of its



members sustains an injury. Larger sections of transcript extracts have been included to allow the participants' voices to come through. IPA is well suited for this purpose as it is a technique which aims to examine the lived experience of individuals in a comprehensive manner. More general claims are developed from these specific experiences to explain or describe the phenomenon of interest (Smith & Osborn, 2015). Moreover, it aims to understand how an individual makes sense of their experience from their own unique context and perspective (Pietkiewicz & Smith, 2014). Also, IPA fits well with the interpretivist-constructivist philosophy of the research, with the researcher playing an integral role in the interpretation of the participants' lived experiences of adjustment to ABI.

### **5.2.1 IPA procedure**

Each case study is presented with its own coding table to enable easy identification of the IPA process that has been applied and subsequent interpretations made. For each case, a table is presented of the main themes for each dyad along with a narrative to interpret the themes in line with the findings of chapter 4 as well as the wider literature previously discussed. Figure 6 visualises the IPA process akin to that outlined by Smith, Jarman, & Osborn (1999).



*Figure 6.* Diagram depicting IPA process

Themes from the IPA are separated into three sections to represent those that relate to coping, those which relate to family change, and those which relate to loss, to enable the reader to examine these in the context of the wider research project. Furthermore, themes and quotes from the IPA will be linked to themes presented in chapter 4, allowing for the dyadic case studies to be interpreted in the context of the wider study sample. IPA themes are identified for each individual dyad and there is no attempt for these themes to transcend into other dyads. The IPA themes are intended to act as a guide which gives an overview of the shared experiences between the individuals. The themes will also provide a template for the narrative which is intended to provide an insight into the experiences of the families concerned.

### 5.3 Case study 1 – Harry and Patricia

Harry was involved in a road traffic accident and suffered a traumatic brain injury as a result. At the time of participation in this study it had been 64 months since Harry's injury. His mum, Patricia, also took part in the study and they both told their story through the semistructured interview process. Harry did not live at home at the time of the injury, and still lived independently from his mum at time of interview. Their responses are presented here as an example of a family that has adjusted well to life after the injury event, having overcome the challenges they faced in the early months after the injury. The dyadic themes which emerged from the IPA of their transcripts are presented in Table 6, and then discussed in the subsequent narrative. How these fit with the themes of the thematic analysis is included to enable the reader to interpret the IPA findings in the context of the wider study.

Table 6

*IPA themes with indicative quotes and related thematic analysis theme*

IPA theme	Harry – individual with ABI	Patricia – Harry’s mother	Thematic analysis theme
Measured coping styles	<i>“I tend to just sit by myself”</i>	<i>“I tend to just sit and go into my room or something. Just chill for a bit”</i>	No relation to themes
ABI not the focus of life	<i>“Talking at home with my husband. Talk it through or if it’s something at work still talk it through at home.”</i>	<i>“If I could take myself away from where it is I would.”</i>	No relation to themes
Grateful	<i>“I just explained it and he was like ‘oh alright’. I think, when it’s times like that and people ask, I will tell them. I won’t just be like ‘oh by the way I’ve had a head injury’, but I think that’s how I cope with it.”</i>	<i>“I don’t know if the word is ‘cope’, but I feel it is much easier as time’s going on. You don’t stop worrying about him but you worry less the more he’s getting on with his life.”</i>	ABI specific coping
Good coping context	<i>“If anything, it’s made it better.”</i>	<i>“I think we’re just so grateful that we’ve still got him.”</i> <i>“Luckily he got all the help and all the support.”</i>	ABI specific coping
Closer family	<i>“I guess it was a good time to do it [have injury].”</i>	<i>“So it was probably, if there is a good time for it to happen, it probably was. It could have been worse.”</i>	No relation to themes
No feeling of loss	<i>“I didn’t really get into contact or anything [before injury], but then after uni I was like ‘I should of like, they’re my family like’”</i>	<i>“It did, and does, and has made us closer.”</i>	Family changes – increased closeness
Adjusted	<i>“They [family] must have supported me so well I just felt I could get on with it.”</i>	<i>“I don’t feel I’ve lost anything.”</i> <i>“He’s able to carry on with his life, where it could have been so different.”</i>	No loss
	<i>“Yeah totally [adjusted], because I’m just constantly thinking of better things.”</i>	<i>“I think just seeing him get on with life. He’s less of a worry than I thought he would be.”</i>	ABI specific coping

### 5.3.1 Harry's experience

*Coping* Harry described himself as a laid back person. He only recognised one coping style in himself when asked how he deals with stress and this was to get some time out:

*"I tend to just sit by myself. I kind of like, recharge. I just kind of sit and go into my room or something. Just chill for a bit."*

Harry did not feel he coped with anything regarding his injury differently, although he did at times talk about 'educating' others about his needs, such as how to talk to him or his need for time out. He was also able to acknowledge the need to manage his injury deficits by changing the way he acted. He now relied on a whiteboard to organise his timetable, and knew that if he thought 'I will do that later' that he will forget, so he now did things that needed doing straight away. Harry couldn't recall if his coping style had changed since his injury. He seemed to have a disrupted sense of self, as in how he was, rather than a specific recall issue:

*"Well I can't remember, that's the thing. I can't remember before...well obviously I can remember before the head injury, but I can't remember how I dealt with stuff. It's weird."*

For Harry, this memory disruption also affected his recall of his early recovery in hospital. He could remember being there and could remember his parent's visiting him regularly. The sense of what it was like in hospital though is very general for him. Even though Harry had to face many new challenges, he doesn't see this time as particularly noteworthy:

*"Hospital's weird because like, obviously I can't remember a lot of it...I didn't really do anything except lay there. Like there was nothing to do, but on weekends I went home. I*

*didn't really do anything. I had like a game console thing. I did that and slept. That's all I did. Well that's what I remember."*

Even though Harry received rehabilitation after his injury to overcome some significant effects of his TBI, this does not come through as part of his experience. It is unclear whether this is due to his noted memory deficit, which seems to at times affect his ability to recall more than a 'gist' of things. It could be that during this time in hospital, the effects of his injury were still acute enough to hinder processing of the actual reality he was experiencing. Of course, it could also be that Harry spent the majority of time feeling bored and lying in bed, leaving this as his primary impression of his hospital experience. Whatever the reality was for Harry, his lasting impression of his early recovery from his TBI is one of indifference. Harry does, however, hint at the hospital stage not being a completely carefree time for him, and that this feeling of boredom was a challenge in itself:

*"Well It's not really stressful is it [hospital]? I mean, I was really stressed that I was in there. I remember once my mum and dad came...and I remember just getting annoyed with my mum, and she was like 'what? What's this about?', and then she was like 'it's because you're frustrated, you've got no one to talk to,' and I was like 'yeah, fair.' I can't remember, it's a long time."*

In terms of the time of life that the injury occurred, Harry felt this was okay. He didn't have financial commitments to worry about such as rent. He also felt he had been given a lot of support and he had control over his rehabilitation, although on reflection he feels he did not fully appreciate it at the time.

*Family change* Harry's disrupted memories for how things were before the injury were evident when talking about family changes as a consequence of his accident. He said he

couldn't remember what things were like before, but he could recognise that his family members interacted with him differently, and that this change came from their greater awareness of how potentially life changing the accident could have been for him:

*"I can't really remember before....I don't feel like much did change, but then again, something might have changed.....they see me differently you can tell, but I can't remember what happened, how we were before... When my dad's driving and stuff, he will point out all the stuff he remembers when he rushed down like. You can tell, they're not going to forget about stuff like that. Like it was a lot worse for them than for me, kind of thing, because I was just sleeping through the traumatic stuff."*

Harry went on to elaborate about the changes in how he feels his family see him after his injury:

*"After uni, when I passed they were just like 'you've done so much, you couldn't even speak and now you're here.' Stuff like that. Well I don't think they treated me differently. Maybe at the start they did, and then yeah, I think anything I do that's reasonably decent, they'll be like 'Oh he's done all this' just because of the brain injury. Just more proud I guess."*

It appears Harry does not feel much family change from his accident. His living circumstances haven't changed, and he doesn't show dependence on his family that is any different to how things were before. The biggest change for Harry is a feeling that his family appreciate his successes more due to the experience they went through, whilst he was protected from this due to being in a coma. Although his day-to-day family environment hasn't been affected, he reflects on a changed perspective of how he connects with his family now. He is mindful not to necessarily attribute this closer family connection to his injury, but is aware of the need to appreciate this connection more:

*“[Before the injury] I didn’t really get in contact or anything, but then after uni I was like ‘I should of, they’re my family’. So I’ve got in contact with them a lot more recently. But I don’t know if that’s my brain injury?”*

*Loss* When discussing feelings of loss after ABI, Harry’s unclear memories of his life before his accident appear to be a protective factor against such feelings of loss. He doesn’t dwell for a time before his injury because he can’t quite remember it. Harry’s experience of his injury does not include details of his injury event, or the most unstable months directly after, so therefore he does not feel it has been as significant for him as it has his family. In fact, Harry feels a positive change from his experience, with a greater appreciation of life:

*“I don’t feel [loss], I just feel like I’m the same, although there was some difficulties, but it wasn’t like I couldn’t carry on. I’ve never really had a, well I guess my family must have, well they did, they must have supported me so well that I just felt like I could get on with it. And it’s not like I was really bad.....If anything it’s made it better, because I actually tried at stuff....even now I’m constantly trying. Before I was like, I didn’t really care, I just got what I was given.”*

Harry’s experience has resulted in him appreciating the opportunities presented to him more, which he now approaches with a newfound determination to make the best of his life postinjury.

### **5.3.2 Patricia’s experience**

*Coping* Patricia expressed the experience of her son’s injury in a factual and calm manner. She did not feel she would have a great deal to contribute to the research but was happy to take part. We started off talking about general coping styles. Patricia reported that she would rely on her husband as her main source of support. Even if something had been stressful at



work, she would wait to go home and talk things through with her husband. When given some prompts during the interview, Patricia was able to identify with venting and avoidant coping styles:

*“There are times when I vent, there are. Especially when you’re in work, and at home, yeah there are times I vent. Also if I could take myself away from where it is, I would, but really it’s a bit of all of it really.”*

This description of her coping suggests Patricia does not face challenges head on, but rather avoids them or feels overwhelmed by them until she can get the support of her husband. The partnership they share provides a secure environment to feel more confident with coping. This partnership was acknowledged when reflecting on coping in the early stages of her son’s injury:

*“Myself and my husband obviously did everything together and we do do everything together anyway, so I think it showed us our capabilities actually.”*

Patricia did not feel her coping styles had changed as a result of her son’s injury, although she did feel she copes differently at times:

*“If anything has changed I wouldn’t put it down to Harry’s injury. I mean it could be, but life isn’t as bad as, you know, things are not as bad. I don’t know if, as I’ve got older I’ve changed. I would vent less and talk more. Whether that’s got anything to do with Harry? I wouldn’t put it down to that.”*

Patricia found it hard to express how she coped with the initial months after her son’s injury. She described it as being on autopilot and a feeling of just getting on with it. Of those early days Patricia said:

*“It was just devastating really. It was hard, but it was harder for him than it was for us, because he is the one...his life has changed. He couldn’t do what he could do at that time, it was hard. Hard for us all really, But we got through it, he got through it.”*

This sense of it being Harry’s injury and Harry who had been affected plays a key role in Patricia’s subsequent adjustment. In the acute phase, the distress came from seeing her son incapacitated and not at the ability she knew he could function. It was the impact this could have on *his* life, rather than her own which caused most concern. As Harry progressed through rehabilitation and later was able to move back home and live independently, this distress was replaced with relief, and a gratitude for the independence Harry had been able to regain. Coping with the injury became easier as time went on. Patricia recognised that her family had been through a difficult period, but because Harry was doing so well she was able to reflect on how resilient she and her family now are:

*“You just don’t think you could cope with anything but when something like that happens you obviously can and you do. And then someone else is going through something, maybe not similar, but it brings it back to you what Harry [went through] and it makes you realise just how lucky we are that Harry is with us.... If you can get through that, you can get through anything.”*

Patricia showed through her interview that she had the ability to look at her experience with a positive perspective. She did not mention anything her son couldn’t do as a result of his injury, although she often referred to Harry ‘before’ the injury and ‘after’ the injury, suggesting she did acknowledge consequences of sorts from the TBI. Patricia spoke repeatedly of Harry’s achievements and how proud she was of his determination and work ethic. This positive perspective was also evident when reflecting on the time of life that the injury occurred:

*“If the other [children] had been so much younger, and then that does put more pressure on...and luckily I had my mum around. So it was probably, if there is a good time for it to happen, there probably was. It could have been worse, it could have been a lot worse.”*

*Family change* Patricia did not feel anything had changed for her as a result of the injury and credited this to Harry not living at home, and making such a recovery that he did not depend on her. She wanted to be involved in his rehabilitation and visited daily to the hospital. When Harry was discharged, Patricia attended educational support groups to understand her son's injury more. But for the day-to-day functioning of her family environment, Patricia felt there had been no impact. The area Patricia felt there had been change was with the interpersonal feeling between family members:

*“So it hasn't changed the way we do things in the home at all. It did, and does, and has made us all closer.....As a family well, I think it brought us closer together. And we are all very much aware of, we haven't forgotten what happened to Harry.”*

*Loss* When asked directly if she had or had not felt a sense of loss from her son's injury, Patricia confidently replied:

*“I personally don't feel I've experienced loss. Maybe at the time I did, in some strange way, but I don't feel I've lost anything. Yeah okay, he's not, he's got a brain injury that he didn't have before. That's his loss more than mine. Yeah I don't feel any, I personally don't feel that I have a loss.”*

Patricia was able to attribute this to the recovery Harry had made. The positive perspective was evident again and seemed to have mediated for any potential loss that could have occurred.

*“I think we’re just so grateful that we’ve still got him. And that, not only have we still got him but we know how easily his injury could be that he is at home with us 24/7 because he needs looking after. But luckily he got all the help and all the support and medical [help] ...and he’s able to carry on with his life, where it could have been so different.”*

Through Patricia’s responses it is evident that she feels immense gratitude for the recovery her son has made. The ability to acknowledge how far he had come and the reality that at one point he may not even have lived, negated for any challenges or set-backs he might have faced as a consequence. Even though Patricia described the event as “devastating”, her lived experience portrays how her positive outlook has nurtured a gratitude for her life after the injury.

### **5.3.3 How the family has adjusted**

Both Harry and Patricia presented a positive picture of life after ABI. Harry had sustained a traumatic brain injury, and his family had experienced a trauma with the event and aftermath. However, there are a number of common factors expressed in their stories which could help understanding as to what has contributed to them feeling adjusted to life after the injury. These form the basis of the IPA themes in table 6 (page 143), and are presented in turn.

*Measured coping styles* This theme describes how the coping styles expressed by this dyad are calm in presentation and do not involve outward emotional reactions. Both Harry and Patricia expressed the use of time out to cope with stress. Their expressions of how they react to stress is one of a measured approach, rather than an emotional reaction. Harry could not identify any other way he coped with stress, showing a very narrow range of options for him. He would report feeling stressed or frustrated at times but could not describe how he would

manage these feelings in the event of not being able to distance himself from them. This could be a sign of impaired self-awareness into how he manages stress, or it could be that he does not feel quipped with different coping strategies. This did not seem to influence how Harry managed life after his injury, and he presented during the interview as a very calm and relaxed character. Patricia also presented in a clam manner and reported using the support of her husband as a key coping strategy. The way she explained this as “waiting to talk things through at home” suggested this was a controlled and thought through coping style that had proven effective for her when managing stress.

Both Harry and Patricia felt they did not compare life before the injury to now. They did not dwell on the past, and felt positive about the future and the outcomes for Harry after his TBI. The recognition of post-injury growth has been reported as an integral factor for good adjustment by adults with TBI in a study by Roundhill, Williams, & Hughes (2007). It could be this same recognition has taken place for Harry and Patricia, with Harry’s recovery far exceeding his original prognosis. Harry and Patricia’s responses to the injury are indicative of a forward facing perspective, which could have provided them with a good foundation from which to cope with the situation they were faced with.

In terms of the literature, it is unclear whether the coping strategy of time out is considered advantageous or not. Dependent on the classification, time out could be seen as disengagement, an avoidant technique generally considered to have negative consequences (Skinner, Edge, Altman, & Sherwood, 2003). However, styles which minimise the impact of immediate emotional stress in a short-term capacity are thought to be adaptive (Gregório, Stapert, Brands, & van Heugten, 2011). What appears evident from both Harry and Patricia’s interviews is that the coping style of positive reframing plays a key role in their adjustment.

This is in line with a key theme found through IPA in a study by Shotton, Simpson, & Smith, (2007), whereby those able to identify positives from their TBI experience achieved good adjustment.

Neither Harry nor Patricia identified positive reframing as a coping style for managing stress, but both referred to the positives of the experience during their interviews with a perspective of 'it could be worse'. This discrepancy between reported and observed coping styles could be due to the response the questions elicited. Although asked to think about general coping styles, it may be that it is hard for people to think of how they cope with stress without them internally referring to some experience they have had and reflecting on how they dealt with it. Therefore, under direct questioning about coping responses, the answer could relate to situational coping behaviours specific to acute stressors which come and go. However, when discussing a general experience of something, such as feelings around an ABI event and subsequent changes from it, more dispositional coping styles come through. These styles are not even acknowledged as ways of coping, they just are how people approach situations, thoughts and encounters.

*ABI not the focus of life* What became apparent from examining the two interviews was that neither Harry nor Patricia felt the injury was of much concern on a day-to-day basis. For Patricia, Harry was not dependent on her and his injury did not affect him living a full and successful life. The injury had left an impression on her relationship with her son, and she admitted she worried about him more than her other children, but the outcome had been so much better than expected for Harry that any deficits were over-ridden with gratitude and pride. For Harry, his reduced recall of how life had been before his injury meant he did not feel a change after it. He was still achieving what he wanted to and had accepted that he needed to implement some additional strategies to enable him to do what he wanted.

The core narrative of Patricia and Harry's stories is that of the injury not leaving a lasting impact on Harry's life. Patricia had been faced with a reality of her son's mortality and the unknown path of rehab that followed. To see him living independently and continuing on a similar life course to the one he was on before his accident meant any consequences were incidental. It is impossible to say whether the family would have adjusted so well to life after ABI if Harry had not made such a good recovery. However, it could be that the use of positive reframing would have protected against feelings of loss even if Harry had not achieved so much post injury. This would be supportive of the findings from studies that suggest positive reframing, a problem-focused coping strategy, leads to better psychosocial outcomes (Roubinov, Turner & Williams, 2015; Shotton, Simpson, & Smith, 2007). This concept requires further investigation though, as problem-focused styles should only be advantageous if the stressor is controllable. How to quantify if managing chronic stressors after ABI is controllable or not is complicated and requires consideration of both the objective and subjective appraisals of controllability. It is conceivable that benefits of any given coping strategy requires the consideration of an objective assessment of controllability, a subjective assessment of controllability, and an assessment of what the strategy is being used for (to solve the stressor or minimise the emotion regarding it). What does seem apparent is that the use of and intentions of coping styles can be illusive even to the copers themselves, meaning we are still some way off being able to harness the true power of coping efficacy. An increase in studies using qualitative methodologies to investigate coping behaviours could help researchers to reach a better understanding of the role positive appraisal plays in ABI adjustment.

