

EXPERIENCES OF LOSS IN ADOLESCENTS WITH A PARENT WITH  
TRAUMATIC BRAIN INJURY

Jennifer Elisabeth Hadden

Submitted in accordance with the requirements for the degree of  
Doctor of Clinical Psychology (D. Clin. Psychol.)  
The University of Leeds  
Academic Unit of Psychiatry and Behavioural Sciences  
School of Medicine

August 2012

The candidate confirms that the work submitted is his/her own and that appropriate credit  
has been given where reference has been made to the work of others

This copy has been supplied on the understanding that it is copyright material and that no  
quotation from the thesis may be published without proper acknowledgement.

## ACKNOWLEDGEMENTS

*I'd like to thank all the participants who agreed to be part of this study. I was so impressed by all of your desires to help others in similar situations even though you had to discuss a very difficult time in your life.*

*I'd like to thank my supervisors David Cottrell and Anne Worrall-Davies, for allowing me to be independent but providing me with support and sharing your knowledge when I needed it. Anne I am particularly grateful for your calming response each time I sent you a worried email. Thank you Dr Emma Dale at BIRT for sharing your expertise and making time for me to discuss my ideas. More importantly you were integral to my recruitment and I could not have done it without you.*

*To all my friends thank you for your encouraging messages throughout this long process and being understanding when I was not around. Mary and Dave I have been so grateful for you answering all my random questions, no matter how stressed you both were, and making me laugh at every opportunity. Rachel, flatmate and transcriber extraordinaire, thanks for providing distractions when I needed it and for making me work when I needed it more.*

*Thanks Alex for supporting me to do my training and for giving me a hug when things were hard. Despite never knowing what I am doing, your pride and belief in me has given me confidence to get to this stage.*

*Thank you Mum, Bex and Sophs for always being there no matter what was happening but also telling me to pull myself together when I was losing focus. I could not ask for a more supportive and fantastic family.*

*Finally thank you Dad. You have shaped who I am today and I will always love and miss you.*

## ABSTRACT

The experiences of children and adolescents who have a parent with an acquired brain injury is a relatively under-researched area. There is mixed evidence about whether or not these young people display emotional and behavioural difficulties as a result of this trauma. Research has suggested that adolescents experience multiple 'losses' during this time. The most prominent of these is thought to be 'ambiguous loss', where the parent is physically present but psychologically absent. This is considered to be a particularly difficult process as it is an ongoing loss that the person has to cope with on a daily basis. There have been very few attempts to facilitate these adolescents to verbalise their experiences. The following study utilised Interpretative Phenomenological Analysis to explore the experiences of loss in adolescents who have a parent with an acquired brain injury and the sense they make of these experiences. Five female adolescents aged 13 to 18 years old participated in face-to-face interviews. The participants reported a number of losses including loss of child role, loss of parent and loss of parental role. Additionally they experienced distress, which included feelings of hopelessness, isolation, annoyance and helplessness. The dominant coping strategy utilised was avoidance. A number of positive consequences of the injury were described such as feeling closer to other family members and feeling more grown up. The clinical implications of the findings are discussed.

## TABLE OF CONTENTS

|  |    |
|--|----|
| ACKNOWLEDGEMENTS .....                               | 2  |
| ABSTRACT .....                                       | 3  |
| TABLE OF CONTENTS .....                              | 4  |
| LIST OF TABLES .....                                 | 6  |
| LIST OF FIGURES .....                                | 6  |
| INTRODUCTION .....                                   | 8  |
| Literature Review .....                              | 9  |
| Impact of ABI on families .....                      | 10 |
| Impact of ABI on children .....                      | 12 |
| Experiences of Loss and Grief .....                  | 17 |
| Summary .....  | 19 |
| Research Aims .....                                  | 20 |
| METHODOLOGY .....                                    | 21 |
| Qualitative Approach .....                           | 21 |
| Methodological Approach .....                        | 22 |
| Grounded Theory .....                                | 22 |
| Discourse Analysis .....                             | 22 |
| Interpretative Phenomenological Analysis (IPA) ..... | 22 |
| Epistemology .....                                   | 24 |
| Positivist/Realist Position .....                    | 24 |
| Radical Constructionist Position .....               | 24 |
| Contextual Constructionist Position .....            | 24 |
| Participants .....                                   | 25 |
| Data Collection .....                                | 26 |
| Ethical Considerations .....                         | 27 |
| Ethical approval .....                               | 27 |
| Informed Consent .....                               | 28 |
| Data Analyses .....                                  | 28 |
| Research Reflexivity .....                           | 30 |
| RESULTS .....  | 31 |
| Sample .....   | 31 |
| Charlotte .....                                      | 31 |
| Jessica .....  | 33 |
| Sarah .....  | 35 |
| Molly .....  | 36 |
| Nicole .....   | 38 |
| Emerging themes .....                                | 39 |
| 1. Loss .....  | 41 |
| 1.1. Loss of the child role .....                    | 41 |
| 1.1.1. Parental role .....                           | 41 |
| 1.1.2. Prioritising others .....                     | 45 |
| 1.1.3. Growing up .....                              | 47 |
| 1.2. Loss of parent .....                            | 48 |
| 1.2.1. Emotional loss .....                          | 48 |
| 1.2.2. Reciprocal relationship .....                 | 50 |
| 1.2.3. Changed person .....                          | 52 |

|  |     |
|--|-----|
| 1.2.4. Change in support.....            | 53  |
| 1.3. Loss of parent’s role.....          | 56  |
| 2. Distress.....                         | 58  |
| 2.1. Feelings of hopelessness.....       | 58  |
| 2.1.1. At initial stages.....            | 58  |
| 2.1.2. Ongoing.....                      | 59  |
| 2.2. Feeling isolated.....               | 60  |
| 2.3. Feeling helpless.....               | 62  |
| 2.4. Feeling annoyed.....                | 63  |
| 3. Coping.....                           | 64  |
| 3.1. Avoidance.....                      | 64  |
| 3.2. Seeking help.....                   | 67  |
| 3.3. Feeling unsupported.....            | 68  |
| 3.4. Acceptance.....                     | 69  |
| 3.5. Feeling grateful.....               | 70  |
| DISCUSSION.....                          | 72  |
| Loss.....                                | 72  |
| Distress.....                            | 77  |
| Coping.....                              | 79  |
| Clinical Implications.....               | 83  |
| Strengths and Limitations.....           | 85  |
| Personal Reflections.....                | 87  |
| Conclusion.....                          | 89  |
| REFERENCES.....                          | 90  |
| APPENDIX 1.....                          | 101 |
| Literature Review Search Strategy.....   | 101 |
| APPENDIX 2.....                          | 102 |
| Participant Information Sheet.....       | 102 |
| APPENDIX 3.....                          | 104 |
| Participant Consent Form.....            | 104 |
| APPENDIX 4.....                          | 106 |
| Parent/Guardian Consent Form.....        | 106 |
| APPENDIX 5.....                          | 108 |
| Interview Guide.....                     | 108 |
| APPENDIX 6.....                          | 110 |
| Demographic Survey Form.....             | 110 |
| APPENDIX 7.....                          | 113 |
| Ethical approval letter.....             | 113 |
| APPENDIX 8.....                          | 114 |
| BIRT ethical approval letter.....        | 114 |
| APPENDIX 9.....                          | 115 |
| Sample analysed transcript page.....     | 115 |
| APPENDIX 10.....                         | 116 |
| Initial emerging themes.....             | 116 |
| APPENDIX 11.....                         | 118 |
| Prevalence of final emerging themes..... | 118 |
| APPENDIX 12.....                         | 120 |
| Quality Control Measure.....             | 120 |