*Grateful* The third theme that emerged from the dyadic IPA is that of feeling grateful. This relates to the coping style exhibited by Harry and Patricia of positive reframing and helps us understand why they both report feeling fully adjusted to life after the accident. For Patricia,

she has experienced a harsh and frightening reality, one which could have ended in the death of her son. However, instead of this traumatic experience leaving negative consequences for Patricia, she has been able to use it as a reference point from which to appreciate the life she and Harry now share. For Harry, the extent of his initial injuries meant he was protected from the full impact of the event and did not have to process information about his prognosis and potential outcomes. As he said, he was “sleeping through the traumatic stuff”. As well as being protected from the trauma, Harry has a vague recollection of his life before the injury, and feels he is a more determined and considerate person as a result of his accident. He recognises that before his injury he was prone to laziness and may not have achieved as much as he has if he hadn’t experienced an event which made him re-evaluate the way he spent his life.

It is somewhat unsurprising to find gratitude as a theme for this well-adjusted family. There is strong evidence in the literature to suggest having a grateful outlook and acknowledging positive attributes of life over negative ones has significant benefits for emotional as well as physical well-being (such as Allen, 2018; Emmons & McCullough, 2003; Măirean, Turliuc, & Arghire, 2019). Although Harry focused on positives and appreciated life more after his injury, the grateful outlook was particularly evident for Patricia. It is not known if Patricia has always had such an outlook, or whether this positivity extends beyond aspects of life unrelated to her son and his injury. It could be that the very experience of overcoming such a traumatic period in her life has left her with a new found gratitude. What is apparent is that Patricia particularly attributes this to her good adjustment to life after the ABI.

*Good coping context* A consideration that could potentially affect subsequent adjustment to life after ABI is that of the context within which the injury event occurs. According to



Lazarus and Folkman (1984), stress only occurs when people appraise a situation to be beyond their coping resources. Therefore, it could be that if an injury event occurs at a time when someone already feels they are near coping capacity due to other commitments and stressors, coping with ABI could be affected consequently. For Harry and Patricia, there was a sense that the event happened at a time when they had the resources to cope with it. For Harry, he did not have family or financial commitments, and for Patricia, she had sufficient family support to lessen the burden of her other family commitments. Having sufficient family and friend support has been found in other qualitative studies as proving an integral coping resource for caregivers (Cairns & Quinn, 2005; DeLongis & Holtzman, 2005). It certainly does appear that for this family, the event occurred at a 'convenient' time to enable good adjustment to take place. They were able to express having good support networks and minimal other stresses, which would lead to the assumption that their appraisal of the situation is accurate. However, how much of this report is filtered through the family's 'grateful' outlook is not known. The use of both Harry and Patricia's positive reframing style could lead to a positively skewed report of it being a good time of life regardless, as they might be prone to viewing the context of the injury in an optimistic fashion. Akin to the Lazarus and Folkman (1984) theory of stress and coping, it is not important as to the reality of the situation, but more the perception of it, so the *experience* of the injury occurring at a good point in life is important here, whether this is attributable to positive reframing or to the facts of the situation is of less importance.

*Closer family* Both Harry and Patricia expressed positive sides to their experience, with one of these being a sense of closeness between family members, bonded by the injury experience. Through their stories you get a sense of Harry being at the centre of this increased closeness. It is his injury event that has shown Patricia that she and her husband are resilient and feel they can withstand anything due to withstanding the trauma of the accident.

Patricia very clearly expressed that the injury experience had brought her family closer together, both at the time, and now some years on. There was a metaphorical rallying around Harry by his parents and siblings, and this supportive grouping has remained. Harry mentioned that the injury acts as a sort of reference point for which his family members judge his achievements, making what would have felt good, but normal, achievements even greater successes. Harry achieved what his peers did, but he did this in spite of his injury, so it deserved a greater recognition.

As was seen in the thematic findings in chapter 4, ABI does not always bring families closer together, and some participants expressed a ‘splintering’ of their family as a consequence of the ABI stress. For Harry and Patricia though, their family had responded as a unit and helped each other through. A unit which appears to have remained even as Harry has progressed and gone on to live an independent life. It was not investigated whether there had been other instances where the family had responded in such a way, or whether the injury was the first test of the family’s resilience. It may be that the family functioned pre-injury as a strong, coherent unit, or it could be that the threat to one of the family members facilitated this cohesion, subsequently changing their family functioning forever. However their response was initiated, it appears that a united family approach to coping with a traumatic event has helped with the adjustment of life after ABI for Harry and his mum.

*No feelings of loss* Feelings of loss regarding ABI have been seen to strongly correlate with feelings of adjustment when measured quantitatively (Ruddle, Coetzer, & Vaughan, 2005). That is, the more loss someone feels, the more poorly adjusted to living with ABI they will be. Patricia and Harry’s experiences both support this view as neither reported feeling any loss around the injury, but both also felt adjusted to life now. When asked why they didn’t feel any loss, Patricia drew on her grateful outlook again, attributing her appreciation of how

well her son had recovered to not feeling any loss. For Harry, it was a mixture of not feeling incapacitated by his injury, and a vague recollection of what his life was like before the injury occurred. From these experiences it can be interpreted that having no sense of losing anything from the injury has contributed to the successful adjustment of Harry and Patricia.

*Adjusted* The final IPA theme presented here is that of adjustment. The core focus of this project has been to seek a greater understanding of the factors which may or may not contribute to a family adjusting well to life after ABI. The aforementioned IPA themes appear to all lead into this positive adjustment and describe attributes both on an individual and family level which have contributed to this adjustment. It is not assumed that the reason for the adjustment lies in Harry's successful re-integration into life. Moreover, there are common elements throughout – positive reframing, a grateful outlook, a supportive family- which seem to influence the adjustment process and provide insights into what has been important for the individuals involved. The appearance of common components between Harry and Patricia's experience could be one factor which explains their adjustment. A closer investigation into pre and post family functioning in the wider ABI population may help us understand the importance of supportive family structures as a protective factor against the impact of trauma.

It is important to note that Harry did make a very good recovery from a significant traumatic injury, and the discrepancy between the initial prognosis and his eventual level of independence could be pivotal for Patricia's adjustment. However, it cannot be known if, had Harry not made such a good level of recovery, that Patricia still wouldn't have achieved this adjustment. If she had still harboured a tendency to have a positive and grateful outlook, then even a markedly worse recovery would have still been something to cherish, as her son was still with her. Further research into the benefits of a grateful outlook in the context of ABI

adjustment would be useful, as therapeutic input to help people nurture such a perspective for themselves and others may prove useful with families struggling to adjust.

## 5.4 Case study 2 – Max and Hazel

Max suffered a TBI and was just 24 months post-injury at the time of the interview. His wife, Hazel, also took part, answering the same semi-structured interview questions. Their home situation has not changed since before the injury, they are still co-habiting spouses. Their dyadic themes which emerged through the IPA process are presented in Table 7. Their stories give insight into how members of the same family unit can experience common, but also uncommon, aspects of the same injury event, and that subsequent adjustment does not have to be influenced by a shared feeling of adjustment as a family. As with case study 1, a table of dyadic themes is presented, followed by individual narratives and an interpretation of how this relates to their family adjustment as a whole.

Table 7.

### *IPA themes with indicative quotes and related thematic analysis theme*

IPA theme	Max – individual with ABI	Hazel – Max’s wife	Thematic analysis theme
Changes to coping after ABI	<i>“A problem was a challenge...now I find the problem is me taking things the wrong way and dealing with it on a personal level...”</i>	<i>“It did make me more willing to ask for help.”</i>	Coping theme 1: Coping change – conscious coping changes
Emotional responses to ABI stressors	<i>“So, personal stresses over the injury. I don’t deal with them as a stressful situation, I just give myself a hard time. I berate myself for not having those skills.”</i>	<i>“I guess the stresses around the injury are a lot more emotional.”</i>	Coping theme 2: ABI specific coping – different reactions

Family changes	<i>"Maybe just me being around an awful lot makes it more stressful for other people, that I'm unpredictable but just the, maybe I'm more demanding..."</i> <i>"I struggle with going out, so making plans is a bit here and there."</i>	<i>"...at the moment I'm the breadwinner. It's difficult to plan things."</i>	Family changes theme 2: Functioning changes – social functioning Family changes theme 3: role changes
Social changes		<i>"It's difficult to plan things because I never know quite how he is going to be.."</i>	Family changes theme 2: Functioning changes – social functioning

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#### 5.4.1 Max's experience

*Coping* Max was very aware of his coping strategies and the impact these sometimes had.

Even though he was asked to speak generally about his coping, he recognised that, for him, this was very dependent on how his ABI related fatigue was affecting him. Subsequently he was able to describe two scenarios. If he was feeling well he would use a problem-solving strategy, akin to his pre-injury style, as a direct attempt to remove the stress. If it was unsolvable he would walk away from it, or take time away from the situation to try and solve it better. This demonstrates flexible coping with a focus on minimising the source of stress, which is thought to be an advantageous approach (Cheng and Cheung, 2005; Cheng, 2003). However, Max now needs to accommodate the effects of his injury and cannot always use his problem solving approach if he is feeling more fatigued:

*"The other end is I will shout, scream and swear and tell whoever it is to fuck right off actually...and probably get more disjointed information. So, a bit of a tirade might come out....the most common outcome is a bit of both. I'm aware of what I'm trying to deal with but I'm unaware of having resources to deal with it, so I meet in the middle and struggle with it, and usually it ends up being stressful."*

For Max he feels a direct connection between his ABI challenges and his coping ability. His impaired problem solving ability clashes with his pre-injury coping style and can

create more stress as a result. He also has a variable amount of capacity to deal with stress due to ABI related fatigue, and this has consequences for the efficacy of his coping efforts. This sits very much in line with Lazarus and Folkman's (1984) theory that coping is dependent on the perceived resources of the individual. The issue for Max is that sometimes he is aware of his resources, other times he isn't and he can create further problems as a result:

*"[Before injury] a problem would be a challenge. Problems wouldn't come about through miscommunication and people taking things the wrong way. Now I find the problem is me taking things the wrong way and dealing with it on a personal level so I, everyone gives me a hard time, me included. So problems are different now."*

This awareness of the ABI deficits alongside the inability to manage them was evident in the way Max responded to specific stress that was being caused by his injury effects. When talking about how he copes with issues around his ABI deficits he said:

*"I give myself a really hard time about not being able to grasp what is going on around me, and the fact I keep asking....I'm guilty. I'm guilty of not being able to retain things, or bring things up as I need to, to have normal conversations sometimes. So personal stresses over the injuries, I don't deal with them as a stressful situation, I just give myself a hard time. I berate myself for not having those skills."*

It appears that Max experiences two very different types of coping dependent on the source of the stressor, although both situations are influenced heavily by the injury, either directly or indirectly. With problems which occur that are unrelated to the injury, coping can be impacted on due to Max's impaired awareness and cognitive skills. If the problem is being caused *because* of this impaired awareness and restricted cognitive ability, then Max internalises his emotional response and reverts to self-blame and guilt. Generally,

counteracting self-critical thoughts can be protective against the negative impact of feeling inadequate with oneself (Warren, Smeets, & Neff, 2016). This self-critical stance has often been present in individuals with ABI who are suffering psychological problems associated with their injury (Ashworth, Clarke, Jones, Jennings, & Longworth, 2015), and focusing on the facilitation of kinder responses to these limitations has been shown to enhance wellbeing, such as through the implementation of compassion focused therapy (Ashworth, Gracey, & Gilbert, 2011; Leaviss, & Uttley, 2015). The self-blaming response Max has to his ABI challenges could be impeding on his subsequent adjustment to accepting and living with such challenges.

*Family change* Max's injury effects have had a direct impact on his home life and the way his family now function. Max seems acutely aware that he, at times, may be more difficult to live with. The dynamics of the family have been changed due to Max no longer working:

*"Maybe just me being around an awful lot makes it rather stressful for other people. That I'm unpredictable but just the, maybe I'm more demanding, maybe I need to explain things more or to not talk to me, or to you know, don't come in the kitchen while I'm cooking, I can't concentrate on two things at once. So that's, yeah, things have changed."*

Max elaborates on how the loss of employment has a wider impact on his family beyond a financial one, recognising that a varied network of social connections had enriched his life:

*"[work] sparks conversation and I don't have that anymore. I don't talk to anybody else about how their day was, what's going on, and I don't tell other people, work colleagues as they were, how I feel, what's going right, what's going wrong, what I'm up to. I have to tell my family that so, it gets boring. Boring's the wrong word but it gets predictable. Oh here*

*comes Max and he's gonna tell me how he's feeling. I don't want to tell the same person how I'm feeling all the time. It really annoys me but I've got to let them out. Maybe that's the biggest change. I've got no other outlet to tell people how I am and I forget I've told them and I have to tell them again. So it's a strain on them."*

Further family changes are more acutely felt between interactions with his wife. Again, for Max the way he interacts is very dependent on the status of his fatigue and how much capacity he feels he has. The support given by his wife is either received gratefully or with resistance:

*"Hazel is really good at saying 'you need to remember this, have you remembered that? Remember we are talking about that.' And again, depending on how tired I am depends on the reaction. Stop telling me what to remember! Leave me alone! Do you think I'm stupid?! Yeah, things have changed..."*

As well as changes within the family relationships, Max also reported changes to the way the family functions. That is, the social planning they undertake has to incorporate and respond to the variability of the brain injury effects. Max, however, feels their previous lifestyle means this is not as detrimental as it could be:

*"I struggle with going out. I get tired suddenly, so making plans is a little bit here and there you know, hit and miss. We can make them, but we're aware that they might change ten minutes before. It doesn't put a strain on the family, we've always been a spontaneous couple, Hazel and I. We don't like to have full diaries."*

One aspect of his rehabilitation journey that Max expressed strongly was a feeling of no control over what was happening to him. He felt the rehabilitation he received was motivated by a litigation claim and he was just part of a process.



*“Everything I felt subjected to. I felt there was a legal obligation for me to do the [rehabilitation] ....I went through the motions...but it was a process that I had to go through to kind of make myself look like I was paying attention.....and I found myself, and I still do, kicking back against that, and I really, really disliked what was happening in my life at that moment and I took it out on everyone.... I have an awful lot of anger over what I went through and I don't know if it will ever go away...”*

Max's experience has evidently left an impression on him, even two years later. The importance of a patient-centred approach is apparent as the consequences for Max of feeling like he was not in control of his rehabilitation pathway were detrimental, and it is possible he did not fully benefit from the intentions of the programme he felt 'subjected' to.

In terms of the time of life his injury occurred, Max does not feel it helped the situation at all. He felt his children had important school pressures, and his wife's employment was in a transition period. He himself was on the brink of a new and exciting work venture which subsequently never came to fruition.

Loss Max gave a unique example of what living with brain injury can feel like if your cognition has been disrupted and you find time a confusing concept. He felt loss, but did not connect with it in this way. He felt emotions associated with loss, but could not quantify what this was related to:

*“One of the reactions is sadness. Sadness isn't specifically over loss. It isn't specifically over being sad. I have lots of ways of telling people the same thing. They're not about anything. I don't know what they're about. I might be specific about some 'thing' that I might attribute to the accident and my feelings around it. That might be anger, that might be sadness that might be happiness, it might be bitterness. It's more normally bitterness and anger that will lead to*

*sadness. But I don't know what loss is. You'd have to put that down to a particular timeline, and I don't have that, so it's confusing."*

Max's expression of his feelings about his injury suggest he is still processing his experience and the emotional fall out from his rehabilitation journey. His cognitive deficits have made this processing difficult, as he struggles to hold timelines together to process the various stages of his pathway. It does not appear that his anger with his early treatment has been dealt with, and he still has a very emotional reaction to things which bring his brain injury to mind. Max's expression of how this disrupted sense of time affects him may give some indication of how his cognitive deficits have impacted on his processing of his injury and rehabilitation treatment:

*"That sense of loss, that loss starts at the beginning of a timeline and just like daydreaming, I'll start to think about what I'm doing and I can't hold that and I start to think of something else so it disappears. So it's just a, it's not about a sense of loss, it's the fact I'm lost in my thinking. I've got no idea why I might be thinking something. It's more about coming across something and expressing an emotion than being able to hold onto it and explain it to myself....So no I don't have a sense of loss but I do have probably this sense of not doing what I was that then gets applied to other things without me really knowing why."*

There is a connection of Max's ABI challenges being present and affecting his ability to understand those challenges and live with them. A sort of catch twenty-two whereby deficits are present and recognised but the very nature of the deficits means adjusting to living with what has happened is compromised.

Even though Max expresses an inability to hold timelines, he does acknowledge skills he has lost as part of his injury effect. These become apparent when he attempts activities

which used to provide value and challenge to him, but are now arduous and a stark reminder of a difference between a before and after Max. Max does not relate to the term loss, but he clearly expresses it when talking about his memory abilities now:

*“I really wish I was who I was. I never wrote things down unless it was, it had to be written down because there was no way people could remember a twelve figure number or, you know, I remembered things. So yeah, I really wish I was who I was. That I was there when I said I’d be there. That I’d bring what I said I’d bring. That I didn’t have to keep asking people.”*

#### **5.4.2 Hazel’s experience**

*Coping* Generally, Hazel described herself as a calm person. She does not vent or express her emotions outwardly. Instead, Hazel said she would use the support of friends and family to talk through anything which was troubling her. She would use this as a way of processing the emotional side of the stress as well as a way of gaining advice to problem solve. This would be classified most commonly as using emotional and instrumental support (Lazarus & Folkman, 1984). According to current thinking on coping efficacy, these two styles should arm Hazel with a good balance of tools with which to cope with stress. However, with the additional issues brought on by her husband’s injury, she feels she cannot utilise one of her main go-to coping styles of talking things through with friends. Here she explains why:

*“It’s difficult trying to explain to people. Like friends, or friends you don’t see very often. They don’t, they just see the person, to them, getting on really well. I feel as though I can’t, I can’t connect with them sometimes, because it, it feels like moaning about stuff that doesn’t really matter. It’s that thing if you say to someone about his memory...and it’s that thing people will say ‘oh yeah my memory’s pretty bad’. They don’t mean to but it’s belittled what*

*you're trying to say. It makes me think 'okay I can't...'. It makes you feel a bit isolated sometimes."*

Hazel expresses how her preferred coping strategy of talking to her friends is stifled by a lack of perceived empathy for what she deals with on a day to day basis. The way her friends bring her issues back to something about themselves and normalise her stresses makes her feel like they don't 'get it'. Therefore, she has stopped using this source of support to cope with issues relating to her husband's injury. The idea of the 'hidden disability' of brain injury is evident. Other people's lack of understanding about the range of issues people can face after ABI is difficult to withstand and very much felt by Hazel:

*"If he was really in a terrible state they'd...I think it's that thing of so many varying degrees of brain injury. And in his case it's his memory, and his fatigue, and it's his cognitive abilities, that don't show to people. I think that's quite hard. It is hard for people to understand. I mean, in the early days it was okay, you could [talk to friends], but as time's gone on, people move on and they expect you, everything to have moved on."*

The consequence of losing this usual style of coping for Hazel has left her feeling isolated in terms of coping with her husband's ABI. It would be worthwhile to understand more about the impact of lost social support regarding ABI stressors due to the feeling of a lack of empathy from others, and whether this is able to be replaced by other forms of support, such as professional counselling or family support groups with other people who have experience of ABI and living with the impact of the 'hidden' deficits. One study of a peer support group based in Australia found those who attended regularly developed new friendships and felt better supported as a result (Bellon, Sando, Crocker, Farnden, & Duras, 2017). Through thematic analysis of post-interview data, attendees were found to value three main areas as responsible for the positive effect of the group: accessing information,

receiving emotional support and giving back to their peers. Similar studies repeated for the UK population would contribute to understanding the usefulness of peer support groups more generally.