## LIST OF TABLES

|   |     |
|---|-----|
| Table 1: Overview of sample .....                                   | 31  |
| Table 2: Initial emerging themes and their prevalence .....         | 116 |
| Table 3: Organisation and Prevalence of final emerging themes ..... | 118 |
| Table 4: Quality control measure .....                              | 120 |

## LIST OF FIGURES

|   |    |
|---|----|
| Figure 1: Overview of emerging themes ..... | 40 |
|---|----|

## ABBREVIATIONS

ABI: Acquired Brain Injury

BIRT: Brain Injury Rehabilitation Trust

CAMHS: Child and Adolescent Mental Health Service

FEM: Family Experiential Model of Recovery

IPA: Interpretative Phenomenological Analysis

I.T.U: Intensive Treatment Unit

TBI: Traumatic Brain Injury

## INTRODUCTION

*One of the most important people in my life is my dad. It's funny, you don't realise how much you need someone until they can't help you anymore. When my dad first went into hospital last July I didn't realise the extent of what was happening. People were gathering around me saying everything was going to be alright. It was three weeks and two days before they finally let me see him. We walked up a long corridor which seemed to go on forever, then we reached the entrance to the I.T.U. My mum rang the doorbell and the nurse came to let us in.*

*When we entered the ward I saw many very ill people. I was most afraid when I reached my dad. He lay on the bed and appeared to be sleeping. I couldn't count how many tubes were going into him. There was a machine monitoring his heart beat, blood pressure, temperature, level of oxygen and how much he was breathing on his own. He had a tube going into his neck helping him to breathe.*

*The nurses told me I should just speak to him so I did. I held his uninjured hand, which was being used as a pin cushion, and talked to him. My whole life had been ripped apart with one fatal blow to the centre of my world. I kept thinking at least he was still here but I couldn't see my dad.*

*That night I went home and cried myself to sleep. I did it for months trying to find out what happened and why. I made regular visits to my dad noticing little improvements each time, now 11 months later, he's still in hospital and has just undergone an operation on his head. He has come a long way since the day I first saw him. He has regained consciousness, has full mobility on his left side with a little more starting on his right. He doesn't communicate but when I talk to him his eyes tell me what he's thinking. When I get there he smiles at me and hugs me but he's not my dad quite yet, at least not my old dad.*

*The way he has made progress and the fact that he hasn't given up gives me so much respect for him. The doctors said he wouldn't live a day but now 11 months later he's still proving them wrong. He has showed me that nothing is impossible and that soon I'll have my dad back. The dad that makes stupid jokes when my friends come over, the dad*



*who always does his best to embarrass me when picking me up from school and the dad that's always so pleased when I tell him about my exams. He's the dad I love and respect.*

*My whole family comments of his improvement and my Gran, his mother, cries every time she sees him claiming he's her most handsome son which always gets a smile from my dad. He is one of the strongest, most stubborn people I know and that's why if anyone can get through this, he can. This is the reason he's one of the most respected, important people in my life. He's showed me that anything and everything is possible.*

I wrote the above at the age of 14 years old after my father had experienced an acquired brain injury as the result of a road traffic accident.

### Literature Review<sup>1</sup>

The consequences of acquired brain injury (ABI) remain relatively poorly understood by the general population. People frequently believe such myths as 'the individual will fully recover if they try hard enough' and 'a second blow to the head can restore a patient's memory' (Gouvier, Prestholdt & Warner, 1988; Springer, Farmer & Bauman, 1997). ABI includes traumatic brain injury (TBI), which is where the individual experiences a trauma to the head, stroke, brain illness and any other kind of brain injury after birth<sup>2</sup> (Medical Disability Society, 1998, cited by Headway, 2012). The reality of the long-term effects of these injuries is forced onto individuals and their families following an ABI. It is estimated that over one million people present at accident and emergency departments in England with an ABI each year (National Institute for Clinical Excellence, 2007). Of these, 15% are adults with moderate to severe injuries. There have been a number of advances in medicine that have resulted in relatively low rates of mortality. Of those who die, 98% do so within the first 48 hours post injury (Park, Bell & Baker, 2008). The increased likelihood of survival has resulted in challenges for services and families in managing the consequences of these often devastating injuries. Whilst physical changes are often linked to longer hospital admissions, it is the cognitive and behavioural changes that

---

<sup>1</sup> Literature review search strategy can be found in appendix 1

<sup>2</sup> Due to the aetiology of the injuries of the parents included the study the more appropriate term is ABI rather than TBI. To avoid confusion ABI will be used throughout.

are among the most difficult to manage following discharge and have been found to have the greatest impact on psychosocial recovery and quality of life (Jorge, 2005).

Behavioural problems experienced by people with an ABI include increased impulsivity, lack of motivation, socially inappropriate behaviour and agitation (Vaishnavi, Rao & Fann, 2009). Additionally, they can display personality changes such as aggressive and disinhibited behaviour, and emotional lability (Kim, 2002; Tateno, Jorge & Robinson, 2004). There is an increased prevalence of psychiatric disorders in individuals following an ABI. Depression and anxiety are the most commonly diagnosed and are linked to poorer outcomes (Fann et al, 2004; Jorge et al, 1993; Jorge, 2005; Larson et al, 2009). These post-injury changes often result in the individual failing to return to work or being able to maintain social relationships, which can lead to loss of identity and role as well as social isolation (Jorge, 2005; Malia, Powell & Torode, 1995; Vaishnavi et al, 2009).

Whilst there is a considerable body of evidence investigating the consequences of ABI on the individual or the spouse or partner, the impact of parental ABI on children and adolescents is still relatively under-researched. A great deal of the current literature comes from clinical observation rather than empirical research or focuses on the family as a unit rather than its individual members (Butera-Prinzi & Perlesz, 2004).

### *Impact of ABI on families*

Families vary substantially in their reactions and adjustment following an ABI (Kreutzer, Sander & Fernandez, 1997). Family functioning has been found to impact on patient outcomes; however, family members of individuals with an ABI often report increased levels of stress, social alienation, isolation and feeling overwhelmed (Ergh et al, 2002; Kreutzer et al, 2002; Kreutzer et al, 1997). Ergh et al 2002 carried out a study with 60 pairs of adults: one person with an ABI and their main caregiver. A series of neuropsychological assessment and measures of family functioning were used. The severity of the injury and use of alcohol were not significantly related to family strain. However, where there were low levels of perceived support, caregivers were significantly more likely to report family strain. Additionally they found increased caregiver and family strain where neurobehavioural and affective difficulties were more significantly present. There were a number of limitations in this study including the use of self-report and the fact that pre-

existing psychiatric history was not gathered. Thus it is not possible to conclude the presence of a causal link. Neurobehavioural and affective changes include problems with emotional regulation, such as sudden mood changes, aggression and argumentativeness, and represent long-term problems for the family (Carnes & Quinn, 2005; Douglas & Spellacy, 1996; Marsh et al, 1998).

Families can display less cohesion and satisfaction in their relationships as well as increased levels of conflict post injury (Maitz, 1990, cited by Carnes & Quinn, 2005). Maitz and Sachs (1995) used four case studies to illustrate the key treatment issues when working with families of individuals with an ABI. They hypothesised that increased levels of conflict were related to changing roles within the family. Members must adapt to new roles with no time to come to terms with these changes, which places further stress upon the family. However, Livingston, Brooks & Bond (1985) found that whilst families reported initial difficulties, they did not report significantly impaired social functioning and learned to function in difficult circumstances. Their study involved 42 males with severe ABI and their families with a control group of 41 males with mild ABI. The participants were surveyed three months post injury. Whilst this evidence questions the impact of ABI, participants with severe ABI were still inpatients while the control group had returned home. Difficulties, particularly neurobehavioural, are often not evident at first and it may be that whilst family members are still in hospital the full impact of the injury is not clear (Butera-Prinzi & Perlesz, 2004). The study would have benefited from more longitudinal evidence. Carnes & Quinn's (2005) study investigating family functioning following an ABI in 123 family members found that the quality of the premorbid relationships within the family is significantly correlated to family functioning post injury. Again this study involved data collection at three months post injury, which may have resulted in a number of issues not yet being present, such as realisation of the full extent of injuries, financial implications and long-term adaptations.

Availability of support is identified as an important factor in family adaptation following injury. Kolalowsky-Hayer, Miner & Kreutzer (2001) surveyed 57 caregivers of individuals with an ABI with the Family Needs Questionnaire. Professional support, including instrumental and emotional, was rated as one of the most commonly unmet needs within families. Whilst this was a relatively small sample with a self-selection bias due to the questionnaires being returned by post and not independently verified, similar findings

have been reported by Sander and Kreutzer (1996). Additionally, Sander and Kreutzer identified the importance of family support systems in family adjustment following injury. Unfortunately it is widely reported that families caring for individuals with an ABI typically have less time available for social interaction and often lose contact with premorbid support systems, which further increases their feelings of isolation (Ergh et al, 2002).

A gender difference in support has also been identified. When wives are injured, their husbands and their families are typically offered increased levels of practical support because services anticipate that they will struggle (Rees, 1988). This evidence was based on a number of small case studies and as such lacks potential generalizability. However, whilst women are apparently likely to be offered less support, female family members are more likely to identify important needs and ask for assistance (Kreutzer et al, 1994). This study surveyed far more women than men (8:1), which may have led to some bias in the results. Nonetheless, both authors found male and female family members report a lack of emotional support from both services and social systems.

Research increasingly focuses on family functioning post-injury with samples typically comprised of spouses and primary caregivers. Where children are included they tend to be of adult age. The information gathered about the functioning of children within these families is often secondary, reported by parents. The spouses and parents involved in this research tend to be women while male partners and spouses remain largely under-represented. This is not surprising given the prevalence of ABI in males. Finally the period of time post injury that has been studied varies enormously from three months to 15 years. Although this is informative about the long-term outcomes of these families, it means that direct comparisons of results should be approached with caution.

### *Impact of ABI on children*

Current literature is often based on clinical observation or the reports of parents rather than empirical research with sample sizes tending to be small thus making findings difficult to generalise. However, there has been a move in recent years to focus research and interventions on this potentially vulnerable group. Difficulties are often not evident at first but present further into rehabilitation (Butera-Prinzi & Perlesz, 2004). A number of studies have reported an increased risk of behavioural difficulties in children whose parents have

suffered an ABI. Pessar et al (1993) included 24 parents with a partner with an ABI who completed a number of standardised measures investigating behavioural and emotional well-being. They found that 90% of families report negative changes post injury. This included the breakdown of the relationship between the injured parent and children, increased acting out and depression in the uninjured parent resulting in less positive parenting. They also found, in accordance with other research, that older children in particular can respond to the increased family stress by displaying behavioural difficulties such as truancy and running away from home (Lezak, 1978, 1988; Pessar et al, 1993). The findings of this study should be interpreted cautiously. First, the sample size was relatively small. Second, the data was collected from the report of the uninjured parent. Issues such as depression, which can result in the parent viewing their situation more negatively, may bias this.

Emotional difficulties have been identified following parental ABI. Kieffer-Kristensen, Teasdale and Bilenberg (2011) compared 35 families with parental ABI to 20 families with diabetes. Forty-six per cent of children in the brain injury group met the clinical criteria for the diagnosis of post-traumatic stress disorder compared to 10% in the diabetes group. This supports the suggestion that parental ABI can be traumatising for children. The study included a relatively small sample size and relied on self-report methodologies. However, there are a number of strengths: the inclusion of a control group of individuals who have parents with a chronic illness and the inclusion of only one child from each family to avoid the complications associated with intra-sibling variance. Emotional and conduct difficulties, such as argumentativeness, school failure, aggression and increased dependency, were identified by Urbach & Culbert's (1991) analysis of three case studies. Whilst this is a small sample size, it is in accordance with research with children of parents with other disabilities or illnesses, such as cancer where they are described as more susceptible to depression, anxiety and changes in behavioural patterns (Aldridge & Becker, 1999; Edwards et al, 2008; Grabiak, Bender & Puskar, 2007; LeClere & Kowalewski, 1994; Osborn, 2007).

The emotional impact of parental cancer on children has been increasingly researched. It is thought these children have a number of experiences that are similar to that of a child of a parent with ABI such as the sudden onset of crisis, mortality, less parental support and changing roles. As such their experiences can be considered when investigating children with parents with ABI. Edwards et al (2008) found that poorer family functioning

and cohesiveness following parental diagnosis with breast cancer resulted in increased emotional problems in adolescents. Additionally, mothers reported significantly more internalising and externalising problems in their children. High stress was also found in 41% of adolescents. Whilst the sample size was too small to make firm conclusions a systematic review of psychosocial difficulties associated with parental cancer confirmed the significantly higher levels of internalising problems (Osborn, 2007). Unfortunately it found only limited evidence of externalising problems. A Danish study analysing data from 11,248 children found higher stress levels in children who have a parent with a disability (LeClere & Kowalewski, 1994). These studies highlight the risk of emotional problems such as stress in children with parents with a disability. However, the evidence remains somewhat mixed; for example, Uysal et al (1998) reported that children did not present with increased behavioural problems compared with the control of children with parents with no disability. The sample size in this study was again small with only 16 individuals in each group but it encourages caution when drawing conclusions about the psychosocial impact of parental disability on children.

A number of studies have reported changes in the relationship between the child and the injured parent after an ABI. Pessar et al (1993) reported that the injured parent was less loving towards their children and the children appeared to want to spend less time with them. This information was gathered from the report of the uninjured parent and did not directly measure the child or their injured parent's perceptions of their relationship. Similarly Uysal et al (1998) reported that the injured parent showed less warmth, love and affection towards their children. This study benefitted from direct information from adolescents themselves.

The relationship change may be due to the child's view of the parent changing. Some children reported a 'yukky feeling' towards parents with obvious impairments as well as embarrassment associated with the stigma of having a disability. They may have feelings of anger towards their parent for the sudden changes in their lives but also guilt for feeling negatively towards them (Butera-Prinzi & Perlesz, 2004). Butera-Prinzi & Perlesz (2004) is one of the few qualitative studies investigating children's experiences of having a parent with an ABI. This is a small study with a sample size of four, which results in an unrepresentative group. They do not describe the qualitative methodology used and included only children who had sought counselling following the parental injury. This may

have resulted in a sample bias as only children reporting difficulties were included. In contrast Uysal et al (1998) found that children view their parent with somewhat of a 'halo effect', stating that they are doing well despite their injuries and minimising any potential problems.

Two studies have suggested that children witness, and are victims of, higher rates of domestic abuse, although they are likely to minimise or deny its presence (Butera-Prinzi & Perlesz, 2004; Perlesz, Kinsella & Crowe, 1999). They reported experiences of domestic violence and that children are rarely asked about this by health professionals and schools. The injured parent, particularly a father, can take less responsibility for their children (Lezak, 1978; Pessar et al, 1993; Rosenbaum & Najenson, 1976). Florian & Katz (1991) suggested in their literature review that this relationship can deteriorate further as the child develops and their abilities begin to overtake that of the injured parent.

One systematic review suggested the contributions of both parents could be negatively affected following ABI (Perlesz et al, 1999). Poorer parenting was related to poorer outcomes in children. Uysal et al (1998) found that parents with an ABI viewed themselves as being less goal-driven and placed less emphasis on rules and obedience, whilst the non-injured parents reported less warmth, love and acceptance of their children. This view was shared by the children involved in the study who reported the non-injured parent being less involved in their care. One major methodological flaw in this study was that the sample was selected non-randomly from individuals who had contact with head injury self-help associations. However, other research identified similar findings, with the non-injured parent reporting being increasingly impatient with their children as well as having less fun (Pessar et al, 1993). The increased strains of time and the stress of caregiving were identified as possible reasons for these changes. The child can be left feeling abandoned by one parent and neglected by the other (Guth, 1989; Perlesz et al, 1999).