As well as not using her friends as much to deal with specific ABI issues, Hazel feels another consequence of her experience is that she is now able to ask for help more readily. Pre-injury, hazel was very independent and liked to tackle problems on her own, but the new challenge of brain injury had forced her to seek help from others. Now this was not so much of a difficult thing for her to do. She even sought professional support to help process the traumatic experience of the injury itself and has implemented strategies for relaxation from this. Hazel felt this was required due to the emotional changes brought on by the experience:

*“I never used to get terribly stressed about things. I feel I am at a certain level of tension...of stress actually that I wasn’t before. I always feel like I...when all the accident first happened and everything I was just running on adrenalin and I think sometimes, very often actually think it’s never quite gone back down. I feel I’m always ready to leap into action.”*

Another change identified by hazel is that of how she responds to stress caused by something related to the injury as opposed to something unrelated:

*“I’ve always been a laid back sort of person...I guess the stresses around his injury are a lot more emotional. A lot of it is you, sometimes it’s hard to cope with moods and he can be fine, and you think everything’s fine. Everything is going along pretty well and you can almost start to put it as if it all, as if it’s all gone away and you start to think everything’s fine and then all of a sudden, you’ll just, you know it’s all too much and he’s you know it’s difficult sort of remembering to always attribute things to a brain injury.”*

The difficulty of the hidden effects of the injury are evident in long term coping for Hazel too, with her finding it hard to be sympathetic at times when newly acquired ABI behaviours become more of a normal part of a person than the person they were before. Hazel's laid back personality and calm approach to problem solving does not materialise when the stress comes as a result of the injury. As Hazel describes, the intimacy of their relationship means the response is more emotive, and the enduring nature of these stresses mean it can be hard to maintain the same level of sympathy for them as it may once have been.

Hazel reflected on coping with the acute phase of her experience when her husband was in hospital. She utilised problem solving strategies to get through this time and describes the feeling of running on adrenaline that she previously mentioned:

*"I think I was just in the moment, and I'm still a bit in the moment....so you know in the beginning you are just literally going from moment to moment aren't you. I wrote lots of lists...I even had things like 'eat' on my list and stuff like that. Literally just to try and get through the day....You try not to think too far forward. Just try and stay calm."*

Hazel's experience of acute coping responses is in line with those expressed by Patricia in case study 1. Both report feeling like running on autopilot in these early stages. It is of note that both are expressing the response to a TBI, that is, an ABI caused by a traumatic external event, which by its very definition is likely to be unexpected and result in a significant level of shock (Bryant, 2011). Although other forms of ABI, such as stroke, are unlikely to come with warning signs, the elements of trauma may leave family members experiencing a heightened sense of shock. The differences between acute stage reactions between TBI and ABI events could reveal if trauma sufferers require additional support to

process the impact of the initial event, or whether responding to the health crisis of a loved one creates this response regardless of injury cause.

In terms of the time of life the injury happened, Hazel felt that it certainly could have been worse. She reflected on the support her children provided due to their ages, acknowledging this would have been harder had they been much younger. The strength of their family bond was attributed to this feeling of the timing playing a supporting role.

*Family change* One explicit change for Hazel is that her husband used to be the main breadwinner of the family and, although Hazel always worked, this responsibility now fell to her. The social planning difficulties described by Max also appear of importance for Hazel as a change to their family after ABI, although Hazel finds these changes harder to endure:

*“It’s very difficult to plan anything, I find it quite difficult to plan things. It’s difficult to plan things because I never quite know how he’s going to be at social events and things like that, ‘cause there’s always that element of...I find it quite stressful. He’ll say ‘oh yeah we’ll do things’ but in the back of my head I’m thinking, you know, he might not be up for it or we’ll get somewhere and he won’t be able to cope with it, you know.”*

Hazel feels an increased responsibility towards making sure her husband is okay in social situations, which has a knock on effect for her own enjoyment of such things. The more care-free attitude toward this variability that Max felt is not shared by his wife, who feels her husband’s unpredictable nature leaves her unable to relax in social situations.

This anxiety around needing to be aware of how her husband is presenting has led to Hazel taking on a protective role in their relationship, and an imbalance in the marital partnership has been created:

*“It’s trying to keep a balance, but I find I’m always several steps ahead. What if this and what if that?...for him you know. For instance if I know he’s got a day where he’s doing a couple of hours in the garden and then he’s perhaps got to do something else in the afternoon, and if someone said ‘oh did you want to come out in the evening’ it’s not gonna be good. It’s protective because I have the foresight to pretty much know when things are gonna go wrong, and he still doesn’t. He’s getting better, building in rests and things.”*

For Hazel, the variability in her husband’s behaviour since his ABI has left her on edge, particularly when outside of the family home. She wants to protect her husband from doing too much which would lead him to become fatigued, and she does not have confidence that he can monitor this himself yet. Therefore, Hazel has taken on more of a parental role than a marital one, when it comes to organising family activities and social events.

Loss Hazel felt a clear and profound loss relating to her husband’s injury. As is the experience of many spouses after ABI (Blais & Bosivert, 2005; O’keeffe, Dunne, Nolan, Cogley, & Davenport, 2020), the relationship between two people as partners has been changed. Hazel first expresses the losses she feels for her husband as a person, and then how this relates to her as a wife:

*“You know I’ve lost... he’s still my best friend, you know we were best friends before we were married, but he was a very different person. Very, very motivational. That’s gone....it’s like he’s lost his sparkle. It’s just a bit like its aged him really. You know, he needs rest and he suffers from his back and he’s just slower. He’s generally slower, with his speech and everything.....I suppose our sex life’s different. You know, he doesn’t really think about it I don’t think. It’s a bit more like we’re friends in a way.”*



The loss of intimacy is one way the marital relationship has been changed, making Hazel feel they have cycled back to how they were before they were romantically involved, losing a large part of the development of their relationship as a couple. Further relationship changes have occurred as a result of the injury effects, which have left Hazel with a sense of isolation in her marriage:

*“He’ll lose himself in things and, I mean, we’ve always gone off and done our own thing, but he definitely seems to spend a lot of time planning his escape, and things like that [laughs]...it feels like we both need more time out from each other. I need time out from him. I do feel quite anxious around him a lot of the time. Not that he’s gonna do anything horrible to me or anything like that, he’s not like that at all, just he can blow hot and cold and get very, you know, when things get too much you just don’t wanna be around him cos...so it can feel a bit lonely. Even though he’s there, sometimes he’s not.”*

The loss apparent to Hazel is reminiscent of many spouses’ experiences when their partner suffers an ABI. Losses rarely relate to specific activities or abilities, but more a sense that the person they married has been altered and they have a loss for that person as a result. Hazel’s experience echoes that of the spouses in themes 1 and 2 of this study (*Loss of person and loss of relationship*) but also of that seen in other qualitative studies. Wives in a study by Bodley-Scott & Riley (2015) expressed a changed love for their partner with ABI. As a response to the behavioural changes experienced in their husband, spouses reported they could not love their ‘new’ husband in the same way as before, but love was still evident. The love shared between them was now a carer’s love, rather than a marital one.

Changes to spousal relationships has received significant attention (Godwin, Kreutzer, Arango- Lasprilla, & Lehan, 2011; Kreutzer, Sima, Marwitz, Lukow, & Herman, 2016), most recently in a study utilising IPA techniques by O’Keefe and colleagues (2020), who have

built on the existing literature highlighting the strain marital relationships face as partners of individuals with ABI face the loss of the person they fell in love with, and the challenge of falling in love again (O'keeffe, Dunne, Nolan, Cogley, & Davenport, 2020). Here, Hazel eludes to feeling this changed love, with her expressions of being 'friends', losing her intimate partner, and taking on protective roles to help manage her husband's ABI.

#### **5.4.3 How the family has adjusted**

Case study one described a family which had responded to ABI in a unified way, with both Harry and Patricia expressing similar experiences and equally positive feelings of adjustment. For Max and Hazel, their response has not been as unified, and they appear to be experiencing the fall out of Max's TBI in isolation from each other. Subsequently, only four IPA themes emerged from the dyadic analysis of their experiences, compared to the 7 seen in case study 1. These themes which are presented in table 7 (p163), are described here in turn, and discussed in the context of current literature as well as how the family have adjusted as a whole.

*Changes to coping after ABI* Both Max and Hazel experienced changes to the way they cope generally with stress because of the injury. For Max, these changes were a direct result of the way the ABI had affected his cognition and ability to not only problem solve stressors, but how he also managed his emotions relating to his coping ability. For Hazel, the changes were brought about by her experience of dealing with the trauma of the ABI event, which she could not do on her own. Previously a very independent copier, Hazel had to seek more help than she was used to due to the unfamiliar and extreme situation she found herself in.

Max's changes in coping appear to interfere with his adjustment to life after ABI. This is due to his new coping abilities clashing with his previous way of dealing with stress,

and highlighting to Max a deficit which is at odds with his pre-injury identity as a good problem solver. Qualitative studies exploring changes in coping after ABI due to ABI deficits are lacking, and the wealth of quantitative research in this area explores little about how ABI deficits affect someone's post-injury coping ability. The need to address this dearth in the literature has been emphasised before (Gregório, Stapert, Brands, & van Heugten, 2011), but so far a focus has remained on the search for the best coping styles to influence post-injury adjustment, such as emotion versus problem focused coping. From Max's experience, it is evident that challenges to problem solving can have implications beyond the immediate stressful situation and can challenge one's whole sense of identity. Moreover, the lack of alternative constructive coping strategies can leave the coper frustrated and angry at their lack of coping efficacy. Neurorehabilitation efforts which address this conflict between normal coping styles and current coping abilities may prove crucial to helping the adjustment process for such individuals.

*Emotional responses to ABI stressors* Both Max and Hazel have experienced different reactions to stressors which are directly related to the ABI event or consequences. These reactions are emotionally heightened and create a stress of their own, perpetuating the impact of original cause of stress. The emotional reactions created by behaviours associated with the ABI are discussed by Max and Hazel separately, but it is not clear if they share the feelings about these reactions with each other. The way they express their views in the interview appears very independent of each other, and neither reference their partner as a source of support for dealing with the emotional situations they encounter around the ABI. This isolated response would be in line with how other marital partners have expressed reacting to ABI specific stressors. For example, the wives interviewed in a recent study admitted concealing their feelings from their husbands with ABI about the changes they had seen in them, and the feeling of isolation this created for them as a consequence (O'keeffe, Dunne,

Nolan, Cogley, & Davenport, 2020). Similarly, the husbands with ABI in the same study did not express their concerns and frustrations with their partner. The impact this hidden strain has on marital relationships could be contributing to the elevated burden spouses report and the high divorce rates seen after ABI (Gosling & Oddy, 1999).

*Family changes* A shared family change that was felt in this dyad was created by Max's lost employment. For Max, this left him feeling a strain on the household in terms of his interactions with others and what he had to offer as a family member. For Hazel, this change was a financial one, with the responsibility of earning the family income now falling solely to her. Employment status after ABI has been seen to affect psychosocial outcomes before (Coetzer, Carroll, & Ruddle, 2011), and the experience of how Max feels from being at home so much and losing the richness of his extended network of work-based colleagues has had implications for his family functioning. It is possible that the lack of meaningful activity to replace Max's employment has impeded on his adjustment process, as he has expressed struggling to come to terms with his changed circumstance and increased time spent around the family home. Vocational rehabilitation is not currently part of standard pathways, but if accessible, can yield encouraging outcomes for return to work after ABI (Murphy et al., 2006; Shames, Treger, Ring, & Giaquinto, 2007). As Max is still relatively newly injured (two years post injury at time of interview), his potential to re-establish his employment status has not been discovered. It would be valuable to ascertain, should Max either return to work or increase his regular meaningful activities, if his feeling of being a strain on his family members would subsequently dissipate. The loss Max feels for his social connections at work means there is potential for new connections to be made that could help minimise this loss, for example through a peer support intervention such as that described in Hibbard et al. (2002).

*Social changes* Another common theme amongst this dyad was that of changes to how they functioned as a couple socially. Planning of social events and the capacity to see these through had been changed by the ABI effects. However, the meaning of these changes was different for each person. Max recognised these changes and how flexible the family had to be due to the variability of his injury presentation. Max, however, did not feel this was much of a problem, as he and his wife had never been strong on planning social events and liked to live quite spontaneously. Hazel also recognised this need for flexibility in their social calendars, but expressed feeling this left her uneasy, and the variability of her husband's presentation caused anxiety. For Hazel, the responsibility she felt for protecting max and others from his fluctuating mood and behaviour had left her anxious about social situations. Although the couple had not been strict planners before the injury, Hazel expressed discomfort at the unpredictability of *how* the social event would be, rather than the actual practical aspects of planning the event.

Taking into consideration the different changes and how they are experienced by the individuals involved poses the question of how much this is communicated between parties. Neither Max nor Hazel appear to talk their issues through with each other, although they had not explicitly said they don't or won't. Moreover, their expressions appear more reflections brought about from the interview questioning, rather than strains on their relationship which are being actively challenged. This appearance of partners concealing the true impact of the injury from each other has been seen in a recent study by O'keeffe, Dunne, Nolan, Cogley, & Davenport (2020). They interviewed six wives who admitted concealing their feelings from their husbands' with ABI, and the isolation this creates as a consequence, but this same disconnect was expressed by the husband's with TBI too. They reported not talking through their emotional outburst with their partner, and not understanding why they behaved in some of the ways they did towards them, but that this lack of understanding meant they resisted

trying to apologise for it. The well documented ‘caregiver burden’ (Knight, Devereux, & Godfrey, 1998) could potentially be eased if communication was increased between partners to discuss these hidden conflicts. A review of studies relating to couple’s therapy was conducted by Yeates (2013) and concluded couples therapy to be highly beneficial at developing new relationships for spousal partners affected by ABI. Yeates concurred that the neuropsychological impact of ABI on couples is often “the elephant in the room” (p.109). However, the reality of such supportive interventions being a part of standard rehabilitation pathways is not apparent, and couples are therefore at risk of either separation or living with a hidden strain (Perlesz, Kinsella, & Crowe, 1999).

Unlike case study 1, a shared theme of adjustment to life after ABI did not emerge for Max and Hazel. This suggests adjustment to ABI is a very personal concept and one which does not rely on the adjustment of other family members. Individuals find their own meaning of the way the ABI has impacted them, which stands alone from neuropsychological sequelae. For Hazel, she felt she had adjusted to her life now. Even though she expressed additional strain and isolation in her marriage, she had accepted these changes as part of the normal course of life. She explained that the injury had been “absorbed altogether” with other life changes, such as her children moving out. For Max, he felt he still had a long way to go before he could accept the impact the ABI had on his life. Max felt being adjusted would mean being happy and content with how you are post-injury, and that he was not anywhere near this feeling yet.

When asked what helped her feel adjusted, the emotions of the family and social changes experienced were not evident, as Hazel rationalised the overall experience of how her life is now:

*“You know it doesn’t mean we can’t do stuff, it just means being prepared to do things at short notice. Being more prepared for things to go wrong or not come off. Not relying too heavily on plans. And I don’t know...just being grateful for what I’ve got. Just trying to make the most of what you’ve got. Make the most of your days...being quite happy with simple things. I’d say I always feel we were lucky that he wasn’t worse damaged.”*

Through Hazel’s account of what helps her feel adjusted, it can be seen that a positive outlook is present, as was seen with Harry and Patricia. This strengthens the theory that perspective, and the ability to see positives through adversity, is crucial for good adjustment after ABI (Nochi, 2000). Despite the strains Hazel reported earlier in her interview, ultimately she has accepted the challenges she now faces daily, and remains grateful there were not harder challenges to deal with. Max, however, struggled to see his positives, and felt resentment when faced with the idea of adjustment:

*“No! No, not at all [adjusted]. I still struggle to recognise that I have a brain injury. I function. I can do loads of things, but I struggle with remembering what I was doing, how to do things, what to bringing, where to be, who I was talking to, when I was talking to them. No I’m really at the bottom of the ladder on that one, and I can’t even see me climbing a rung.”*

Although Max recognised he wasn’t completely incapacitated by his injury, this was not seen in a positive light due to focusing on the things he couldn’t do. His expression of his disability appears to relate more to his identity, and how his limitations, particularly with his memory deficit, stops him feeling like ‘Max’. This was evident when Max spoke of his loss of self (section 5.4.2) and how he wished he could be the person he was before his injury.

It was seen through the thematic analysis in section 4.5 of this study that anger was evident for both participants who did not feel adjusted to life after ABI. Closer investigation

of Max's experience here suggests it would be of benefit to further investigate the impact of anger on the adjustment process, and if it is the presence of anger and resentment which hampers people's ability to focus on more positive aspects, such as what they can do, rather than just what they can't.

Case study 2 shows how a family can be affected by the same traumatic event but in different ways. For the two individuals who made up this dyad, their lasting impression of living a life after ABI is very different. For one, Hazel, she felt strain and loss as a result of the ABI, yet could accept these and focus on positives that are still present. For the other, Max, he could not yet accept the changes he felt within himself and did not feel the recognition of anything he *could* do mediated for his feeling of loss. Specific elements which may inform couples therapy interventions have been discussed, and the possible importance of anger in the adjustment process has been highlighted. Considering both case studies together, the IPA results show that families are capable of reaching good levels of adjustment, but they can also express a more complicated adjustment process and outcome. Thus, individual perspectives of family adjustment should not be used in isolation as there is significant risk of concealing the struggles of those who are experiencing a different journey.