The impact of sudden role changes within the family has been identified as another difficult adjustment for children. Older children in particular feel the need to step up and take on increased responsibility for roles previously occupied by the injured parent. This is particularly true when there are younger siblings in the family, resulting in them suppressing feelings and emotional responses to the trauma of the injury (Romano, 1976). This theory

has been repeated throughout the literature but there has been no further investigation since the relatively dated study carried out by Romano in 1976. Despite this there has been some discussion that role changes can be encouraged by the non-injured parent who increasingly relies on the child for assistance, consequently causing further difficulties in the child's relationship with the injured parent who can begin to resent them (Florian & Katz, 1991; Uysal et al, 1998). This requires further research as the current evidence is suggestive of the above but not conclusively.

Consistent and reliable support has been identified as an important protective factor for children. A literature review found that school, peers and family are relied upon by children of cancer patients to provide as much normality in their lives as possible (Grabiak et al, 2007). Pets were highlighted as important in coping as they are not affected by the parental ABI (Butera-Prinzi & Perlesz, 2004). However, children can report losing peer support and increasing isolation following parental ABI (Butera-Prinzi & Perlesz, 2004; Uysal et al, 1998). This is due to both embarrassment about bringing friends home because of concerns that they will not understand their situation and loyalty to their families, who they want to protect from others finding out about difficulties within the home. Research suggests that females are more likely to verbalise their need for social support and will seek this from their friends (Shulman, 1993). Again this study is flawed with a small sample size that includes predominantly female participants. Both parents can be viewed as being less available for support. One study found that children did not want to overburden the already strained, non-injured parent and instead confided in their siblings (Butera-Prinzi & Perlesz, 2004). The difficulty appears to be that children are rarely asked how they are coping and what additional supports may need to be put in place.

It is important to highlight that children's experiences of family disability are not always negative. It has been suggested that following a traumatic experience older adolescents experience more personal growth compared with their younger counterparts (Milam, Ritt-Olsen & Unger, 2004). Beach (1997) interviewed 20 adolescents who were the children or grandchildren of people with Alzheimer's disease. They found that children can report better relationships with their siblings, particularly those who live away from home who will make more of an effort to spend time with them. Where the mother has taken on a caregiving role there is an increased strength in the relationship between her and her children with the latter displaying respect and appreciation. Beach also found that children



became more selective in their peer relationships, seeking out empathetic friends who can be invited home. These relationships allowed them to talk openly about the situation as they prepared their friends to visit the family home. They also reported the importance of friends' objectivity when voicing the challenges of their situation. Whilst only a small sample size was utilised, the potential resiliency of children in these difficult situations was highlighted.

### *Experiences of Loss and Grief*

Research suggests that while there is mixed evidence about the direct impact of parental ABI and the variation of coping strategies within affected families, children undoubtedly experience multiple losses, including potential loss of both parents, social supports, and financial and lifestyle changes (Butera-Prinzi & Perlesz, 2004; Carnes & Quinn, 2005; Kolakowsky et al, 2001; Kreutzer et al, 1994). Butera-Prinzi & Perlesz (2004) carried out a qualitative study in Australia with children aged 7 to 12 whose fathers had an ABI. It was found that after four years the children were still experiencing grief and loss. They described conflicting feelings towards their fathers because they were angry about the changes, both physical and psychological, but at the same time they felt guilty, as they were aware that the changes were not their father's fault. It is often difficult for family members to admit that they feel a sense of loss because the person is still there and they believe they should feel grateful for this (Osborne & Coyle, 2002). Since the original work carried out by Freud (1917), a number of models of loss have emerged (Bowlby, 1969, 1973, 1980; Kubler-Ross, 1973; Worden, 1991). However, the literature on areas such as ABI has favoured the similar ideas of psychic loss and ambiguous loss.

Shabad (1989) proposed the theoretical idea of psychic loss, which has been described as a loss "in which the person lives on but the relationship changes profoundly" (Miller, 1996). The grief stems from a loss of hope and aspirations rather than a physical loss of the individual. Miller (1996) utilised this model with families where individuals had severe mental illness. He stated that these families go through a period of protracted grief that results from the difficulty they feel in identifying and expressing their sense of loss. When retaining hope is seen as an important factor in better outcomes for individuals with an ABI, it is difficult for families to admit loss at the risk of affecting that individual (Kean, 2010). Miller suggested a model based on an adapted version of Worden's four tasks of

grief therapy (1991). The final two stages were adapted to involve accommodating changes in the relationships with the person who is ill, but also people outside that relationship, rather than encouraging emotional withdrawal from the person. Reminiscence was identified as a key process in coming to terms with this loss and ultimately better outcomes for families. Whilst this model appears to provide an interesting framework for considering the loss of families with an ABI, the research has mainly focused on mental illness such as schizophrenia.

Ambiguous loss is the most prominent model of loss to emerge within the ABI literature. It is a theoretical model first developed by Boss (1999) and has gradually been utilised within a number of areas such as families with a member killed in the armed forces; incarcerated in prison; with dementia; or with an ABI. It is described as a relational disorder and has been described as “the goodbye without leaving” (Boss, 2007; Frank, 2008). There are two forms of ambiguous loss described: the first is where an individual is physically absent but psychologically present such as military families where the loved one is missing in action; the second is where the individual is physically present but psychologically absent (Boss, 2004), the latter being descriptive of the experiences of families with parental ABI. Dupuis (2002) proposed three stages of ambiguous loss: anticipatory, progressive and acknowledged loss. Anticipatory loss refers to the period where the individual considers the losses that could occur in the future. Progressive loss describes the period of watching a family member deteriorate and often leaves families feeling helpless. The final stage involves the acknowledgment of physical losses, which Dupuis proposed often occurs after a family member has been placed into institutionalised care. The result is an ambiguity and confusion that leaves families with greater levels of stress and increased difficulty in identifying and utilising effective coping strategies. These higher levels of stress can lead to poorer family functioning (Blieszner et al, 2007).

Ambiguous loss is thought to be the most difficult grief process to resolve because it is ongoing; the parent may seem different but look the same (Betz & Thorngren, 2006). A child whose parent dies receives support from those around them and can participate in rituals to allow them to come to terms with the loss. However, it is theorised that a child experiencing ambiguous loss has no such process. They are reminded on a daily basis of this loss and yearn to be closer to their remaining family members. However, they feel abandoned by these family members because there is a sense that they do not know what to

say to provide support (Boss, 2007). These children typically become isolated from their friends and other supports as feelings of guilt and embarrassment stop them from sharing their experiences. They also report rarely being asked by health professionals how they are coping (Butera-Prinzi & Perlesz, 2004), suggesting that this grief process can be overlooked. This complicated grief can result in the child entering denial by joining in the instrumental and expressive tasks, such as household maintenance and emotional support of younger siblings, or moving into a functional, self-preservation mode (Tubbs & Boss, 2000).

### *Summary*

The research into the impact of parental ABI on children is somewhat mixed. Studies have tended to involve clinical observation rather than empirical research. Sample sizes are generally small resulting in unrepresentative groups. Additionally the parents have often been fathers with mothers being relatively under-represented. A number of studies have focused on the experiences of families as a whole with interviews being done in front of parents or a reliance on parent report rather than the children themselves. Despite this the evidence indicates that there is a clinical need within this population, particularly for older children who are more likely to display behavioural difficulties and changes in their role within the family (Lezak, 1978; 1988; Milam et al., 2004; Pessar et al., 1993; Romano, 1976). Butera-Prinzi & Perlesz (2004) is one of the few studies that has provided an in-depth qualitative insight into the experiences of younger children. It comments on the multiple losses experienced by children while also tackling a number of other issues.

Various models of loss have been proposed but the idea of ambiguous loss is the most widely accepted within this population. It is particularly relevant for the families of individuals with ABI because they experience a continued loss of the injured family member which they are reminded of on a daily basis as they witness the changes in their loved one. They are often not given opportunity to acknowledge this loss because the person is still alive. This may have a particular impact of the adolescents in the family who are at a time in their development where they are expected to take on more responsibility and increased independence. Given the vast changes within the family structure as a result of an ABI, more research is required to better understand the grief process and the role that services can play in supporting these children.

## Research Aims

The study was designed to examine the following research aims:

1. What are the experiences of loss in adolescents who have a parent with an ABI?
2. How do they make sense of these experiences?

## METHODOLOGY

### Qualitative Approach

A qualitative approach was deemed the most appropriate in order to investigate the research aims of this study. In recent years qualitative methodologies have become an increasingly valued tool in clinical research. Such methodologies are concerned with meaning and how people make sense of the world. They require a depth of information about the quality of an experience in order to make meaning of it (Willig, 2009) and are concerned with enriching understanding rather than proving or disproving previous findings or theories (Elliot, Fischer & Rennie, 1999). This is in contrast to the drive to find the cause-effect relationships normally associated with quantitative research.

Qualitative data collection must be naturalistic in that it provides an accurate and comprehensive representation of the participants' words and descriptions of their experience (Willig, 2009). The researcher must ensure as little information as possible is lost in interpretation which produces a great volume of data. This can lead to questions of validity within this methodology because the need to keep a vast and comprehensive record results in questions about whether or not the data collection actually answers the question. However, it has been argued that open-ended questions and flexibility of the approach result in an opportunity for the participant to challenge the researcher's attitudes and assumptions in a way that is not possible through the rigidity of quantitative design (Willig, 2009). Reliability does not carry the same meaning in qualitative research as it does in quantitative. Quantitative researchers use the term to describe a measurement producing the same results if applied again. In qualitative research the phenomena being explored can be unique with the focus being on bringing meaning to a particular experience. There are mixed opinions about the meaning of reliability within qualitative research. It is widely accepted to refer to the 'trustworthiness' of the findings (Golafshani, 2003). Researchers argue that the standardised methods of analysis applied to these unique experiences should provide similar findings with different researchers (Willig, 2009). In addition to this peer reviewing and providing examples of analysis further prove the 'trustworthiness' of findings. In order to overcome some of the concerns raised about the validity and reliability of qualitative research a number of guidelines have emerged to provide a framework for qualitative researchers to utilise in the shaping of their design (Elliot et al, 1999).

## Methodological Approach

Whilst I chose a qualitative approach for this study, I considered a number of methodological approaches.

### *Grounded Theory*

Grounded theory was developed by two sociologists (Glaser and Strauss) as a method of generating theory to provide meaning to experience. It allows researchers to investigate and theorise about the participants' actions through the identification of categories and the integration of meaning (Willig, 2009). It is a bottom-up process that allows theory to emerge from the data. Willig (2009) argued that this methodology focuses on the identification of theories about social processes and is less adept at generating theories about understanding the individual experience on a phenomenological level. As such I did not consider it appropriate for this study.

### *Discourse Analysis*

Discourse analysis refers to a group of methodologies designed to consider the role of language in the construction of the individual's social world (Willig, 2009). It explores how individuals use language and how that impacts on society and societal rules and expectations. It is considered particularly useful in group settings and when looking at interactions. However, it has been suggested that the focus purely on language does not address underlying mental states or subjective questions such as those that look at image of self and self identity (Willig, 2009). Due to these limitations I did not consider discourse analysis to be an appropriate methodology for this study.

### *Interpretative Phenomenological Analysis (IPA)*

IPA is used to investigate how individuals make sense of their world by exploring the meaning they infer from their experiences. It is concerned with "where ordinary experience becomes 'an experience' of importance as the person reflects on the significance of what has happened and engages in considerable 'hot cognition' in trying to make sense of it" (Smith, Flowers & Larkin, 2009). There are three main theoretical components that IPA

draws on: phenomenology, hermeneutics and idiography. Phenomenology is concerned with the 'lived experience'. This is the world as it is experienced by particular people, at particular times, within a particular context (Smith et al, 2009). As researchers aiming to capture and understand the lived experience, we are also aware that this experience is never directly accessible to others. Hermeneutics has therefore been included by researchers as part of the theoretical framework for IPA. Hermeneutics refers to the theory of interpretation. The term is derived from Hermes, the god who took messages from the gods to mortals in Greek mythology, and the theory was originally developed to look at biblical texts. Hermeneutic phenomenology aims to allow the lived experience to 'speak for itself' whilst simultaneously interpreting that experience. Hermeneutic phenomenologists propose that this paradox is resolved because the lived experience cannot but be meaningfully (hermeneutically) experienced. Likewise, IPA is based on the assumption that humans are not merely passive observers of reality but they actively interpret and formulate their world to make sense of it (Brocki & Wearden, 2006). Heidegger proposed that "interpretation is at the heart of humanity, we cannot not interpret" (cited in Smith et al, 2009, p17). As researchers we carry out our interpretation of the participants' interpretation of their experience. This is known as a double hermeneutic (Smith & Osborn, 2003).

Smith et al (2009) conceded that pure experience might never be truly accessible because we witness it after the event. In reality we aim to get as 'experience close' as possible. IPA is idiographic because it is specific and concerned with the particular. It considers the individual aspects and nuances of an experience: a valuable contribution to increasing our knowledge and understanding about the complexity of human psychology (Smith et al, 2009).

IPA relies on the researcher taking both an empathetic and questioning stance with the participant. In one instance the researcher wants to stand in the participants shoes and gain an 'insider's perspective' of their experience. However, they also have the opportunity to ask questions and puzzle and analyse the participants' experience. This allows us to find out what something is like for someone whilst attempting to bring meaning (Smith et al, 2009). The exploration of individual subjective experiences and the meaning individuals attach to these experiences provides an ideal methodology to consider adolescents' experiences of loss for this study.

## Epistemology

Epistemology refers to a branch of philosophy that considers the nature of knowledge and asks the question: 'how, and what, can we know?' There are a number of epistemological stances utilised in research. This is dependent on the researcher's view of their role in the process and how they impact on the outcome. It is important for the researcher to be clear about the objectives of the research and what it is actually possible for us to find out (Willig, 2009). Thus the researcher must adopt an epistemological stance.

### *Positivist/Realist Position*

The positivist or realist position is ideally suited to quantitative analysis because it assumes that there is a clear-cut relationship between the world and our understanding of it (Willig, 2009). The researcher believes that the world can be described in a way that is true for all observers. The aim of researchers working from this stance is to provide objective information and not to influence the data. It allows the data to speak for itself (Willig, 2009). Whilst this position is utilised in some qualitative methodologies, Fossey et al (2002) argue that it cannot be used when investigating subjectivity such as individual experiences and the meaning that is given to them. Therefore I did not consider it an appropriate stance for this study.

### *Radical Constructionist Position*

The radical constructionist position challenges the idea that there are any absolute foundations for knowledge (Madill, Jordan & Shirley, 2000). Researchers working from this stance believe that we construct our own unique understanding of reality and thus cannot be seriously challenged on our interpretation, as it is specific to the individual. It questions the idea that language can represent reality because we do not require a shared understanding of language (Madill et al, 2000).