## **Chapter 6. Use of quantitative measures in the field of family adjustment**

### **6.1 Introduction**

This chapter will make the claim that the use of quantitative statistics and standardized measures is not an effective approach when trying to understand how families are affected by and subsequently adjust to the impact of ABI. The three key areas of this project (coping, family functioning and loss), are discussed within a quantitative methodology and the challenges of using standardized measures in this field are highlighted. This chapter will outline three quantitative instruments for measuring each of these constructs. The Family Assessment Device for family functioning, the brief COPE for coping styles, and the Brain Injury Grief Inventory for loss and adjustment.

The rationale for this chapter has arisen from the original choice of a mixed methodology for this project. I initially chose to use a mixed methods design as I wanted to study factors associated with adjustment in depth as well as breadth. I felt the use of standardised measures would allow for more generalisability of the results and comparison with existing literature. However, the uniqueness and variability of ABI lent itself to a qualitative element to allow the individual stories to emerge. Sixty participants completed the quantitative data collection interview using the measures outlined herein. The full data set collected can be found in Appendix 8 for reference. The aim of this chapter is to discuss the use of these methods based on a critique of their use in research, the feedback received from the participants who completed the measures, and researcher observations and interpretations. The data presented comes from the full cohort of participants who took part, characteristics of which can be found in Appendix 2.

## **6.2 The Family Assessment Device**

### **6.2.1 About the measure**

The Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983) is the most commonly used measure of family functioning and is derived from family systems theory (Miller, Ryan, Keitner, Bishops & Epstein, 2000) which denotes each member of the family is interconnected within a system and functions as a whole, rather than separate parts. The measure is designed to be used by at least 2 members of the same family, working on the basis that only by combining individual perspectives do we get an understanding of the family as a whole.

The FAD was developed from the McMaster Model of Family Functioning (MMFF; Miller, Ryan, Keitner, Bishop, & Epstein, 2000). This model defines six key dimensions of family functioning which subsequently make up the six scales of the FAD. These dimensions were identified from Epstein and colleagues' clinical experience of working with families for over 30 years (Miller, Ryan, Keitner, Bishop, & Epstein, 2000), but there is no evidence of these families being involved in this development process in terms of validating the accuracy of the measure. The dimensions appear to have been created through clinical observation, and the lived experience of family functioning for individuals has not been considered. Therefore, although the clinical practice the FAD has been developed from is extensive, it is arguably unidimensional and does not portray the meaning of different types of functioning for those family members concerned. Instead, validation efforts have focused on the FAD's ability to discriminate between 'healthy' and 'unhealthy' families, based on the assumptions of the practitioners who developed the measure as to what this functioning represents. Moreover, although found to be highly statistically significant, the FAD only identified 67% of

nonclinical families and 64% of clinical families correctly (Epstein, Baldwin & Bishop, 1983).

To complete the FAD, respondents rate a variety of statements based on how they feel their family interacts on a scale from strongly disagree to strongly agree. The measure consists of 60 items making up the scales of general functioning (*an overall assessment of how 'healthy' the general functioning of the family is*), communication (*how information is exchanged between family members*), roles (*each members' recurring behaviours which support family functioning*), affective responsiveness (*the appropriateness of emotional responses within the family*), affective involvement (*the interest taken for each members' activities*), problem solving (*how the family resolves problems*) and behaviour control (*standards within the family on how members should behave*). The complete FAD instrument can be found in appendix 3.

The main reason this measure was chosen was because it is the most widely cited family functioning measure in the literature (Hamilton & Carr, 2016), and this would allow for cross-study comparison. Also, the measure separated out dimensions of family functioning to allow for a comprehensive assessment to take place, but also provided a general functioning scale that gave more of a summary of overall functioning. This general functioning scale has often been used as the sole measure of family functioning (Boterhoven de Haan, Hafekost, Lawrence, Sawyer, & Zubrick, 2015; Kosciulek, 1994; Sandler et al., 2002; Shek, 2001) as it has been found to give a respectable overview of the other 6 scales. Therefore, a retrospective general functioning measure could be created to assess pre-injury functioning, without adding an additional lengthy item to the inventory.

The main disadvantage of the FAD is the absence of a manual for administrators. The authors advocate that at least two family members are required to complete the measure, yet

give no guidance of how to incorporate the resulting sets of scores to understand what the different scales mean in terms of the family unit. This leads many researchers to use the measure with just one or two family members, with resulting analysis of these scores being viewed in isolation (such as Evans, Bishop, Matlock, Stranahan, & Noonan, 1987; Kosciulek, 1994; Sandler et al., 2002). Without an appropriate system to statistically compare multiple perspectives of different family members, the FAD becomes ineffective in a research capacity for interpreting families as a whole.

At the start of this project, the FAD appeared to be a logical choice as the main measure to capture how families were interacting as a unit, which would then be used to investigate family behaviours in relation to feelings of adjustment. However, the more familiar the scale items became, combined with the feedback received from the participants, it became apparent that my selection of the FAD was flawed, and I was left re-evaluating my choices, not only of the measures I had used, but of my whole belief in their ability to contribute to our understanding of the way people adjust to life after ABI. Here follows a critique of the FAD as a research tool for assessing family functioning with ABI populations, using both quantitative and qualitative elements of the original incarnation of this project. This has been split into three sections: *family functioning as a statistic*, which will use the dyadic case studies to illustrate how quantitative data can misrepresent family responses, *the participants' experience*, which uses field notes from the interview process to reflect on the feedback that was given by participants when completing the questionnaires, and lastly *reflections as a researcher*, which gives an account of the experience of administering the questionnaire, and reflections on scale items which have come from a personal consideration of the FAD, rather than explicit feedback from participants. It is important that reflections that have come from participants and those that have come from the researcher are separated

to keep clarity as to what is the direct experience of someone responding to interview questions on the FAD, and what are those which have come from a theoretical perspective.

### **6.2.2 Family functioning as a statistic**

As part of the initial mixed-method study that this project started out as, 66 participants completed the FAD (44 individuals with ABI and 22 relatives). Of these, only ten individuals with ABI (23%) presented with clinically healthy family functioning across all eight domains. For relatives, only two participants (9%) presented with complete healthy family functioning. These results could be taken in isolation and used to describe the ABI population as one which has, for the majority, clinically impaired functioning in at least one domain. However, what this assessment does not tell us is what this ‘unhealthy’ functioning means to the people involved. What is their *experience* of this functioning? Do they feel unhealthy? It should be considered that such families may have had to develop unconventional ways of functioning in order to accommodate the unconventional ways of ABI life. Taking a standardised test aimed at identifying differences in functioning from one family to another is in this respect flawed. If we categorise families as poorly functioning based on falling above or below a standard score, we risk assuming the way they interact is abnormal and subsequently causing issues for their wellbeing. Well intentioned family interventions could then potentially un-do the positive functioning of the family in an attempt to re-align them with their societal norms. Without considering what the specific functions are doing, how they are interacting with other aspects of ABI life, and the meaning they hold for the family members, we risk disrupting good adjustment to living in a changed family unit which no longer holds up to wider standards of healthy functioning behaviours. Moreover, the experiences of the participants in this study show how normal ways of family life had been altered by the effects of the ABI, whether for the individual who sustained it, or their

relative. There is currently no standard of functioning that takes into account the complexities of interacting and living as a family unit when one of its members has been compromised in ways of communication, emotional affect, mobility, or awareness, such as in the case of ABI. If we intend to remain on a path of measuring families against norms, we need to establish a new norm for those people so as not to make assumptions as to what is affecting them and how it should be addressed.

The dyadic case studies presented in chapter 5 can be taken as examples of how statistical analysis of factors involved in adjustment are difficult to interpret and can actually detract from the lived experience rather than add to it. Table 8 shows the quantitative results of questionnaires answered by Harry and Patricia. Harry and Patricia presented in their semistructured interviews as a well-adjusted family who reported positive outcomes from their ABI experience. Neither felt they had long lasting negative consequences, and they actually reported an increased sense of gratitude and quality of life as a result of what they had experienced. However, if we had wanted to assess their family functioning through a standardised measure such as the FAD, we would have been concerned that they both showed impaired affective responsiveness scores and that they may need support to overcome this. Also, Harry has an impaired score for his general functioning now, and an unimpaired score for his functioning before his injury. On face value, this would suggest Harry has been negatively affected by his injury and is now presenting with unhealthy general family functioning. From his interview though, he reported no such negative impact.

It is not clear from this evidence whether the qualitative methods were more successful than the quantitative at capturing the most accurate representation of how Harry's injury has affected his family functioning. However, the lived experience for Harry is that he has not felt an impact, so therefore it is unlikely that highlighting this finding on the FAD

would be of benefit for him. What does appear apparent though, is that more work is needed before a standardised measure is able to sufficiently capture the *experience* of how family members feel they function as a unit.

Table 8

*FAD scale scores for dyadic case study 1: Son-Mother relationship*

FAD scale	Harry	Patricia
Problem solving	2.5*	1.8
Communication	2	1.9
Roles	1.9	2.5*
Affective responsiveness	3*	2.3*
Affective involvement	1.7	1.9
Behaviour control	1.7	1.6
General functioning	2*	1.8
Retrospective general functioning	1.7	1.7

*Note:* \* denotes score above clinical cut-off. Scores range from 1.0 (healthiest functioning) to 4.0 (unhealthiest functioning).

With the second dyadic case study, Max and Hazel, their general functioning scales, both now and retrospectively speaking, are healthy, yet for Hazel, three other scales are unhealthy and for Max two other scales are unhealthy. The couples' FAD scores are presented in Table 9. The authors of the FAD do not give guidance as to how one should interpret a healthy general functioning score amidst unhealthy scale scores for other

dimensions. Therefore, it is left to the researcher to decide if this family is showing healthy or unhealthy functioning, and whether there is cause for intervention or concern as a result.

Whether the family is showing good family functioning is therefore an interpretation of the administrator, not a reflection of the impact of that functioning on the individual.

Table 9

*FAD scale scores for dyadic case study 2: Husband-wife relationship*

FAD scale	Max	Hazel
Problem solving	2.3*	2
Communication	2	2.1
Roles	2.2	2.5*
Affective responsiveness	1.8	2.2*
Affective involvement	1.7	2
Behaviour control	2.9*	2.3*
General functioning	1.5	1.9
Retrospective general functioning	1.2	1.2

*Note:* \* denotes score above clinical cut-off. Scores range from 1.0 (healthiest functioning) to 4.0 (unhealthiest functioning).

By comparing the FAD scores from the two dyadic case studies, interpretation becomes even more problematic. We know from the semi-structured interviews that Harry and Patricia did not feel much had changed for them as a family, particularly in terms of functioning. Harry does not live with his mum and therefore the day-to-day living that the FAD investigates is not relevant in terms of their relationship. They have not had to



reimagine how they function in the home because the ABI has not had this level of impact for them as a family unit. Consequently, Max and Hazel reported in their interviews that the ABI had changed the way they interact as a family, and the activities they now take part in. Their marital relationship had been changed and they had to reconsider the way they went about life on a day-to-day basis as they lived together as a unit. Yet taking their general functioning scale scores, which the authors claim give an “overall health pathology of the family” (Epstein, Baldwin, & Bishop, 1983, p. 173), the numbers do not reflect this presentation. Harry showed the highest score of 2, which meets the clinical cut off of unhealthy functioning. Patricia scored 1.8, Max scored 1.5, and Hazel scored 1.9. These three scores showed healthy functioning, yet Harry’s unhealthy score is only marginally higher than Hazel’s of 1.9. The meaning of the way their family now functioned has been lost in the statistics, if it was captured at all. Through her interview, Hazel felt an increased strain from the way she now had to interact with her husband and felt a burden from how they now functioned socially. On the contrary, Harry felt very little impact of his injury on his family life, and to use his words, if anything it was better. Two very different reports of the family impact of ABI, yet only a difference of 0.1 statistically. This comparison shows how the meaning of family interactions is not sufficiently captured by quantitative means.

### **6.2.3 The participants’ experience**

The experience of administering the FAD multiple times left me with a respectable amount of feedback about how people felt when completing the measure. As I had read the questionnaire to every participant to ensure understanding and consistent completion of the measure, I had also witnessed the variety of ways participants interpreted and responded to certain questionnaire items. Outlined here is a discussion about the FAD items which caused the most controversy during interviews, and the items which were hard for participants to

answer with much conviction. The evidence presented here was collected in situ as field notes on cover sheets to the completed questionnaires, meaning at times quotes are presented. As this data was not explicitly collected from the participants for this purpose, quotes have been left anonymous and used only to represent the experiences of those taking part.

*Scale item no. 4: When you ask someone to do something, you have to check they did it; Item 45: If people are asked to do something, they need reminding*

These items were problematic for participants to answer due to a common deficit of ABI being one of memory impairments. Some individuals with ABI recognized the challenges they experienced with their memory and would indicate through their response to these items that reminders would always be required as a result. Likewise, family members would refer to compensating for their relative's memory deficits, and would either agree or strongly agree with the above items due to their relative needing support with their memory. However, as these items are from the 'roles' scale of the FAD, it aims to identify how committed family members are to their given duties within the family, and pays no mind to whether someone actually has the cognitive ability necessary to remember tasks assigned to them. Moreover, the importance this necessary reminding has for those concerned is not captured. It may be of no consequence to the individual with ABI, or their relative, if reminders are needed. The act of the individual being able to take part in whatever role they are being reminded of may negate any negative consequence of them not doing it independently of someone checking.

*Item no. 17: You can easily get away with breaking the rules*

This item is part of the behavior control scale, but closer inspection of this statement reveals complications with how results are interpreted. For instance, item 17 refers to the

breaking of rules. Many participants expressed they didn't have rules to break, because the wording of the statement implies there is some kind of explicit agreement among family members as to how they will behave. It may be that in reality, many families are more likely to have implicit rules which develop over time and are created through feedback from many different experiences and conversations. Therefore they are felt more as a way of life, rather than rules to be broken, and the wording feels an outdated representation of modern family functioning. One participant exclaimed "what rules?!" when asked this question and instantly disagreed with the statement, but this does not then subsequently mean family members do whatever they want and pay no mind to the consequences. It appeared more a reaction to the idea of an authoritarian family unit rather than a reflection of individuals' behaviours towards each other. For many others though, the statement needed explanation, as the idea of breaking rules within a family context did not resonate.

*Item 23: We have trouble meeting our financial obligations*

The effects of ABI leaves most people unable to work initially, and for some they may never return to paid employment (Ownsworth & McKenna, 2004; Shames, Treger, Ring, & Giaquinto, 2007). Additionally, other family members may leave their place of employment to take on caregiving duties for their loved one. These changes brought on by ABI can leave families in a difficult financial position, and it can lead to debt, selling assets such as houses, or having to re-evaluate how they spend leisure time (Koller et al, 2016; Sabella, Andrzejewski, & Wallgren, 2018). The statement in item 23 does not take into consideration *why* a family may not be able to meet their financial obligations, and furthermore does not consider how this subsequently makes them feel. The financial status of one family may be held in much more regard than for another family, and to make assumptions of how this impacts their family life is a very subjective approach.

*Item 27: We have no clear expectations about toilet habits*

This item was omitted from the questionnaire after approximately 10 interviews due to the reaction it created in the participants. This statement created offense for some due to the perceived insinuation that they did not follow good bathroom hygiene. For some, this question also resulted in confusion, as it was felt standards of toilet habits were something that was not explicit in their family, it just ‘was’. The notion that any family did not have expectations of toilet habits seemed preposterous to the participants and the resulting conversation around this item distracted from the flow of the questioning. Therefore, the item was removed and scoring procedure was adapted accordingly.

*Item 32: We have rules about hitting people*

As with item 27, the idea that a family needed to have a ‘rule’ about hitting people seemed absurd to participants. It is not clear whether this item is referring to ways of applying discipline to family members, or whether it is about expressions of emotion. Either way, the response of participants when asked this question was one of amusement as it should not be needed to be asked. Again, as with item 27, the idea of this being an explicit family value was confusing. The reaction to this item could suggest that people are prone to respond desirably, rather than honestly, due to the cultural norm felt among this sample that it is not accepted to hit others, for whatever reason it occurs.

*Item 58: We don't have reasonable transport*

As with many of the items discussed, the limitations from ABI may be the cause of restrictions put on a family, and the ability to overcome or manage such limitations may mediate any negative effect of the initial limitation. An individual may strongly agree with this statement based on the effects of their ABI leading to them losing the ability to drive.

The fact they have good public transport links or access to other modes of transport may not diminish this feeling of having inadequate transport, because the loss of the driving license is so personal they may never feel it is adequate in any other way. For others, if they didn't drive anyway, live in a more connected community, or are more accepting of the restricted independence brought on by transport issues, then they may feel they have adequate transport, and so disagree with this statement. When viewed in this way, taking transport provision as an indicator of family functioning is difficult to comprehend.

This item makes up part of the 'roles' scale, which measures to what degree behaviours support family functioning. The item wording however leaves too much to the interpretation of the participant as to what is good transport, but most importantly omits what this means for the participant. They may acknowledge the restriction on their family of inadequate transport but have varying degrees of satisfaction with this restriction. Some participants felt the fact they could not drive a car to be inadequate, whereas another participant felt no restriction on their transport as their partner now drove them wherever needed.

Some participants asked advice on how to respond, saying they had lost independence with their transport, which felt inadequate, yet they could get to where they need to be by means of either someone else driving or using public transport. Equally, if someone relies on public transport, the adequacy of this is based on the infrastructure of their local community which is unconnected to their family functioning. The variety of unrelated factors that could lead to someone either agreeing or disagreeing with this statement means it is ill equipped to reflect how families function.

*Item 57: We cry openly*

This item has been chosen as an indicative statement which participants found hard to respond to with much conviction. This was always the case when the respondent either lived alone or with just one other family member. This created a common response of “it depends”, and “I would, but they wouldn’t”, referring to the dichotomous functioning that sometimes occurred in dyads. . These kinds of statements created a division between how the respondent felt they behaved, and how they felt their other family members behaved.

For those who lived alone, the questions were hard to answer as they didn’t have to involve other family members in their day-to-day lives. This did not mean to say they did not relate to family, but they did not have to include their family in day-to-day functioning. It may be that the FAD should not be used with people who live alone due to the emphasis it places on house-hold functioning, and as such representations of participants who live alone are not representative of how they feel about their family interactions.

#### **6.2.4 Reflections as a researcher**

*Item no. 48: Anything goes in our family*

How this statement is interpreted will influence the subsequent scoring of healthy or unhealthy functioning yet may be perceived by the respondent in a different way. For example, for one person, they may agree with the statement ‘anything goes in our family’ and feel this is a negative response due to wishing there were clearer boundaries for them to feel secure in their family set up, with a less ‘free’ family environment making them feel more confident. However for another person, ‘anything goes in our family’ may be agreed with, but in a positive light. They may feel that they are supported by their family no matter what and they would be able to express sexual, religious or political beliefs freely and without judgment. In this scenario, ‘anything goes in our family’ would be positively agreed with. Here the FAD is inadequate for identifying the meaning of this statement for the individual,

and whether it is subsequently viewed positively or negatively. A lack of boundaries may suit one person, or be detrimental to another. The FAD assumes that if ‘anything goes’ in a family they are lacking structure and behavioural boundaries which will lead to impaired functioning. This simply may not be the case depending on the meaning of this statement for each individual.

*Item 52: We don't talk to each other when we are angry*

The difficulty with this item comes from the assumptions that it makes. Agreeing with this statement is scored negatively, that is, it is seen as poor functioning to not talk to family members when feeling angry. However, for some family members, getting some space and time out to calm down before confronting the issues that have caused the anger may be a proven strategy that helps restore harmony in the most efficient way. Moreover, some individuals with ABI may have been affected by emotional changes as a result of their injury, and anger management may need to be considered in a different way for the family now. An individual with ABI may be antagonized by talking to other people when they or the other person is angry. Therefore, a family strategy may be to either avoid these confrontations or wait until the anger has subsided. When considered in this way, it does not seem conducive to assess the level of functioning a family has based on how they choose to manage emotional responses.

### **6.2.5 Summary and conclusions**

In summary, the FAD has been widely used as a way to assess how families function and to draw conclusions as to whether they fall within the criteria for unhealthy family functioning. However, evidence has been provided here to illustrate the argument that by trying to statistically capture the dimensions of family functioning, the meaning behind the ways families function has been ignored. Many items of the FAD are open to interpretation,

and respondents are not given the opportunity to rate how their functioning impacts on their wellbeing. The case studies presented showed how the quantitative data did not reflect the expressions of the interviews, and it could easily mislead a researcher to thinking a family has either healthy or unhealthy functioning as a result.

Quantitative methods have their place in research, but it would appear they are not well placed to measure complex and subjective concepts such as family adjustment. There is considerable work needed before we can establish the most important variables to measure statistically. In this study, the semi-structured interviews have provided meaningful insight into how families adjust to life after ABI. If the FAD is used for research purposes as a way to investigate the impact of the family environment on adjustment after ABI, then there should be an acknowledgement of the assumptions being made about the meaning of the functioning for those individuals concerned. As the FAD was developed from clinicians' perspectives of what constitutes healthy family functioning, the lived experience of this functioning, and the meaning for family members involved, is ignored.

## **6.3 The brief COPE**

### **6.3.1 About the measure**

The brief COPE (bCOPE; Carver, 1997) is a shortened version of the full COPE measure which assesses to what extent people use a variety of different coping strategies (Carver, Scheier, & Weintraub, 1989). It differs from many coping measures in that it does not aim to categorise good or bad coping or emotion versus problem coping. Instead it rates how commonly people use certain strategies and is designed to be used in conjunction with other variables of interest to see how they interact. It is used as a tool for assessing the breadth of coping styles people may use, with a higher score on a scale denoting a commonly used style. Scores for each scale range from 2 (not used at all) to 8 (used most of the time).



The full bCOPE questionnaire is provided in Appendix 4. Carver does not supply scoring information or interpretation beyond the minimal outlined here, nor does he claim to attempt to identify any theoretical underpinnings to the coping styles, such as emotion-focused or problem-focused coping (Carver, n.d.). Instead, the bCOPE is designed to give an overview of the types of ways people cope, and can be used from a situational or dispositional point of view.

The bCOPE was originally chosen for use in this study as it assesses coping styles beyond that of emotion versus problem focused categories, and would be more inductive as a result. It was intended to identify a variety of ways of coping that could potentially correlate with adjustment to ABI, and no assumption was being made about which styles would be most effective. The measure could also be used to ask about general coping styles rather than specific responses to stresses relating to ABI, which suited the dispositional coping approach of the study. Initially, the motivation to measure coping styles in this way was to identify if there were patterns among the sample which would suggest that certain types of coping approach should be avoided if they correlated with poor psychosocial outcomes. Herein, evidence from the statistical analysis, participant feedback, and researcher observations is presented to demonstrate the reasoning for omitting this analysis from the study.

### **6.3.2 Coping as a statistic**

Capturing how often someone uses a particular coping style is less problematic than trying to capture how they function as a family, but there are still some limitations researchers should be aware of when using a statistical approach as an attempt to understand someone's coping mechanisms. As with the FAD, the dyadic case studies give us insight into the discrepancies between qualitative and quantitative methodologies and the subsequent interpretations that are made from these.

Using the dyadic case studies to illustrate, Harry reported only one mode of coping through his semi-structured interview and that was the strategy of taking himself away from the stressor to get some time out. Therefore, if the bCOPE was to measure Harry's coping styles as per his perceived report of his coping, then he should score highly on the scale of self-distraction and fairly low on the other scales. Harry's bCOPE scores are presented in Table 10. An inspection of these show Harry reported to very rarely use self-distraction. A score of 3 is just above the lowest possible score of 2, which would denote he never uses selfdistraction as a way of coping. Harry actually scored at maximum for the scales of acceptance and planning. Through Harry's interview, the acceptance scale suits his presentation as a laid back person who takes his injury in his stride, but this is an observation, not something Harry expressed himself. With the planning scale though, a maximum score would suggest Harry thinks a lot about ways to solve problems and develops strategies to overcome the sources of stress. This side of Harry's coping ability did not come through in his interview. Even though both forms of data collection aimed to capture Harry's coping styles, they have given very different reports of how he generally copes, even though both these reports came from Harry himself.

As can be seen in Table 10 Patricia also represented her coping styles differently depending on the mode of questioning. When given the choices of the bCOPE, Patricia rated most highly on active coping and planning. With scores of 8, Patricia has indicated she uses these types of coping strategies most of the time. However, when asked to express her coping styles more freely through the interview, Patricia described mainly using a mixture of instrumental and emotional support from her husband, with some use of venting and distraction when this was not available. At no point did Patricia express the use of active coping and planning to manage stress, styles that would involve thinking in depth about problem-solving strategies.

Table 10

*Scores per scale for the bCOPE measure for case study one*

Coping scale	Harry – individual with ABI	Patricia - Mother
Self- distraction	3	6
Active coping	7	8
Denial	2	4
Substance use	2	5
Use of emotional support	6	6
Use of instrumental support	6	4
Behavioural disengagement	2	2
Venting	4	6
Positive reframing	6	5
Planning	8	8
Humour	2	3
Acceptance	8	7
Religion	2	6
Self-blame	8	5
Coping total scores	66	75

*Note Coping total scores = sum of all scales. Scale scores range between 2 (I do not use this at all) to 8 (I do this most of the time).*

Table 11 presents the bCOPE scores of the dyadic case study 2, Max and Hazel, who like Harry and Patricia, report different styles of coping dependent on the method by which they were asked. Although for Max and Hazel the bCOPE captured a more similar description of their coping styles as from the interview, it still did not represent how Hazel and Max felt they coped when asked in a more open way. In the interview, Hazel reported talking to family and friends as her main coping style, along with problem-solving. The bCOPE captured the problem solving aspect with Hazel scoring at maximum for the active coping scale and near maximum for planning scale. However, Hazel's main style of talking things through with friends and family was not so well represented, with the use of instrumental support scale only scoring 4.

Table 11

*Scores per scale for the bCOPE measure for case study two*

Coping scale	Max – individual with ABI	Hazel - wife
Self –distraction	5	7
Active coping	5	8
Denial	5	2
Substance use	2	4
Use of emotional support	8	6
Use of instrumental support	7	4
Behavioural disengagement	7	2
Venting	8	3
Positive reframing	3	8
Planning	4	7
Humour	2	4
Acceptance	2	8
Religion	2	4
Self-blame	8	2
Coping total scores	68	69

*Note Coping total scores = sum of all scales. Scale scores range between 2 (I do not use this at all) to 8 (I do this most of the time).*

Max's responses were the most similar across the two measures, with self-blame and venting being represented strongly in both bCOPE scores and his interview. However, Max did not express using the emotional support of others as a coping style, yet he scored at maximum for this on the bCOPE. This is not to say Max does not use emotional support to cope, just that he did not identify with this when using more free recollection of his coping strategies.

There could be two main reasons why there is a discrepancy between the self-reported coping styles of these participants. One possible reason could be that the presence of a comprehensive list of coping strategy choices given by the bCOPE helps respondents reflect on a more varied range of styles that they may use rather than just those that seem most salient to them when they are not given prompts. It certainly seems that the variety of styles expressed in the interviews is more limited than the types of styles participants subscribed to through the bCOPE options. It is possible though, that the bCOPE is overestimating the variety of styles used due to the difficulty of knowing what people are referring to when they answer. For example, when asked to explain general coping styles in the semi-structured interview, participants answer with a limited range of styles, appearing to reflect on their most 'go-to' way of coping with stress. When investigating dispositional coping, this is what would be expected and aimed for. With the bCOPE however, it could be that as a strategy is suggested, respondents are drawn to specific experiences when they used this style, thus subscribing to its use, even if it is not one they would use generally. Concurrently, self-report through the interview without examples or prompts may lead to an under-reporting of coping styles when this method is used. Without giving examples of coping strategies, participants may not fully express all their ways of coping when asked in the moment. These two considerations when combined could be why the qualitative and quantitative reports of coping differ.

The ability to be confident about how accurately participants can self-report their use of coping styles is one explanation, but it does not explain why some coping styles are reported through the interview, but the same styles are not subscribed to when prompted by the examples given in the bCOPE. This could be due to how people interpret ‘coping’ and what they associate with as coping strategies. For example, Patricia expressed her coping strategy in her interview as primarily support from her husband. She did not describe the act of positive reframing as a way to deal with stress, and did not use acceptance of stressors as a way to cope. However, Patricia scored at maximum for positive reframing and acceptance on the bCOPE. When Patricia’s whole interview is taken into account, a pattern emerges in her descriptions of feeling adjusted to her son’s injury, with this being due to how it could be worse (positive reframing) and that in the early days of her son’s injury she coped with it by ‘just getting on with it’(acceptance). This example suggests two possible aspects of how Patricia has self-reported her coping. One is that she does not identify with positive reframing as a coping style, and two, she possibly answered on the bCOPE with reference to her ABI experience rather than her dispositional coping style, as she had done in the interview.

Max also showed a possible difference in the response to being asked to describe general (dispositional) coping styles. In the interview, Max did not report using the emotional support of others when talking generally about his coping, yet he scored at maximum for this scale on the bCOPE. In the latter parts of Max’s interview, he does talk about how he tells his family member’s his feelings, and in his view he does this too much. Here it appears the direct prompt of using other’s for emotional support given with the bCOPE led to Max subscribing to this strategy strongly, yet when talking freely about his family he described this act as a way he had changed with his family interactions, not a way of coping. For Max, using his family members to talk about his feelings was just something he now did, rather than a way he coped. These examples suggest researchers need to consider how people relate to

behaviours as ‘coping’ in order to represent more accurately what role the coping behaviour plays for that person. It leads to the question that if a person does not consider the behaviour as coping, is it actually coping? As much of the current coping research has stemmed from the seminal work of Lazarus and Folkman (1984), coping measures need to hold the respondent’s appraisal of the coping behaviour at the core of their questioning, just like appraisal is held at the core of stress and coping theory. Only then can the effects of coping behaviours on individuals’ wellbeing start to be understood.

### **6.3.3 The participants’ experience**

When conducting the 66 quantitative interviews, as with the FAD, participants would sometimes give insights into how they were interpreting the questions through comments they made or feedback they gave. For the bCOPE, the main concern for participants was not having a specific reference point from which to be able to explain their responses. They would often say “it depends” or would want to elaborate on examples of different situations, having to be reminded to think generally and to not rely on specific stressful situations for reference. This appeared difficult for many participants, and at times some appeared frustrated by this lack of ability to elaborate and justify their response.

Another observation was that of varying reference points being used. That is, with each statement that was given from the bCOPE, participants at times voiced reactions which suggested they were not thinking generally about their coping, and instead were answering about specific stressors which related to situations they had dealt with in the past. Often these reference points related to challenges with ABI. The combination of taking part in a study about the injury and being asked about coping strategies was difficult to keep separate. One participant even stopped the interview mid-point and said “it’s hard because I deal with things differently now than I did in the beginning. I would have avoided talking about it [the



injury] much more than I do now”. It could be that this connection between coping and ABI challenges was created by the context of the research participation, or it could be that for people living with something as life-changing as ABI, this is what their focal point becomes, around which everything else revolves. Although this study has attempted to capture dispositional coping styles of the participants, both qualitatively and quantitatively, it is hard to tell if either method was successful. This leads to questions about the effectiveness of dispositional coping as a theory, and whether it is realistic to expect participants to be able to accurately report their dispositional styles. If people find it hard to express general coping styles without specific reference points with which to reflect on, it would appear people are actually just expressing lots of discreet situational responses. If people are vacillating between one coping response to another when answering dispositional coping measures, it becomes the challenge of the researcher to decipher what is a situational style and what is dispositional. The analysis of the statistical outcomes along with the experiences of the participants has created a demand for the attention of a theoretical debate about the classification of coping styles and subsequent conceptualisation. With research investigating the efficacy of specific coping interventions (Anson & Ponsford, 2006b; Appleton et al., 2011; Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010) it is important for us to first gain an accurate understanding of what coping efforts mean for those concerned.

#### **6.3.4 Reflections as a researcher**

As a measure of an individual’s coping styles, further work is needed to ascertain how to capture these most accurately. The discrepancies between the qualitative and quantitative methods applied in this project suggest coping reports are at risk of being either under or over reported. The difficulties already presented in the literature about people’s ability to selfreport situational coping responses are evident in this study too (such as that seen in Stone

et al., 1998, and Todd, Tennan, Carney, Armeli, & Affleck , 2004), even though a dispositional approach was employed. It would be worth investigating to see whether conversations around the use of coping styles with people that have completed both a qualitative interview and standardised coping measure such as the bCOPE helps us gain insight into where the discrepancies come from, and more of an understanding as to why people give the responses they do. A similar methodology was applied to the ways of coping questionnaire (WOCQ Folkman & Lazarus, 1980) in a study using college students, who were asked to describe their responses to the WOCQ (Stone, Greenberg, Kennedy-Moore, & Newman, 1991). A similar technique applied to the ABI population could help decipher how the complications of ABI deficits interact with coping efforts and abilities.

As a researcher, using the bCOPE did not feel as though it was measuring dispositional approaches due to the comments people would say when replying. They often referred to ABI stressors, or ways of coping with things in their home. The subsequent statistics the measure produced did not add any additional value over that which had been gained through the interviews. A further interview with the participants to discuss the outcomes from the two sets of results may help with understanding as to why people report coping differently dependent on mode of questioning. This information could then possibly contribute to the development of a measure which elicits a truer picture of coping in those facing the challenges of ABI. Only then we will start to understand if this is an area worthy of therapeutic intervention and further clinical resource.

## **6.4 The Brain Injury Grief Inventory**

### **6.4.1 About the measure**

The Brain Injury Grief Inventory (BIGI) is a twenty-item questionnaire developed by Coetzer, Vaughan, and Ruddle (2003) and comprises two scales: loss and adjustment. The loss scale aims to assess how much injury-related loss is a focus for the individual, and the

adjustment scale aims to measure how well such losses have been adjusted to (Ruddle, Coetzer, & Vaughan, 2005). This measure was developed for use with patients, so for this study a second version was revised to be read from a relative's perspective. For example 'I miss the things I cannot do since I had my injury', becomes 'I miss the things I cannot do since *they* had *their* injury'. All revisions to the original questions can be found in Appendix 5, along with the original patient version of the BIGI in Appendix 6. The use of a relative's version of the BIGI, although endorsed by the original author, has not been published, therefore no reliability data is available for this version. The test-retest reliability correlations for the patient version of the loss scale is 0.89 ( $p < 0.01$ ) and for the adjustment scale is 0.58 ( $p < 0.05$ ).

#### **6.4.2 Loss and adjustment as a statistic**

The BIGI is quick to administer and provides a score for each of the two scales. Scores for the loss scale range between 0, representing no loss at all, and 22, representing the greatest feeling of loss. The adjustment scale yields scores between 0 (no adjustment achieved) to 18 (greatest adjustment achieved). Results are interpreted on a sliding scale, with no clinical cut off scores provided by the authors. Therefore, there is no way to interpret scores in terms of the likelihood of intervention being needed.

Taking the dyadic case studies as examples again, it can be seen that the BIGI was more consistent than the FAD and bCOPE in terms of continuity between quantitative and qualitative results. The BIGI scores for Harry and Patricia are presented in Table 12. Both Harry and Patricia reported feeling adjusted to life after the injury when asked the question directly in the semi-structured interview. It can be seen from their scores of maximum (Harry) and near maximum (Patricia), that the BIGI has captured this same report. Also, the Loss scale results match the representation of no loss reported by the dyad in their interviews.

So, as a quick measure of how this family are doing, the BIGI has provided excellent data for a researcher or clinician. What the BIGI doesn't reveal though, is the 'why' element to the scores. Through the interview process we not only gained the same information that the BIGI did, but also the additional elaboration as to why Harry and Patricia felt no loss and high levels of adjustment. Therefore for this study, the BIGI does not add to the qualitative data, but it does reinforce it.

Table 12

*BIGI scale scores for case study one*

BIGI scale	Harry	Patricia
Adjustment	18	17
Loss	2	4

*Note:* Scores range from 0 (no loss) – 22 (most loss) for the loss scale and 0 (worst adjustment) - 18 (best adjustment) for the adjustment scale

For Max and Hazel, the BIGI results (presented in Table 13) are also representative of the lived experience expressed through their interviews, however the scores require a closer inspection when they are not at the extremes as with Harry and Patricia. For example, Max has scored 7 on adjustment and Hazel has scored 12. Max expressed not feeling adjusted to his ABI when asked in the interview, so the low score of 7 would corroborate this report. However, Max felt very strongly that he was not adjusted, even claiming to struggle with the very idea of a brain injury. Taking this into consideration, the BIGI has added a measure of contentment to his qualitative report, as he has scored just under mid-way, rather than considerably low. Looking at these two reports in parallel, it is hard to see how someone would score exceptionally low on the BIGI adjustment scale, when Max had one of the strongest reactions to the adjustment question qualitatively.

Table 13

*BIGI scale scores for case study two*

BIGI scale	Max	Hazel
Adjustment	7	12
Loss	10	10

*Note:* Scores range from 0 (no loss) – 22 (most loss) for the loss scale and 0 (worst adjustment) - 18 (best adjustment) for the adjustment scale

Looking at Hazel's adjustment score, her responses on this scale resulted in a score of 12. Although this is not a low score, she did feel adjusted to living with her husband's ABI when asked in her interview, just like Harry and Patricia felt adjusted. The BIGI picked up some discomfort around Hazel's adjustment that she did not present when asked out right. Whether the inaccuracy lies with the expression of Hazel's adjustment in her interview, or the questioning of the BIGI is not known.