### *Contextual Constructionist Position*

This position recognises the subjective role the researcher plays in the findings. It rejects the idea that there can be one objective reality and states that knowledge is local, provisional and situation dependent. Therefore researchers working from this stance believe that findings will differ according to the context in which the data is both collected and analysed (Madill et al, 2000). All accounts are considered subjective and are therefore not



excluded because they differ from other perspectives. This is unlike the quantitative approach where outliers can be excluded from data analysis as they are considered anomalies.

The nature of the contextual constructionist position allows it to lie between the positivist/realist position and the radical constructionist position. As such it was most in line with the aims of this research and was the position I used in this study.

### Participants

Recruitment was undertaken in conjunction with the Brain Injury Rehabilitation Trust (BIRT). BIRT offers a range of services designed to meet the needs of individuals and their families at different stages of rehabilitation; from assessment to comprehensive rehabilitation, long-term housing and care, and community based support. It is part of the Disabilities Trust, which is a charitable organisation that provides services to people with physical disability, learning disability and autism as well as brain injury. I recruited participants from BIRT units nationwide.

All participants were adolescents who had contact with BIRT through their families. Staff within BIRT identified potential participants using the following criteria for recruitment:

#### Inclusion criteria:

1. Individuals must have a parent with an ABI
2. Individuals who are aged between 13 and 18 years old.
3. The parent with the ABI was at least six months post injury. Carnes & Quinn (2005) found that prior to this, families were potentially less aware of the impact of the ABI.
4. The adolescent was living with the parent with ABI at the time of injury

Exclusion criteria:

1. Where alcohol or drug problems played a role in the cause of the ABI, as well as cases where the parent had attempted to take their own life. For the purposes of this study there is an assumption that there has been a significant change within the family following ABI and there is evidence to suggest that families with drug or alcohol problems already display poorer family functioning prior to injury (Seaton & David, 1990).
2. Where the person with ABI had previous ABIs. Again this is because there is an assumption that the injury has caused a significant change in the family that may not be evident in a family who has been through this process already.
3. Individuals who do not speak English.
4. Where a sibling had already agreed to participate.

I recruited five individuals. A sample size of between three and six is recommended for postgraduate research (Smith et al, 2009).

Once potential participants were identified, BIRT staff contacted them and their families to ask if they would be interested in finding out more about the project. Following an expression of interest I sent the adolescent and their parents information sheets (see Appendix 2). I then contacted them and arranged to meet with the adolescent and their family to give them more information and answer any questions. The uninjured parent was required to attend this meeting for consent purposes. Additionally the injured parent was invited to attend so they would be aware of the study. I sought consent at this point. Once I had obtained written consent from both the adolescent and their uninjured parent, arrangements were made to interview participants (see Appendix 3 and 4).

### Data Collection

I discussed the location of interviews with the adolescent. Smith et al (2009) recommend that interviews be carried out in a location that is familiar and comfortable to the participants. I offered the participants the opportunity to be interviewed at home. However, a criticism of previous research is that interviews have been carried out with

families as a whole with children and adolescents potentially unable to voice their thoughts and feelings freely. In order for interviews to be carried out at home it was agreed with the adolescent and their parent that a private area within the home was identified where no interruptions could take place. All participants chose to carry out the interviews at home.

I carried out semi-structured interviews face-to-face with the adolescent. Semi-structured interviews facilitate “a conversation with purpose” (Smith et al, 2009). It provides the researcher with opportunity to explore the participant’s description of their experiences but also allows them to ensure the research question is covered without asking it directly (Willig, 2009). Additionally it gives triggers for the researcher to ensure they do not lose sight of the research question whilst providing flexibility to hear about the individual’s potentially unique experience. I created an interview guide and used it in each interview (see Appendix 5). Interview lengths varied from approximately 40 to 90 minutes. Interviews were audio recorded and then fully transcribed. Transcription was carried out by a third party transcriber. I interviewed each participant only once. I carried out a pilot interview with a 21-year-old female with a parent with an ABI prior to commencing the full data collection to allow myself the opportunity to familiarise myself with the recording equipment and interview procedure. I made changes to the interview schedule as a result of this interview in order to make the interview process more efficient.

Each participant was given a brief form to complete providing demographic information (see Appendix 6).

## Ethical Considerations

### *Ethical approval*

Ethical approval was received from the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine joint ethics committee (see Appendix 7). Approval was also received by BIRT’s own ethics committee (see Appendix 8).

### *Informed Consent*

I gave potential participants information sheets about the study. These were assessed as easy to read by a 10-year-old reader. Though the adolescent was the only participant required for the study, consent was required whilst remaining sensitive to the family context. Information was shared with the adolescent and their family through the information sheet and meeting with the principle researcher. At this point I asked both the adolescent and their uninjured parent to sign consent forms.

### Data Analyses

As already discussed the method of analysis utilised was IPA. Analysis involved thorough interpretation of the full transcripts from the interviews. A sample analysed page can be found in Appendix 9. There are a series of steps involved in the analysis of each individual transcript (Smith et al, 2009):

*Step 1:* Reading and re-reading: The researcher familiarises themselves with the data. I listened to the audio recording before reading the transcript several times. This allowed me to develop an overall model of the interview structure and see how different aspects of the interview connect. I noted any initial responses to the participant and the transcript. At the end of this stage I wrote a summary of the participant's story including information such as reflections on how the interview went and key things that stood out in the script. The aim of this is to provide a context for each individual and to allow the reader to have relevant information about the person, their situation and the experience of the interview. Elliot et al (1999) highlighted "situating the sample" as an important stage in producing qualitative research that is reliable. In each of these pen portraits I provided information about the participants family situation both prior to and post parental ABI. Additionally I outlined their experience of their parent after their injury and that of the family as a whole.

*Step 2:* Phenomenological coding: I divided the transcript into meaning units. This involved examining the semantic content and language use on a tentative level. I made notes on the transcript about particular things that stood out and I made descriptive summaries every few lines.

*Step 3:* Interpretative coding: I started to identify things such as patterns, keywords, contradictions, metaphors and use of imagery. At this point I started to consider what these may mean or represent. I made a mind map of these to gain an overview of the interview.

*Step 4:* Identification of themes: I reviewed steps two and three and began to identify initial themes in the text, asking the question ‘What is important?’ At this point I moved from working directly with the transcript to working primarily with the notes. Once themes were identified I collected example extracts for each. I summarised the key message of each theme and used it to highlight what each theme tells us about the experience. I arranged the themes chronologically.

*Step 5:* Clustering themes: I reviewed themes to identify any connections between them. This process allows the researcher to produce a structure that highlights the most interesting and important aspects of the account. Not all themes were included in this section and some were discarded at this point. I printed each theme so that I could visually identify links between them. This aided grouping the themes.

*Step 6:* Peer/supervisor review: I discussed the themes with my research supervisor and other professionals to confirm the interpretations of the data were evidenced within the text. This provided me with an opportunity to discuss if the themes made sense. This was done in detail with my initial transcript to ensure quality control (Elliot et al, 1999).

I repeated these six steps for each transcript. Following this I carried out an integrative analysis where I compared themes across cases. I did this by using cut outs of each theme from each participant. The aim was to identify patterns. Here I brought together the themes of the individual cases and theoretical knowledge about higher order concepts (Smith et al, 2009). I created a table with supporting citations for each theme. I then met with others to discuss the initial organisation of the themes (see Appendix 10) and used these discussions to reorganise the themes in a more accessible, integrative form (see Appendix 11). This involved firstly identifying which of the themes were most prevalent amongst the participants and looking for links between them. These final themes were discussed in supervision. As a final quality control measure I asked a mixture of lay people

and health professionals to match quotations to the themes (see Appendix 12). This ensured the themes were grounded in the original material.