Although not an exact replication of the participant expressions in the interviews, the BIGI bodes well under comparison with how people express their loss and adjustment through semi-structured interviews. The consideration when using the BIGI is whether it adds any value in a research capacity when it does not explain the factors contributing to feelings of loss and adjustment. When simple screening is required, the BIGI would be a good choice for identifying families who may require further interventions and support, but further discussion would be needed to ascertain the meaning of these results for individual members within that family.

When the BIGI was analysed on an individual basis it gave a good representation of loss and adjustment for the dyads, but when looking across a sample the measure does not

represent these stories quite so well. In order to see if the BIGI represented the whole sample used in the original study, a crude mid-way cut-off point was applied to identify those who could be classed as feeling below average loss and adjustment. Therefore, for the loss scale, those scoring 11 or below were considered to have low feelings of loss and for the adjustment scale those scoring 9 and under were considered to be feeling less adjusted. This was applied to see the range within which people were mainly falling, not to assume the need for intervention. Using this range, 32 of the 66 individuals with ABI presented as having lower levels of loss, and 10 individuals with ABI emerged as feeling less adjusted. This isn't representative of the sample as a whole when looking at the qualitative data though. When asked during the interviews, 37 of the 40 participants reported a sense of loss of some kind. It may be that loss is under-reported on the BIGI due to it not considering the variety of types of loss people can feel. It has been shown that loss is not unidimensional and can relate to specific activity losses, but also to identity, future plans or relationship losses (Buckland, Kaminskiy & Bright, 2020). The loss items on the BIGI mainly relate to one specific type of loss relating more to activity than more abstract concepts such as ambiguous loss.

The lack of what constitutes a clinically significant outcome on the BIGI makes it hard to assess whether a certain score in isolation represents a positive or negative outcome. With the adjustment scale scores, Max scored 7 out of 18, which would indicate he did not feel particularly adjusted to his life after his injury. However, Max had the strongest reaction to the question of being adjusted when asked in the interview stage and was the only individual with ABI to say they categorically did not feel adjusted. Moreover, Max was not the lowest scorer on the BIGI adjustment scale, with three individuals with ABI scoring lower, and two individuals with ABI scoring the same as Max. These participants had expressed feeling adjusted to their life with ABI when asked in their interview. Further investigation would be needed to ascertain whether these participants felt the BIGI was more

accurate, or whether they stood by their interview response. It could be that for these participants, they have a general feeling of adjustment, which led them to report this in their interview, but that the BIGI brought out specific elements of living with ABI which they did find difficult still. Therefore, researchers run the risk of making assumptions about the levels of adjustment amongst the ABI population, when the ABI population does not necessarily feel this as a lived experience.

For this study, a new version of the BIGI was created in an attempt to capture the same loss and adjustment data for relatives as for individuals with ABI. Therefore, a 'relatives' version' of the BIGI was created (see page 205 for full explanation of this revised version). Accordingly this provides an opportunity to assess whether the patient version of the BIGI is directly transferable to relatives, or whether their experiences warrant a separate measure. For relatives, the average score on the adjustment scale was 15 (standard deviation 2.9). With a maximum score of 18 on this scale showing the best adjustment, a group average of 15 suggests relatives, on the whole, are well adjusted to life after ABI. As mentioned earlier though, there is no clinical cut-off or criteria for the BIGI which tells us if this is an appropriate interpretation or not. Taking the reports from the interviews in this study, the BIGI appears to represent the relatives of individuals with ABI well. Indeed, 84% of relatives reported feeling adjusted to their life after their loved one's ABI when asked in the interview. When the loss scale is inspected, the results do not hold up so well against a comparison to the qualitative data collected. Quantitatively, relatives on the BIGI scored low on the loss scale with a mean score of 6.5 (standard deviation 2.4). Again, the interpretation of a low score is based on that of the researcher as no official ratings are available. From these results, it can be assumed that the sample used for this study do not feel a great deal of loss and are well adjusted on the basis of not feeling this loss. However, the interview responses give a very different representation of the family member experience. Relatives felt specific and

profound loss as a result of the ABI impact. If the BIGI alone had been used to describe this population, the experiences of loss would have been underreported.

The thematic analysis of the loss data in the interviews showed that experiences of loss differed dependent on the participant type. Loss was experienced differently for those who had the injury compared to those related to them. It could be then, that the BIGI translates well to relatives on the adjustment scale but not on the loss scale. Questions relating to areas of loss most prominent for relatives could be incorporated into a relatives' version of the BIGI to capture the unique differences in loss experienced after ABI.

The need for this revision to the BIGI, or indeed clarification of what the BIGI is capturing, also occurs when the data for individuals with ABI is inspected. Once again, the adjustment scale appears to capture the experience of the participant in a quick and efficient way. Mean adjustment scores for individuals with ABI on the BIGI were 13.4 (standard deviation 4.5). Although slightly lower than the relatives, 13.4 can be considered high on a scale which ranges from 0-18, with 18 showing the best adjustment possible. This reflects the study sample well in terms of how they also presented in the interviews. Individuals with ABI made up more of the 'partially adjusted to ABI' section than did relatives, so it corresponds well that their BIGI average is slightly lower than that of relatives. The same difficulty in interpretation appears when inspecting the loss scale as did for relatives. The mean score on the BIGI loss scale for individuals with ABI was 7.9 (standard deviation 4.7), suggesting a low level of loss present in this population given the score is out of 22 (with 22 representing the highest loss). However, qualitatively, individuals with ABI spoke vividly of the loss they felt as a result of their injury.

This disparity in loss results could be representative of the multifaceted ways in which loss can present. The emergence of five distinct loss themes seen in this study could be



suggestive that the BIGI does not capture all of these different ways in which people can experience loss. Moreover, considering the way quantitative measures function, someone may present with a high score on one particular aspect of loss (for example the question which relates to activities – “I miss the things I cannot do since I had my injury”) yet score much lower on other aspects of loss (such as mood, e.g., “I have been feeling low since my injury”, or “I feel it is unfair that I had a brain injury”). The lower score on one aspect of loss would counteract the high score on the other aspect of loss, thus leading to an interpretation that this person feels minimal impact in terms of loss. However, the one aspect that was of importance to the respondent will be neglected, and so the loss will remain undetected and subsequently unaddressed.

This analysis suggests that the BIGI is a suitable tool to measure peoples’ levels of adjustment to life after ABI, regardless of whether they had the injury themselves or whether they are related to that person. The results of the thematic analysis of peoples’ experience of loss may provide insight as to why the loss scale does not correlate so well under the same analysis. Further research into adaptations to the BIGI loss questions to encompass the different forms it can take would be useful if a quantitative measure is to be used to describe this complex experience.

### **6.4.3 The participants’ experience**

The administration of the BIGI was on the whole very straightforward. The feedback from one participant highlighted how adjustment is a process, and that there is a journey people can go on. He said that his answers would have been very different had they been asked five years ago, often referring to having ‘been through it’ and now ‘out the other side’. The main issue fed back by participants concerned the wording of some of the items. These

are presented here in turn with a brief description of the feedback received during administration.

*Item 9: I have a strong desire to talk about my injury and the effects it had on me*

For some participants, saying they did not feel a desire to talk about their injury would be interpreted as they had an issue talking about at, so they wanted to discuss this item in more detail before answering. Some wanted to agree with this statement, following it up with comments such as ‘I am happy to talk about it’. When this was presented, participants were asked to clarify if this meant they really felt the need to talk about the effect of their injury. Some participants re-evaluated their answers when the meaning of the statement had been explained further. This feedback suggests administrators should be vigilant to indications that the intention of the statement has been misunderstood.

*Item 12: I think I have overcome the losses resulting from my brain injury*

For those participants who did not feel they had any losses, this statement felt leading and some felt they wanted to discuss how they were to respond. Some participants reported ‘never’ if they didn’t feel losses, because they did not have losses to overcome. However, the BIGI would interpret this as someone who had experienced losses but had not overcome any of them and would thus increase their loss score as a consequence. An option to express that no losses were experienced would be useful for those who feel this way. Moreover, if someone who has not felt loss responds to indicate they have overcome these losses, it misrepresents their experience of ABI and makes them appear adjusted to a situation that wasn’t ever an issue.

*Item 17: I do not feel sad or depressed*

The responses to this item are ‘never’, ‘sometimes’, or ‘mostly’. It required confirmation that when people answered ‘never’ they were trying to express feeling sad and depressed most of the time. Every time this was challenged the respondent changed their answer to ‘mostly’, as the negative answering had confused them. It would be useful for administrators to check the participant has answered in a way which reflects their feelings towards this statement.

*Item 13: I have been feeling low since my injury*

The complication with this item is that it assumes the low mood is a consequence of the injury. It may be a more accurate statement if people were responding to whether they feel low ‘because’ of their injury. There could be numerous factors which contribute to low mood, which are not connected to the injury itself. Indeed, participants expressed this through some of the interviews, when asked about changes to coping or their family. For some, it was hard to separate the injury from other life events, such as a cancer diagnosis for one or development of obsessive-compulsive disorder for another. For some other participants, the natural course of life had created changes that could equally be attributing to mood, such as children entering or leaving the family home, or divorce.

Analysis of the items which caused issues for some participants shows that either the measure itself would benefit from revised statements, or guidance notes should be included to make sure the intentions of the statements are understood and accurate responses are given.

#### **6.4.4 Reflections as a researcher**

The BIGI provided a mechanism by which to cover various feelings about brain injury in a general way. The difficulty with the BIGI lay more with interpreting the outcomes.

When scoring the scales the data did not seem to provide any benefit when coupled with the responses of the interviews. When the BIGI scores ‘matched’ the experiences of the participants as expressed through their interviews it did not add to the importance of the interview data. When BIGI scores seemed at odds with what people were saying, this just detracted from the story being told. Therefore, it was not felt that by omitting the BIGI data from the study there was any weakening of the overall results. This highlighted the progression of myself as a researcher. At the start of this journey I firmly believed that the best way to investigate this subject matter was by means of mixed methods, allowing for the ‘best of both worlds’ to be utilised, resulting in a robust and thorough examination of family adjustment after ABI. This is not the researcher I have become.

It has become apparent that in terms of researching family adjustment, it is hard to approach this in a standardised way. Just as each ABI is different, so is each family. Therefore, a unique system is created by which there is no standardised way of assessing factors, variables and influences which ultimately lead to positive or negative family outcomes. What benefits one family simply may be detrimental for another.

#### **6.5 Summary**

The use of standardised testing can help researchers generalise to populations and measure the impact of interventions and therapies. However, as a means to describe the ‘why’ and ‘how’ of family adjustment, it has not proven to be beneficial. The data collected from the quantitative stage of the original project design did not add any additional value to

that collected from the semi-structured interviews. In fact at times it created more questions than answers, distracting from the unique and powerful expressions of people's lived experiences of ABI. Based on the evidence presented here and the experience of applying a mixed methodology to a family adjustment study, it is concluded that future studies should focus on qualitative methods when attempting to understand what makes for good and poor adjustment to life after ABI. The ways people manage are unique to their family circumstances and the complexity of factors which lead to them feeling adjusted to their changed life could be extensive. When attempting to generalise these results across a population, the uniqueness of these factors is watered down and the richness of life is lost. The meaning for family behaviours is more crucial and informative than the behaviours themselves. We cannot assume that the way people adjust their way of life to accommodate ABI is either good or bad. But it is important to know how satisfied they are with these adjustments they have made. Only then can we start to truly understand how families live with the lifelong impact of ABI.

## **Chapter 7. Conclusions and suggestions for future research**

The current study has generated a number of potential research questions worthy of further investigation to increase our understanding of how families adjust to life after ABI. The recommendations discussed throughout this thesis are summarised here under the three main research topics of coping, family change, and loss, concluding in recommendations for how we might better research adjustment to ABI as a whole.

### **7.1 Further coping research**

*How do the emotional and cognitive effects of ABI impact on existing coping strategies, and do these limitations impact on the ability to develop new strategies?* Through the analysis of interview data relating to changes in coping behaviours after ABI, it was highlighted that people can be faced with trying to use previous coping styles which are no longer as easily accessible due to the limitations of the ABI. Current research suggests those who are most able to be flexible with their coping strategies reach a better level of psychosocial functioning (Cheng, 2003; Cheng & Cheung, 2005). The impact of executive dysfunction after ABI on the ability to be flexible has been investigated previously (McDonald, Flashman, & Saykin, 2002; Wood & Worthington, 2017) but not in the context of developing new coping strategies that take into account this dysfunction. Research which helps us understand how much someone's coping style has been affected by the ABI sequelae would help towards developing interventions which support the development of more effective coping strategies post-injury.

*Why do people report different types of coping style dependent on how they are asked?* As could be seen from the critique of quantitative measures in Chapter 6, participants reported different types of coping behaviours through the two types of questioning; qualitative enquiry

and quantitative enquiry. Further investigation into why this occurs could help researchers understand more about how people interpret coping styles, and how the type of questioning affects someone's response. This would not only help us understand coping as a concept more, but also have wider implications for understanding participants' experience of the different research methodologies in general. The discrepancies seen between reports of coping dependent on the mode of questioning raises questions about the validity of both qualitative and quantitative methods of coping research. Extensive work to investigate these differences and the reasons for their occurrence is required to decipher how to most accurately capture people's coping behaviours, both objectively and subjectively. Until this is established, concerns remain about the validity of coping research and the assumptions being made about adaptive versus non-adaptive styles.

## **7.2 Further family change research**

*Are spousal relationships unique, or is it about the expectations set out in the relationship pre-injury?* In this study some differences were identified between the experiences of spouses compared to other relationship types, although some similarities were seen between spouses and siblings who were co-habiting. Much research has deduced that couples experience specific changes to their relationship after a spouse suffers an ABI (Kreutzer, Gervasio, & Camplair, 1994; Verhaeghe, Defloor, & Grypdonck, 2005; Zeigler, 1999), but it could be that there needs to be a greater understanding of the 'relationship expectations' and whether it is this that results in the different experiences. For example, the majority of research looking into relationship status and subsequent experiences of ABI compares outcomes for spouses with those of parents. It would be of interest to know if these specific challenges seen for marital couples are due to the impact of being a romantic couple rather than family from birth, or whether there is something about the partnership of the relationship that suffers. That

is, it could be that siblings who live together would suffer similar strain on their relationship due to the pre-existing expectation that the relationship functions quite equally. It is possible that spouses who shared a more unequal relationship pre-injury are not as impacted by the specific spousal strains as those who lived more co-dependently. By understanding why spouses experience different forms of change after ABI to other relationships, it would mean that less common co-habiting relationships do not go unaddressed in terms of the support needs they may have.

*How are relationships changed by ABI on a dyadic versus family level?* As described in the family change results section, some participants felt general family wide changes to their relationships, and others felt relationship changes with a specific relative. The factors influencing these two different experiences is not known, and it could be due to the interpretation of the interview questions and what people were focusing on at that time. However, it could be there are specific changes to families that create this division. It is possible this type of research might reveal specific ways in which relationships get changed which are more detrimental than others and could therefore inform family therapies accordingly.

*How are families affected as a whole unit, from the multiple perspectives of every family member involved?* This research invited any family member to participate, and did not specify the inclusion of main caregivers as much current research has. However, the study is limited in the deductions it can make about family changes to the perceptions and experiences of just the individual with ABI and one of their relatives. The overwhelming majority of research into family adjustment follows this same pattern, involving one or two family members, most commonly the individual with ABI and a main caregiver. Whilst this is useful, it is limiting in that it does not explain how ABI impacts on the wider family and



gives a more restricted view of just one or two people's perspectives. There is a gap in the literature involving whole family units. Although methodologically difficult, it would be beneficial to understand how those with a less direct relationship (i.e. beyond the main caregiver) are affected by ABI. The differences between the needs of first, second and third degree relatives are not well understood and these family members may feel a neglect of their needs as a result.

*Would specific support for families aimed at increasing communication about the ABI impact increase overall functioning?* Many experiences of individuals with ABI and their relatives spoke of hidden challenges or emotions relating to the impact of the injury. The specific experiences of participants revealing how ABI can impact on communication within the family unit suggests it would be worthy of further investigation to see if families can be better supported to communicate their feelings about the impact of the ABI more openly. Some family members are experiencing isolation due to attempting to hide the impact of their loved one's ABI and feeling they need to cope with the additional strain felt on their own. By supporting families to open up communication about the how the ABI has affected them individually, families could regain unity and avoid the splintering of relationships due to hidden pressures and recurrent misunderstandings. In addition, enabling relatives to develop peer support networks could be beneficial for their own communication needs, gaining support from those who can truly empathise.

*What are the connotations of the role changes experienced by spouses and which types of role change have the most impact on relationships?* Role changes were expressed in this study by spouses. This is an area which has been seen to create specific difficulties for couples concerning changes to the roles each spouse plays in the marriage. As this type of relationship is often perceived as a partnership, it could explain why spouses feel increased

burden over other relationship types in many studies (Blais & Boisvert, 2005; Gosling & Oddy, 1999; O’Keefe, Dunne, Nolan, Cogley, & Davenport, 2020; Peters, Stambrook, Moore, & Esses, 1990). If changes to roles in this partnership are better understood, couples therapy may be better informed, and thus more effective.

### **7.3 Further Loss research**

*Which specific relationship changes result in the most loss?* The loss results from this study showed how multi-faceted loss can be, and that there are distinct types of loss people can feel. One aspect which requires further investigation is that of relationship changes, and how these influence feelings of loss. By understanding not just when a relationship has changed, but also what the impact of this is for those involved, we can better tailor support to counteract any negative effects to wellbeing that might occur.

*What is the impact of executive dysfunction on how people experience loss post ABI?*

Executive dysfunction is a common consequence of ABI and how this interacts with feelings of loss is not understood. By investigating this, a better understanding of the experiences of those living with ABI will be revealed and therapies can be more tailored to the specific type of loss that is being experienced.

*Can a specific loss questionnaire be developed based on the qualitative findings of this study, and does this result in more types of loss being reported?* Although 5 themes of loss were identified through the interview data, very few people subscribed to more than one of these themes. To establish whether this is due to the study methodology, a new set of questions could be devised which asks people if they experience the various types of loss reported. This would then show if feelings of loss are specific as found in this study, or whether they have broader implications when people are given suggested types of loss to subscribe to. This

would need to be developed from a wider body of first-person narratives and the further development of conceptual frameworks of loss before a sufficient standardised measure could be considered. An excellent example of the development of this kind of outcome work is available in the field of mental health recovery. The CHIME framework has been developed using the principles of recovery as dictated by the experiences of people in recovery from mental health issues (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Such a conceptual framework which can be applied to adjustment to ABI would be useful for the development of and guidance of rehabilitation services.

*Would a specific therapy, akin to bereavement therapy, support those feeling ambiguous loss?* Ambiguous loss is complex and enduring and was expressed vividly through some of the participant experiences in this study. It can lead to significant issues with long-term wellbeing, yet currently support for living with ambiguous loss does not form part of standard rehabilitation therapies. Trials which establish the efficacy of such an intervention are much needed to support those living with this type of loss.

*Can research with the wider family tell us more about the complexities of loss after ABI?*

With current research using primarily two family members to assess family functioning, it is time to extend this to whole family units to gain a broader perspective of the implications of ABI on families. This will help family interventions become better informed and less pivotal family members will not be forgotten in the rehabilitation process after ABI. Very little is known about the ‘ripple effect’ of loss and how secondary and tertiary family members, who may be completely neglected by support services, experience losses resulting from their family members’ ABI.

## **7.4 Further adjustment research**

*Is an adult child with ABI reaching normative life goals integral to parental adjustment?* The experiences of parents in this study suggest there could be a connection between their adjustment and the realisation of their adult child with ABI continuing on a normative path of life. Research to investigate this further could reveal benefits for life planning and/or goal planning activities as part of rehabilitation therapies for families who do not feel they are achieving expected goals and thus struggling with the adjustment process.

*Is there a benefit in life coaching to help people reach a 'new normal'?* A strong theme which emerged from the adjustment data was that of a 'new normal' being important for people feeling adjusted to life after ABI. The benefits of life coaching sessions for those struggling to find their new normal could be an advantageous addition to community rehabilitation programmes for those who do not feel at ease living with the long term implications of ABI. For instance, the work of Gracey and colleagues has highlighted through the development of the 'Y-Shaped model' the benefits of working within rehabilitation frameworks which hold concepts of identity at their core as a means for helping individuals recreate a new self-identity after ABI (for example see Gracey, Evans, & Malley, 2009). The premise of such models could be extended to relatives' adjustment too, as well as family identity adjustment to support family members to find a new identity in their changed family units. Such a model of rehabilitation could prove particularly advantageous when working with specific family dyads who are exhibiting marked changes in the way their relationship functions as a result of ABI.

*Does the discrepancy between initial prognosis and actual outcome influence adjusting to ABI more than the actual outcome itself?* In this study, a number of participants referred to how outcomes ‘could be worse’, and that this helped them explain why they felt adjusted to life after ABI. It is not currently known whether it is the actual outcome of someone’s ABI which induces a feeling of ‘it could be worse’, or whether there is something about the way people experience the highs and lows of the initial prognosis that helps this feeling. Research into the discrepancy between initial diagnosis, actual outcome, and levels of adjustment would help to better understand the experiences of those involved.

*What is the impact on long-term wellbeing for those involved in a litigation claim after ABI.* As was seen with Max, the treatment he experienced as a result of his litigation process left him feeling angry and resentful. This appeared to contribute in part to his lack of adjustment to his life as it was after his ABI. Of the research relating to litigation after ABI, the majority is concerned with investigating how effects of ABI can be exaggerated or dwelled on through this process, but little research has considered the long-term implications on the individual having to go through this process at an already vulnerable time in the rehabilitation journey.

*Does the implementation of compassion- focused therapies help alleviate feelings of anger and resentment relating to the ABI?* The two participants who did not feel adjusted both felt a lot of anger and resentment regarding the ABI. Compassion-focused therapies aim to encourage more sympathetic perspectives for oneself, but it would be worth investigating if this extends to feelings of others, or to feelings of the treatment received. For instance, can this external blame be rectified through therapeutic interventions and would this aid the individual to a more successful transition to life after ABI?

*Can stages of adjustment be identified, akin to stages of bereavement, which help establish the stage of adjustment someone is at, and does adjustment follow a cycle like that of*

*bereavement?* It was seen through thematic analysis of the adjustment responses that adjustment can take many years and some people feel they are on a journey towards this feeling of adjustment. Research into the processes people go through could help identify stages of the adjustment process, like those of the well- established stages of the bereavement process (Kübler-Ross & Kessler, 2005). This would be particularly useful from a research perspective due to refining the way we are researching adjustment in an attempt to understand what factors are important to this process. Furthermore, a conceptual framework of the adjustment process could be beneficial in helping those at the start of the journey to understand the stages involved, and somewhat normalise this process as a result.

In conclusion, there is still much to understand about the process by which families come to terms with and adjust to a life changed by ABI. Just three potential areas, coping, family change and loss, have been investigated here in an attempt to add a bit more of this understanding to the current literature. Going forth, research efforts that hold the lived experience of the participants at the heart of their methods stand the greatest chance of producing valuable and informative findings in the quest to better support individuals with ABI and their families.

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## **Appendix 1**

### **Full interview schedule**

1. What is the experience of coping with brain injury like for a family member/ the families?
2. How do feelings of choice, loss and grief affect the adjustment process?

### **Opening**

I am asking people about their experience of having a family member with a brain injury. I will ask you about some of your thoughts and feelings around how your life is with regards to the injury and how you feel you cope with certain situations. As discussed this interview will be recorded and transcribed. Your name will be changed to help protect your identity and unique features which may lead to identification will be used sensitively.

Can I confirm you are aware and happy for this interview to be recorded? ☐

It is important for people's experience to be understood so professionals can better provide for any needs there may be, so it is highly appreciated that you have agreed to take part. You are free to change your mind at any point and can choose not to answer any particular questions that I may ask.

We should expect to be talking for approximately one hour and you are free to ask any questions should you need at any time. If you require a break at all please just say. We will limit the interview to one hour thirty minutes maximum.

Let's begin by thinking about how things have been since (your relative) had their injury...

## **Body**

**Question 1** I would now like to ask you about your typical coping styles. Could you describe how you feel you generally cope with things that cause you stress? (examples may be needed such as ‘do you try to distract yourself or tackle problems head on etc)

**Question 2** Would you view your coping style to be the same as before the injury?

**Question 3** Has the injury changed anything for you as a family? **Prompts:**

What aspects of your life changed as a result of their injury?

a) Could you tell me a bit more about that?

b) Could you describe that in more detail?

**Specifying questions as required:** Could you expand on that point? Do you have any examples of this? Could you say something more about that? How did you react to that? Have you experienced this yourself?

**Question 4** Do you feel you have changed the way you cope with any issues regarding the injury as time has gone on?

a) Could you explain how it has changed?

**Question 5** Would you say you cope with issues around the injury any differently from other forms of stress you encounter?

a) Could you explain why you think that is?

**Question 6** Would you consider that you and your family were in a good position to deal with the brain injury?

a) Could you tell me why you think that was?

**Question 7** To what degree do you feel you actively choose to be involved in the day to day support of (relative)?

**Question 8** We have talked about how you have dealt with things since the injury. I would like to talk a bit now about your feelings around what happened and how life may have changed. Could you describe whether you have or have not experienced a sense of loss since the injury? (May need clarification, for instance, have you felt you think about times before the injury and things you did then?)

a) What are the main areas of loss you have felt?

b) Could you explain why you haven't felt loss?

**Question 9** Have you ever found yourself dwelling on pre-injury life?

a) Why do you think that is?

b) What helps you?

**Question 10** Would you consider yourself to have adjusted to life as it is now after the brain injury? (Change to more directed question if participant has already expressed clearly having or having not adjusted)

a) Why do you feel that?

b) Could you explain that a bit more?

c) what would/does being adjusted look like to you?

**Question 11** I am taking this opportunity to explore what people's idea of being 'adjusted' is. Could you explain what you feel this means to you?

**Question 12** Is there anything else you would like to add?

### **Closing**

I appreciate your time in taking part in this interview and thank you for your openness and honesty. It is important to gain an understanding of the impact of brain injury from the family members' perspective. Would it be okay to call you if I have any clarifying questions? Thank you again.

## Appendix 2

### Full cohort characteristics

	Individuals with ABI	Relatives	Total/ combined
Marital status			
Married	11	16	27
Divorced	3	2	5
Single	7	1	8
Mean age at test ( <i>SD</i> )	51.3 (15.1)	58.7 (12.2)	54.9 (14.1)
Mean age at time of injury	45.1	51.1	48.1
( <i>SD</i> )	(14.7)	(10.6)	(14.1)
Gender			
Male	16	6	22
Female	5	13	18
Mean months since injury	97	92	95
( <i>SD</i> )	(71)	(75)	(72)
Employment status			
Retired	7	11	18
Part time employed	2	2	4
Full time employed	3	3	6
Unemployed	9	1	10



Self employed	0	2	2
Co-morbid health condition	7	4	11

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*Note.* Relatives' time since injury refers to their family members' with ABI. Relatives' age at injury refers to age when their family member sustained their ABI.

## Appendix 3

### Family assessment device



SKYLAND TRAIL

## FAMILY ASSESSMENT DEVICE

Developed by: Nathan B. Epstein, MD; Lawrence M. Baldwin, PhD; Duane S. Bishop, MD

Client Name:	<input type="text"/>	Number:	<input type="text"/>
Your Name:	<input type="text"/>	Date:	<input type="text"/>
Relationship:	<input type="text"/>	Age:	<input type="text"/>

### INSTRUCTIONS

**Please print two copies.** The client should complete one copy. At least one immediate family member should complete the second copy. Although not required, additional copies may be completed by other family members. This assessment contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.

For each statement are four (4) possible responses:

SA	Strongly Agree	The statement describes your family very accurately.
A	Agree	The statement describes your family for the most part.
D	Disagree	The statement <b>does not describe</b> your family for the most part.
SD	Strongly Disagree	The statement <b>does not describe</b> your family at all.

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have difficulty, answer with your first reaction. Please be sure to answer *every* statement and mark all your answers in the space provided *next to* each statement.

### ASSESSMENT

1. Planning family activities is difficult because we misunderstand each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
2. We resolve most everyday problems around the house.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
3. When someone is upset the others know why.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
4. When you ask someone to do something, you have to check that they did it.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
5. If someone is in trouble, the others become too involved.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
6. In times of crisis we can turn to each other for support.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
7. We don't know what to do when an emergency comes up.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>

Client Name: \_\_\_\_\_ Date: \_\_\_\_\_

8. We sometimes run out of things that we need.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
9. We are reluctant to show our affection for each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
10. We make sure members meet their family responsibilities.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
11. We cannot talk to each other about the sadness we feel.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
12. We usually act on our decisions regarding problems.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
13. You only get the interest of others when something is important to them.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
14. You can't tell how a person is feeling from what they are saying.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
15. Family tasks don't get spread around enough.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
16. Individuals are accepted for what they are.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
17. You can easily get away with breaking the rules.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
18. People come right out and say things instead of hinting at them.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
19. Some of us just don't respond emotionally.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
20. We know what to do in an emergency.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
21. We avoid discussing our fears and concerns.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
22. It is difficult to talk to each other about tender feelings.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
23. We have trouble meeting our financial obligations.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
24. After our family tries to solve a problem, we usually discuss whether it worked or not.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
25. We are too self-centered.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
26. We can express feelings to each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
27. We have no clear expectations about toilet habits.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
28. We do not show our love for each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
29. We talk to people directly rather than through go-betweens.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
30. Each of us has particular duties and responsibilities.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
31. There are lots of bad feelings in the family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>

Client Name: Date: 

32. We have rules about hitting people.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
33. We get involved with each other only when something interests us.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
34. There is little time to explore personal interests.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
35. We often don't say what we mean.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
36. We feel accepted for what we are.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
37. We show interest in each other when we can get something out of it personally.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
38. We resolve most emotional upsets that come up.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
39. Tenderness takes second place to other things in our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
40. We discuss who are responsible for household jobs.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
41. Making decisions is a problem for our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
42. Our family shows interest in each other only when they can get something out of it.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
43. We are frank (direct, straightforward) with each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
44. We don't hold to any rules or standards.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
45. If people are asked to do something, they need reminding.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
46. We are able to make decisions about how to solve problems.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
47. If the rules are broken, we don't know what to expect.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
48. Anything goes in our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
49. We express tenderness.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
50. We confront problems involving feelings.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
51. We don't get along well together.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
52. We don't talk to each other when we are angry.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
53. We are generally dissatisfied with the family duties assigned to us.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
54. Even though we mean well, we intrude too much into each other's lives.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
55. There are rules in our family about dangerous situations.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>



Client Name: Date: 

32. We have rules about hitting people.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
33. We get involved with each other only when something interests us.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
34. There is little time to explore personal interests.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
35. We often don't say what we mean.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
36. We feel accepted for what we are.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
37. We show interest in each other when we can get something out of it personally.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
38. We resolve most emotional upsets that come up.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
39. Tenderness takes second place to other things in our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
40. We discuss who are responsible for household jobs.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
41. Making decisions is a problem for our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
42. Our family shows interest in each other only when they can get something out of it.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
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44. We don't hold to any rules or standards.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
45. If people are asked to do something, they need reminding.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
46. We are able to make decisions about how to solve problems.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
47. If the rules are broken, we don't know what to expect.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
48. Anything goes in our family.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
49. We express tenderness.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
50. We confront problems involving feelings.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
51. We don't get along well together.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
52. We don't talk to each other when we are angry.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
53. We are generally dissatisfied with the family duties assigned to us.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
54. Even though we mean well, we intrude too much into each other's lives.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
55. There are rules in our family about dangerous situations.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>

Client Name:

Date:

56. We confide in each other.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
57. We cry openly.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
58. We don't have reasonable transport.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
59. When we don't like what someone has done, we tell them.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>
60. We try to think of different ways to solve problems.	SA <input type="checkbox"/>	A <input type="checkbox"/>	D <input type="checkbox"/>	SD <input type="checkbox"/>

*Developed by: Nathan B. Epstein, MD; Lawrence M. Baldwin, PhD; Duane S. Bishop, MD*

## Appendix 4

### bCOPE

		I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
1	I turn to work or other substitute activities to take my mind off things				
2	I concentrate my efforts on doing something about it				
3	I say to myself "this isn't real"				
4	I use alcohol or drugs to make myself feel better				
5	I get emotional support from others				
6	I give up trying to deal with it				
7	I take action to try to make the situation better				
8	I refuse to believe that it has				

	happened				
9	I say things to let my unpleasant feelings escape				
10	I get help and advice from other people				
11	I use alcohol or drugs to help me get through it				
12	I try and see it in a different light, to make it seem more positive				
13	I criticise myself				
14	I try to come up with a strategy about what to do				
15	I get comfort and understanding from someone				
16	I give up the attempt to cope				
17	I look for something good in what is happening				



18	I make jokes about				
----	--------------------	--	--	--	--

	it				
19	I do something to think less about it, such as go to the movies, watch TV, read, daydream, sleep or shop				
20	I accept the reality of the fact that it has happened				
21	I express my negative feelings				
22	I try to find comfort in my religion or spiritual beliefs				
23	I try to get advice or help from other people about what to do				
24	I learn to live with it				
25	I think hard about what steps to take				
26	I blame myself for things that happened				

27	I pray or meditate				
28	I make fun of the				
	situation				

## Appendix 5

### Relatives' BIGI

#### **The Brain Injury Grief Inventory - Relative**

**Coetzer ©, Vaughan & Ruddell, 2003.**

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the response which comes closest to how you have been feeling in the past week.

If you find it difficult reading and filling in the items, you can ask someone else to read each question out to you.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Please rate each statement below as 'never', 'sometimes' or 'mostly'. Please underline one only.

1. I try to avoid thinking and reminding myself about them having a brain injury

Never   Sometimes   Mostly

2. I am able now to think through what their brain injury means to my life

Never   Sometimes   Mostly

3. I feel angry that they had a brain injury

Never   Sometimes   Mostly

4. Although life has changed for me, I feel able to get on with my life now

Never   Sometimes   Mostly

5. I am upset by things that remind me about their injury,  
e.g. the anniversary

Never   Sometimes   Mostly

6. I have stopped comparing how things were before their brain injury

Never   Sometimes   Mostly

7. I have found myself longing for the time before their injury occurred · Never  
Sometimes Mostly
8. I am less preoccupied with the effects of their brain injury now than I was ·  
before  
Never Sometimes Mostly
- F2 ·  
F1 ·
9. I have a strong desire to talk about their injury and the effects it had on  
me  
Never Sometimes Mostly
10. I feel I can reach out to people ·  
Never Sometimes Mostly
11. I miss the things I cannot do since they had their injury · Never  
Sometimes Mostly
12. I think I have overcome the losses resulting from their brain injury ·  
Never Sometimes Mostly
13. I have been feeling low since their injury · Never  
Sometimes Mostly
14. I feel it is unfair that they had a brain injury · Never  
Sometimes Mostly
15. I think I understand what has happened to them ·  
Never Sometimes Mostly
16. I think about their brain injury so much that I find it difficult to do other things ·  
Never Sometimes Mostly
17. I do not feel sad or depressed ·  
Never Sometimes Mostly
18. I feel less able to care for other people since their injury ·  
Never Sometimes Mostly
19. I have accepted the fact that they have a brain injury ·  
Never Sometimes Mostly

20. Life is empty since their injury  
Never Sometimes Mostly

F1 . .

F2 Thank you for completing this questionnaire.

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## Appendix 6

### BIGI

<b>The Brain Injury Grief Inventory</b>
<b>Coetzer ©, Vaughan &amp; Ruddle, 2003.</b>
<p>This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the response which comes closest to how you have been feeling in the past week.</p> <p>If you find it difficult reading and filling in the items, you can ask someone else to read each question out to you.</p> <p>Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.</p>

Name: _____	Date: _____
-------------	-------------

Please rate each statement below as 'never', 'sometimes' or 'mostly'. Please underline one only.
---

- |  |  |                          |
|--|--|--------------------------|
| 1. I try to avoid thinking and reminding myself about having had a brain injury    |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 2. I am able now to think through what the brain injury means to my life           |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 3. I feel angry that I had a brain injury  |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 4. Although life has changed for me, I feel able to get on with my life now        |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 5. I am upset by things that remind me about my injury,<br>e.g. the anniversary    |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 6. I have stopped comparing how things were before my brain injury                 |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 7. I have found myself longing for the time before my injury occurred              |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |
| 8. I am less preoccupied with the effects of my brain injury now than I was before |  | <input type="checkbox"/> |
| Never      Sometimes      Mostly   |  |                          |

F1 ☐    F2 ☐

9. I have a strong desire to talk about my injury and the effects it had on me ☐  
Never Sometimes Mostly
10. I feel I can reach out to people ☐  
Never Sometimes Mostly
11. I miss the things I cannot do since I had my injury ☐  
Never Sometimes Mostly
12. I think I have overcome the losses resulting from my brain injury ☐  
Never Sometimes Mostly
13. I have been feeling low since my injury ☐  
Never Sometimes Mostly
14. I feel it is unfair that I had a brain injury ☐  
Never Sometimes Mostly
15. I think I understand what has happened to me ☐  
Never Sometimes Mostly
16. I think about my brain injury so much that I find it difficult to do other things ☐  
Never Sometimes Mostly
17. I do not feel sad or depressed ☐  
Never Sometimes Mostly
18. I feel less able to care for other people since my injury ☐  
Never Sometimes Mostly
19. I have accepted the fact that I have a brain injury ☐  
Never Sometimes Mostly
20. Life is empty since my injury ☐  
Never Sometimes Mostly

F1 ☐ F2 ☐

Thank you for completing this questionnaire.