### Research Reflexivity

This refers to the awareness of the researcher's impact on the interpretation and construction of meanings throughout the research process. This includes individual's values, beliefs and interests as well as gender, cultural identity etc (Willig, 2009). It is important the researcher is explicit about their contribution throughout the research and 'owns one's perspective' (Elliot et al, 1999). I am aware of one particularly important feature that may have influenced my expectations. As an adolescent of 13 my own father suffered a severe ABI following a road traffic accident. He was hospitalised for two years and returned home with 24-hour support. He died approximately five years ago due to health problems related to his immobility. I am aware of the impact this had on my family and me. This has definitely fuelled my interest in the subject. I interviewed adolescents who were of similar age to the age I was when my father was injured. The opening excerpt of the introduction is direct evidence of my interpretations of the experience at the time. I was aware that I identified particularly with Charlotte because she was the same age as me, the oldest child and employed similar coping strategies. However, I did not identify with them all. Whilst some of their experiences resonated with mine, others did not. I will discuss my personal reflections on the process of the study with regards my experience in more detail in the discussion.

In addition to my childhood experiences I have worked within neuropsychological services with people who have an ABI. This has involved direct work with patients but also their partners or carers. This systemic work has been a theme of my career so far and I have enjoyed working with families within a number of different specialities. I have not worked with the children of these patients so this is a new experience. I have experience carrying out qualitative research in the past but not on this scale or using IPA. As a result I think it took me some time to become comfortable with using this method of analysis. I felt more skilled as the study progressed and this was reflected in my confidence analysing my last transcript compared to my first.

## RESULTS

In this section I will outline the findings of the analysis. As previously discussed IPA methodology was utilised to carry out the analysis. I initially outline the sample and then provide an in-depth discussion about the emerging themes. Each of the participants will be discussed under their chosen pseudonyms in order to maintain their confidentiality.

### Sample

I interviewed five people in this study. All the participants were female aged 13 to 18 years, of white ethnicity, and from a variety of socio-economic backgrounds. An overview of the data gathered from the completion of the demographic information form is illustrated below in Table 1.

| <b>Name</b>      | <b>Age</b> | <b>Educational Status</b> | <b>Parents relationship status</b> | <b>Parent with injury</b> | <b>Parent's living status</b> | <b>Years post injury</b> |
|------------------|------------|---------------------------|------------------------------------|---------------------------|-------------------------------|--------------------------|
| <b>Charlotte</b> | 14         | School                    | Divorced                           | Mother                    | Inpatient                     | 0.5                      |
| <b>Jessica</b>   | 13         | School                    | Married                            | Father                    | With family                   | 1                        |
| <b>Sarah</b>     | 13         | School                    | Married                            | Father                    | With family                   | 2                        |
| <b>Molly</b>     | 17         | College                   | Married                            | Father                    | Inpatient                     | 4                        |
| <b>Nicole</b>    | 18         | F/T work                  | Married                            | Mother                    | Inpatient                     | 0.5                      |

*Table 1: Overview of sample*

The pen portrait of each individual is provided below. The aim of this is to provide context to the emerging themes.

#### *Charlotte*

Charlotte was a 14-year-old girl whose mother had an ABI approximately one year ago. Prior to the injury she was living with her mother and 11-year-old sister following her

parents separation five years ago. Her mother worked as a support worker but remains an inpatient since her injury. Charlotte is currently at school and beginning her GCSE studies. Since their mother was admitted Charlotte's younger sister has been living with their father and his girlfriend and children. She described having a difficult relationship with her father and had chosen to live with her maternal aunt and cousins. She described it being difficult being separated from both her mother and sister but thought that the extended family had been very supportive and she had grown closer to them as a result.

Charlotte reported that her mother had memory problems since her ABI, describing her frequently forgetting the beginning of conversations and becoming confused. This resulted in Charlotte not thinking she could talk to her mother or get support from her as she had previously. She reported filtering her conversation topics to talk about nothing meaningful because she hated repeating herself. She said she was annoyed with her mother at times but felt guilty for this, as she knew it was not her fault. There also appeared to have been personality changes including some disinhibition. Charlotte seemed to find this particularly difficult to cope with and found herself angry with her mother in these instances but feeling unable to voice this anger. She described not feeling as close to her mother but needing her as she was growing up and wanted her support.

I got a sense from Charlotte that she had taken on a lot more responsibility in the family. She was proud of the support she could provide her sister and felt they were closer as a result, arguing much less. It made her feel more grown up. It seemed like she felt the need to protect those around her, not sharing how she felt so that she did not upset her mother, or her grandparents, or her sister. She appeared to minimise her own feelings saying that she would just have to cope and avoided her emotions by trying to ignore them and keep busy. She described how pleased she was that this experience had resulted in her beginning to rebuild her relationship with her father but I got a sense that she did not feel like she belonged anywhere while her mum was in hospital. There was a definite sense of a loss of security, both current and future. She had changed her plans for travelling after finishing school, which she trivialised and adapted to. However, there was a real fear about the future. Fear that she was going to have to become her mother's carer. That she wouldn't be able to leave the house. That she would have to do everything for her. That she would not have her own life. In conjunction with this it seemed like she was willing to take this on, that she had a duty to fulfil.



The interview with Charlotte lasted approximately fifty minutes. It was my first interview and I felt we were both anxious to begin with. Initially it felt like Charlotte was worried about what was expected of her and might not open up but she appeared to become more comfortable as it progressed. At one point she became tearful and appeared very vulnerable and fragile. I moved on from these areas rather than probing them. I think this was related to my values and not wanting to take away from her the feeling she was coping. She asked that I waited until she had fixed her make up before I left, as she did not want her grandparents to see that she had been crying. I asked Charlotte why she had agreed to take part and she said it was because she wanted other people to know that it gets better. This summed up the impression I got of Charlotte very early on: someone who wants to support others.

### *Jessica*

Jessica was a 13-year-old girl who lived with her mother and father. She was the youngest of five with her nearest sibling being approximately seven years older. Her father previously worked away and her mother was unemployed for health reasons. She described a difficult family history, which included a period of separation for her parents and difficult relationships with her siblings. Her father suffered from an ABI following an assault that Jessica witnessed. She described this event as very upsetting and remained distressed with regards the consequences of the injury.

Jessica reported a number of changes in her father since his ABI that included increased tiredness, which she described as laziness, and changes in his social interactions such as not initiating conversation. These seemed to be very distressing for her. She described a series of idealised, happy memories of her father prior to the injury. They appeared to spend a great deal of time together alone where her father would take her places and she felt special. Following his injury she stated that they did not spend time together anymore, as he was always asleep and she did not think he wanted to talk to her. She described feeling alone, empty, ignored and unwanted. She frequently talked about her father no longer being able to drive. This seemed to be a constant reminder of his ABI.

Her relationship with the rest of her family had changed as well. She reported arguing with her mother more than previously because she thought that her mother did not

support her or look out for her. She did not think she was listened to so ceased sharing how she was feeling with others. I had a sense that she felt she had lost a protector in her father and was left isolated within the family. She said that her father had held the family together and now everything was falling apart. She had initially received support from professionals at school but as she moved on these supports had not continued. She believed that people thought there was no longer a problem because time had lapsed since the assault. She described changes in her relationships with friends. This was particularly clear with her best friend who had also witnessed the assault. I got a sense that her friend was avoiding seeing her father because it had been a distressing event for her and Jessica needed her to think things were better now.

Jessica reported feeling overprotective of her father since his accident. She worried about something happening to him, and her mother, and being left alone. She did not think she would cope well with losing them, which made the future seem hard. She was frequently late for school due to wanting to check on her father including seeing how his walking was and making sure he got to where he needed to be. She reported not wanting to tell school this so got regular detentions as a result. She said that she no longer wanted to leave home to go to college because she did not want to leave her parents.