<p>© B. R. Coetzer, North Wales Brain Injury Service, Conwy &amp; Denbighshire NHS Trust, Colwyn Bay Hospital, Hesketh Road, Colwyn Bay, LL29 8AY, United Kingdom.</p>
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## **Appendix 7**

### **Participant information sheet**

#### **Section A - Participant information sheet – Client**

##### **Study title**

The role of family adjustment in brain injury rehabilitation

##### **Summary of research**

You are invited to take part in a research study about the effect family adjustment has on the rehabilitation of people with a brain injury. The research aims to investigate how the family environment potentially interacts with rehabilitation outcomes for a person who has had a brain injury.

Helping people rebuild a strong sense of self-identity after a brain injury has been shown to have a positive effect on how people respond to other cognitive or physical rehabilitation therapies. This research aims to extend this idea further and investigate how the family experience and the individual experience interact.

##### **Purpose of the research**

This research is being conducted in conjunction with Headway Cambridgeshire as part of a PhD dissertation. The results will form part of a written thesis and be shared with Headway Cambridgeshire to help them develop their services for individuals and families living with brain injury.

##### **Who is conducting the research?**

The primary researchers name is Sharon Buckland, a PhD student at Anglia Ruskin University.

##### **Supervisor name**

This research is being supervised by Professor Peter Bright at Anglia Ruskin University. The second supervisor is Dr.Emma Kaminskiy who is a lecturer at Anglia Ruskin University.

##### **Why have I been asked to take part?**

You have been asked to take part because you have had an acquired brain injury at least 2 years ago.

##### **How many people will take part?**

It is expected that 35 people will take part in a semi-structured interview which is part of a larger questionnaire study for which you will have already taken part.



### **What are the benefits of taking part?**

By taking part in this research you will be contributing to information about people's experiences of living with a brain injury and how families cope with this. It is hoped this information will help with understanding what makes for a good rehabilitation environment. Headway Cambridgeshire aim to use the results of the research to inform how they develop services for individuals and families living with brain injury.

### **Can I refuse to take part?**

Yes. You may take your time to think about whether you would like to take part. Taking part in this research is not compulsory and does not form part of your Headway Cambridgeshire service. If you decide to take part you may withdraw at any time and without penalty. You can also withdraw any data collected from you as part of this study up until the time it has been included in the analysis write up (approximately December 2018). This research is separate from your Headway services and declining to take part will have no negative effect on the services you receive or wish to access in the future. If you start the interview and change your mind you are still entitled to stop at any time.

### **Has the research got ethical approval?**

This research has been granted ethical approval by Anglia Ruskin University. It also has the backing of Headway Cambridgeshire who pride themselves on providing a client centred service.

### **How is the research being funded?**

The research is being funded by a variety of external grants to minimise the impact on Headway Cambridgeshire finances. The first and second years of research have been funded by The Pixel Trust.

### **What will happen to the results of the research?**

The results will be written up as part of a PhD thesis. The results will also be presented at relevant conferences such as the annual Headway UK conference. This is to maximise the impact the research has for people living with a brain injury. Results will also be presented at academic conferences as part of the PhD requirements.

The results may also be published in academic journals and other relevant publications such as organisational magazines.

### **Who do I contact for further information?**

For more information please contact the primary researcher Sharon Buckland

## Section B – Your participation in the research project **What**

### **will I be asked to do?**

For this research you will take part in a semi-structured interview. This means that the interviewer has some pre-prepared questions to guide the interview, but that this is not fixed and questions may change slightly through the course of the interview based on your answers. The whole interview will be recorded on a Dictaphone. The questions are designed to see how you have adjusted to life with an acquired brain injury and what your experience of the rehabilitation journey has been like. You will be able to look at the pre-prepared questions to help you decide if you want to take part. An example question would be ‘how have things changed for you as a family since your brain injury?’ It is expected the interview will last approximately 30 minutes although this will vary depending on how elaborate your answers are and whether you wish to take breaks.

At any time you are allowed to stop the research. You may have a break or withdraw completely if you feel you no longer want to take part.

### **What will happen after I take part?**

You will be given a sheet of written information about the study to take away. This is called the Participant Debrief Sheet. It includes details of how you can withdraw from the study if you change your mind and how to access follow up support should you need it. The researcher will discuss the debrief sheet with you after you have taken part in the study.

### **Will my participation in the research be kept confidential?**

The information you give during the interview will be shared as part of the project, therefore your answers are not confidential. However, your information will be anonymised at the earliest convenience by way of giving you a participant identification (ID) number. Only the primary researcher, Sharon Buckland, will have means of tracing the ID number to the person. Your spoken word will be turned into text (transcribed) and all names will be changed. However, due to the descriptive nature of the interviews it may be possible that you are identifiable by people familiar with your family circumstances or any unique features that are described through your responses. Such information will be dealt with sensitively and any unique features will only be included should they be considered important to the understanding of the research. You will not be named in the write up of the research and every effort will be made to ensure your anonymity throughout.

### **Will I be reimbursed travel expenses?**

Unfortunately for this research project there is not the opportunity to claim expenses. Every effort will be made by the primary researcher to minimise any financial impact. This will be by meeting at Headway Cambridgeshire’s Fulbourn or Peterborough premises or at your home.

**Are there any possible disadvantages or risks to taking part?**

There are no foreseen disadvantages to taking part although due to the nature of the questions it is possible there may be some negative effect from reflecting on the challenges of brain injury and the impact this has had on you and your family.

Should you feel uncomfortable answering the questions or feel emotional distress you should take a break or consider withdrawing from the study altogether.

You also have the option of talking to the Headway Cambridgeshire community brain injury co-ordinator who will help you manage any adverse emotional effects that arise from the questions.

**What will happen to any information that is collected?**

The information will be anonymised in the first instance and then collated with other people's data. Once your interview has been transcribed and anonymised it will be deleted. The transcript will be kept for analysis on a password protected computer and destroyed once the write up of the research has been completed.

**Complaints**

If you feel you would like to complain about the study or how it has been conducted and you feel this cannot be resolved through discussions with the research team, please contact Email address: [complaints@anglia.ac.uk](mailto:complaints@anglia.ac.uk) or postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

PARTICIPANTS SHOULD BE GIVEN A COPY OF THIS TO KEEP, TOGETHER  
WITH A COPY OF THE CONSENT FORM.

## Section A - Participant information sheet – Client

### **Study title**

The role of family adjustment in brain injury rehabilitation

### **Summary of research**

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Email address: [complaints@anglia.ac.uk](mailto:complaints@anglia.ac.uk) or postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

PARTICIPANTS SHOULD BE GIVEN A COPY OF THIS TO KEEP, TOGETHER  
WITH A COPY OF THE CONSENT FORM.

## Appendix 8

### Quantitative data set

*Table showing means (M) and standard deviations (SD) of participant responses to the FAD scales*

Fad scale	<u>Individuals with ABI</u>		<u>Relatives</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Problem solving	2.0	0.4	1.9	0.4
Communication	2.1	0.4	2.1	0.2
Roles	2.1	0.4	2.2	0.4
Affective Responsiveness	2.3	0.6	2.1	0.4
Affective Involvement	2.1	0.5	109	0.3
Behaviour Control	1.9	0.4	108	0.3
General Functioning	1.9	0.4	1.8	0.5
Retrospective General Functioning	1.9	0.5	1.7	0.5

*Table showing means (M) and standard deviations (SD) of participant responses to the*



*bCOPE*

bCOPE scale	<u>Individuals with ABI</u>		<u>Relatives</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Self distraction	5	1.9	5	1.6
Active coping	6	1.7	7	1.4
Denial	3	1.8	3	1.2
Substance use	2	1.0	3	1.2
	6	2.0	6	1.7
Use of emotional support				
	6	1.7	5	1.7
Use of instrumental support				
	3	1.3	3	1.6
Behavioural disengagement				
Venting	5	1.9	5	1.8
	6	1.8	6	1.6
Positive reframing				
Planning	6	1.7	7	1.5
Humour	5	2.1	5	1.8
Acceptance	7	1.7	8	0.6
Religion	3	2.1	4	2.3
Self blame	5	2.3	5	2.0

*Table showing means (M) and standard deviations (SD) of participant responses to the BIGI*

BIGI scale	<u>Individuals with ABI</u>		<u>Relatives</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Loss	8	4.8	7	1.7
Adjustment	13	4.2	16	2.2

## Appendix 9

Abstracts for posters, presentations and publications

After a person experiences an acquired brain injury (ABI), there can be grieving for what has been lost. Little is known about the loss felt by relatives of people with ABI. This study investigates concepts of loss among individuals with ABI and their families. Forty participants, recruited from a brain injury charity client pool, took part in a semi-structured interview. Of the participants, seventeen were in dyadic relationships (53% spouses, 41% parent/child and 6% sibling relationships). They also completed the Brain Injury Grief Inventory (BIGI; Coetzer, Vaughan, & Ruddle, 2011) as a quantitative measure of loss after ABI. Five main themes emerged from the interviews: loss of person; loss of relationships; loss of activity/ ability; loss of future; unclear loss. There were distinct differences qualitatively between individuals and relatives and only two dyads experienced similar loss, but there were no significant differences in loss as measured quantitatively by the BIGI. The differences between relatives' loss and individuals with ABIs' loss are discussed. This research suggests that it is important when supporting families to consider individual experiences, because even though the loss originates from the same injury, the loss as experienced may substantially differ among those affected by it.

*Abstract 2 Abstract for oral presentation at the Neuropsychological Rehabilitation special interest group of the World Federation of Neuropsychological Rehabilitation 16<sup>th</sup> annual conference*

**Background and aims:** Acquired Brain Injury (ABI) can have a life-changing impact on families whom are left to adjust to a different way of functioning. Much attention has been given to how patients cope with their changed circumstance who often receive a rehab package to assist such adjustment. Relatives however are often left to find their own way to a new way of living, and can be lost in the patient focus. This study aims to investigate the way patients and relatives experience loss and how this relates to their adjustment.

**Method:** A mixed methods approach was taken. Participants were 12 dyadic relationships (6 patients and 6 relatives). Participants took part in a semi-structured interview, analysed using thematic analysis, along with completing the Brain Injury Grief Inventory (BIGI). Quant and qual data was analysed using side-by-side comparisons.

**Results:** Deep expressions of loss does not always mean people are adjusting poorly. Quantitative measures are more accurate with adjustment than highlighting levels of loss. Relatives experience greater senses of loss than patients. Most patients experience 'some' loss relating to activities they can no longer do such as driving. Relatives' express more global loss effects such a whole family changes or a different lifestyle. Despite differences in qualitative results between relatives and patients, mean BIGI results do not significantly differ.

**Conclusions:** Quantitative measures give a distorted picture of the impact of brain injury if used in isolation. Relatives' experience a deeper loss than patients, and have loss for different things. Family interventions need to be mindful of this and consider the type of loss being experienced and the differences in impact, rather than taking the lead of the patient.

Abstract 3 *Abstract for oral presentation at the Faculty of Science and Engineering 8<sup>th</sup> annual conference*

It is common for patients to experience a period of grieving after injury for the losses brought on by their ABI. The experience of what losses the family members feel is less known. This study aims to investigate how relatives conceptualise loss and how this relates to family functioning after their loved one's ABI. We employed a convergent mixed methods design. Participants were 13 family members (8 spouses and 5 parents), interviewed to explore family interactions and loss after family member ABI, analysed using thematic analysis. The Family Assessment Device (FAD) and Brain Injury Grief Inventory (BIGI) were also administered. Quantitative and qualitative data were combined using side-by-side comparisons. Emerging trends indicated two main themes relating to family changes: *relationship imbalance* (subtheme increased responsibility) and *protectiveness* (subtheme loss of confidence). These themes only applied to spouses. Parents elicited one main theme relating to family changes: *increased closeness* (subtheme openly affectionate). FAD results showed impaired levels on all scales for spouses, with less impaired scales seen in parents. Spouses reported 'loss' of the future, whereby parents experienced loss of the past, even though low levels of loss and high levels of adjustment were reported on the BIGI. Impairment on the FAD scales for spouses, along with the expressed experiences, suggests family role changes and loss may be areas of particular importance when working with families. The discrepancy between qualitative and quantitative data highlights how mixed methods approaches can provide new insight into how loss is being experienced within family relationships.

*Abstract 4 Abstract for poster presentation at the United Kingdom Acquired Brain injury Forum 10<sup>th</sup> annual conference and the datablitz presented at the Neuropsychological Rehabilitation special interest group of the World Federation of Neuropsychological Rehabilitation 15<sup>th</sup> annual conference*

**Background and aims:** The impact a patient's brain injury can have on the family as a whole is widely known but not necessarily understood (Degeneffe, 2001). This study aims to investigate how family functioning is affected after injury and the impact this has on family adjustment.

**Method:** We employed a convergent mixed method design. Seven family members were interviewed to explore family interactions and loss after family member ABI, analysed using thematic analysis. The Family Assessment Device (FAD) and Brain Injury Grief Inventory (BIGI) were also administered. Quantitative and Qualitative Data was combined using side-by-side comparisons.

**Results:** We report interim data on seven interviews. Emerging trends found two main themes relating to family changes; Relationship imbalance (subtheme increased responsibility) and Protectiveness (subtheme loss of confidence). These themes only related to spouses. Parents elicited one main theme relating to family changes; increased closeness (subtheme openly affectionate). FAD results showed impaired levels on the role scale for 5 out of the 7 interviewees. Spouses qualitatively reported 'loss' of the future, whereby parents experienced loss of the past, even though low levels of loss and high levels of adjustment were reported on the BIGI. Anticipated data collection to be completed by June 2018.

**Conclusions:** Impairment on the FAD 'roles' scale, along with the expressed experiences of spouses, suggests this may be an area of particular importance when working with families. The discrepancy between qualitative and quantitative data highlights how mixed methods approaches can provide new insight into how loss is being experienced within family relationships.

**Objectives:** It is common for patients to experience a period of grieving after injury for the losses brought on by their ABI. The experience of what losses the family members feel is less known. This study aims to investigate how family members conceptualise loss and adjustment and how this relates to family functioning after their loved one's ABI. **Design:** We employed a convergent mixed methods design.

**Methods:** Participants were twelve family members (8 spouses and 4 parents) known to Headway Cambridgeshire and interviewed to explore family interactions and loss after family member ABI, analysed using thematic analysis. The Family Assessment Device (FAD) and Brain Injury Grief Inventory (BIGI) were also administered. Quantitative and qualitative data were combined using side-by-side comparisons.

**Results:** We report interim data on twelve interviews. Emerging trends indicated two main themes relating to family changes: *relationship imbalance* (subtheme increased responsibility) and *protectiveness* (subtheme loss of confidence). These themes only applied to spouses. Parents elicited one main theme relating to family changes: *increased closeness* (subtheme openly affectionate). FAD results showed impaired levels on all scales for spouses, with less impaired scales seen in parents. Spouses qualitatively reported 'loss' of the future, whereby parents experienced loss of the past, even though low levels of loss and high levels of adjustment were reported on the BIGI. Anticipated data collection to be completed by August 2018.

**Conclusions:** Impairment on the FAD scales for spouses, along with the expressed experiences, suggests family role changes and loss may be areas of particular importance when working with families. The discrepancy between qualitative and quantitative data highlights how mixed methods approaches can provide new insight into how loss is being experienced within family relationships. Quantitative measures alone may not be sufficient when investigating complex social constructs such as loss and adjustment in families.

**Research purpose:** The impact a patient's brain injury can have on the family as a whole is widely acknowledged but not necessarily understood (Degeneffe, 2001). It is common for patients to experience a period of grieving after injury for the losses brought on by their ABI. The experience of what losses the family members feel is less known. This study aims to investigate how family functioning is affected after injury and the impact this has on family adjustment and feelings of loss for relatives.

**Research design:** We employed a convergent mixed methods design. Nine family members were interviewed to explore family interactions and loss after family member ABI, analysed using thematic analysis. The Family Assessment Device (FAD) and Brain Injury Grief Inventory (BIGI) were also administered. Quantitative and qualitative data were combined using side-by-side comparisons.

**Research findings:** We report interim data on nine interviews. Emerging trends indicated two main themes relating to family changes: *relationship imbalance* (subtheme increased responsibility) and *protectiveness* (subtheme loss of confidence). These themes only applied to spouses. Parents elicited one main theme relating to family changes: *increased closeness* (subtheme openly affectionate). FAD results showed impaired levels on the role scale for 7 out of the 9 interviewees. Spouses qualitatively reported 'loss' of the future, whereby parents experienced loss of the past, even though low levels of loss and high levels of adjustment were reported on the BIGI. Anticipated data collection to be completed by June 2018.

**Research conclusions:** Impairment on the FAD 'roles' scale, along with the expressed experiences of spouses, suggests this may be an area of particular importance when working with families. The discrepancy between qualitative and quantitative data highlights how mixed methods approaches can provide new insight into how loss is being experienced within family relationships. Quantitative measures alone may not be sufficient when investigating complex social constructs such as loss and adjustment in families.



*Abstract 7 Abstract for poster presentation at the Anglia Ruskin University doctoral school conference*

It is becoming widely accepted that psychosocial wellbeing and rehabilitation outcomes are influenced by how the patient is able to adjust to life with a brain injury, yet the significance of the family context within which the patient is being supported has not been adequately addressed.

By examining coping styles and other potential factors which may influence patients' adaptive coping strategies, this research will identify practices which lead to positive adjustment to the experience of living with a chronic condition such as brain injury.

In addition to coping styles, feelings of loss and grief, family dynamics, and problem-solving skills have been examined to investigate what influence these factors have on overall psychosocial adjustment after brain injury, both for the patient and the family. Concurrently, a selection of participants will be interviewed to explore the influence of subjective experiences and adaptation in coping style on adjustment.

A convergent mixed methods design will bring together the results of questionnaires and psychometrics with interview data. The questionnaires have been selected to gain a range of data to represent the population as a whole, whereas the interviews are designed to describe the subjective experience. The two phases will then be merged to identify trends among people with a brain injury and their families. The aim is to develop a more comprehensive characterisation of life after brain injury so that a family unit perspective is gained.

Anticipated completion of data collection is December 2018. A longitudinal element will be added approximately one year on, containing a smaller sample of the original cohort who will be re-tested to examine changes to coping styles and feelings of loss and adjustment over time.

Preliminary results of the quantitative data gathered will be analysed and presented to highlight emerging trends. From this research, factors showing a positive influence on adjustment will be identified to inform interventions and rehabilitation services for the long term care of patients and families living with the effects of brain injury.