The interview with Jessica lasted approximately one and a half hours. At times it felt a bit chaotic and hard to follow. She spoke very quickly and lost focus on the topic easily, frequently telling seemingly unrelated stories. In retrospect I think she wanted me to see how difficult things were for her and how alone she felt. She felt very young for her age and I wondered if this was because she was the youngest in her family by quite a few years. She seemed very angry but also very vulnerable. It seemed like she was terrified of losing more of her father who used to be the centre of her world. I think she had felt the centre of his also. It seemed like her behaviour had become a problem both at home and at school. She was angry with everyone around her and felt abandoned. When asked why she had decided to take part in the study she said it just felt so good to talk to someone. I got the feeling that she felt lonely and isolated and appreciated the support.

## *Sarah*

Sarah was a 13-year-old girl who lived with her parents and younger sister, who was nine years of age. She described herself as sporty with a large group of friends. Her father previously worked in computing and her mother ran her own business. Whilst the latter continued to do so, her father had been made redundant. Two years ago her father developed an abscess on his brain, which resulted in him being hospitalised for approximately seven months. Sarah described this time as lost time where things were not the same. Although she had contact with her dad she missed him being around to support her. She noticed some changes in his father since his injury. She thought that he was increasingly stressed particularly when he was in noisy, busy environments. This resulted in them spending less time around other people and trying to be quiet around the house to make this easier for him. He also had some word finding difficulties, which she found frustrating because she wanted to help him but did not think he would want her help.

Throughout the interview Sarah stated that the family had become closer and appreciated time together more. She reported that they had always been close. For example, she described herself as a daddy's girl who did not like to be away from her parents. However, her father's ABI had resulted in them spending more time at home together. She felt this time was more special because of what had happened. She described having to be brave for her sister but feeling they were closer because of this experience. She felt special being able to help her and viewed herself as a role model. She stated that she was able to share how she was feeling with her mother and grandma, who made her feel supported. There was increasing structure in the house to assist her father with his anxiety. This resulted in her doing more chores and helping out more. Whilst this was initially irritating to her, she began feeling happy that she could help her mother.

Despite her apparent positive attitude to the changes in her family she said she felt different from other families because of her father's stress. She experienced him as more over-protective than previously and wanting to avoid him feeling stressed about her being out of the house. This made her feel annoyed but she did not want him to know this because she worried about him feeling guilty. She compared him to 'normal dads' when talking about his stress. It appeared important to her that her father did not think they had had to make changes because of him as she worried about him blaming himself.

The interview lasted for approximately forty minutes. I felt Sarah was somewhat guarded throughout the interview. It was like she had more to say but was desperate to focus on the positives. Initially I found this difficult to probe because I did not want to push her when she seemed to be coping. However, she became tearful in the interview and rather than pulling away from these topics, which I had done in previous interviews, I asked about them further because she felt less defensive. Despite this she did not elaborate further. I got a sense that she was cut off from her emotions. I wondered if she felt guilty for feeling upset because she did not want to upset her father but also because she had seen people in the units that made her think they were lucky. It felt difficult to get her to discuss negatives but I think this may have been connected to my expectations. She was my third interview and I had come to expect people to have experienced a great deal of distress following their parental injury. Additionally she was tearful on a number of occasions, which suggested some distress. When asked why she had agreed to participate in the study she said it was because she wanted people to know that other people have been through similar experiences and that it is ok to talk to be people about how you are feeling.

### *Molly*

Molly was a 17-year-old girl whose father had a heart attack approximately four years ago. This led to him having a lack of oxygen, which caused an injury to his brain. She was currently living with her mother and younger sister. Her father remained an inpatient. Her mother previously worked part time and her father worked away from home. Neither was employed since her father's heart attack. Molly is currently studying at college and working part-time. She reported that she has a difficult relationship with her younger sister but believed that this was due to them both being teenagers. Since her father's heart attack she thought her relationship with her mother had become much stronger.

Molly reported that her father had memory problems following his heart attack. She saw him once a week and said she could not cope with spending more time with him as she found it very distressing. I got a sense that this made her feel guilty but she had realised she needed to do what she could to protect herself. It was particularly distressing that he could not remember who she was, describing him as having lost the last 25 years of his life. She stated that he was no longer her father because he was not there mentally and that this was

very difficult to cope with. She missed her dad a great deal and wanted him home but knew that she would be unable to cope with the strain of caring for him. Molly stated that she struggled to cope with the changes in her father initially. This resulted in her getting in trouble at school, pushing people away and getting into fights. She reported that as she got older she came to terms with the fact that her father would not return home and had tried to turn her life around to make her parents proud. She felt she had been successful in doing so thus far.

I got a sense from Molly that she had been very distressed at the changes in her father and had been unable to cope. It felt like she had been very angry at the initial stages and blamed everyone around her. She was very reflective on the past and keen to make amends for the difficulty she had caused her mother previously and the mistakes she had made with regards to her education. She was enormously grateful for her friends, stating that they were perfect, and that she would not have been able to cope without them being there when she needed them. She described herself as taking everything day-by-day and dealing with things as they emerged.

The interview with Molly lasted approximately one hour. She became tearful very early on in the interview and had to leave to get tissues. I could hear her sobbing with her mother in the other room. This was a very difficult experience for her but I got a sense that she wanted people to hear her story. When I reminded her that we could stop she was adamant that she wanted to do it. I think she had felt alone, like this had not happened to anyone else and wanted to make sure that others did not feel that way. I also think she felt she had advice to give others. She had a lot to say and in retrospect I felt that there were a lot of things I would have liked to ask about that I just lost track of. At times it felt very chaotic, she would lose her train of thought and it was easy to do the same listening to her. She appeared more reflective than the previous people I'd seen and I wondered if this was because she was older, or perhaps that she was the participant who was furthest post injury. I got a sense that she had learned to protect herself. She wanted to help her family but knew her limits. There was a real sense of pride in how she'd turned her life around and I felt this for her too. It seemed important to her that people saw this. Despite this she still seemed very young to me; like a child who someone needed to tell it wasn't her responsibility. That she was young enough to make mistakes and get help. That she did not need to do it on her own. Molly said she had wanted to take part to help with my research but also so that other

people knew that they were not alone. She said she did not need her information to be confidential because she was happy for people to know that this was her story.

### *Nicole*

Nicole was an 18-year-old girl whose mother had a brain haemorrhage approximately six months ago. Her mother remained an inpatient. Prior to the brain injury she lived with her mother and father, however, her father was often away with work. She had an older sister who had recently moved away. Her father was now living with her full-time and her sister has returned home to help. Prior to her brain injury her mother worked as a cleaner but the family had been told she was unlikely to return to work. Nicole worked in the care home her mother worked in. She started a few days before her mother's haemorrhage. She described having an argumentative relationship with her sister previously and not spending time with her father. She stated that she considered her mother a friend and was very close to her.

Nicole talked about finding her mother in the living room and stated that she found this very distressing. She had initially been unable to speak but had since made improvements in the area. She described some personality changes in her mother, stating that she was rude to people and inappropriate at times. This had been difficult for Nicole because she felt like she had to look out for her and apologise so people knew she did not mean it. She found it embarrassing and worried what she might say to people. She described feeling like she was taking on a parental role, which was difficult because she was used to being looked after. She found it particularly hard that her mother did not accept that something had happened to her. She thought her relationship with her mother had changed because she no longer felt able to talk to her about important aspects of her life, as she could not trust her not to tell people. She also felt she had to be more careful about what she said in case it encouraged her mother to repeat things and be rude to people.

I got a sense that Nicole had been very much looked after by her mother in the past and now felt quite lost without her. She described how quiet the house was and how she visits her mother for four hours every night. She said she would no longer plan anything for the future because she did not want to leave her mother alone. She stated several times that she felt guilty about spending more time with her father because she did not want her mother

to be jealous and think he may replace her. She thought she would be jealous of her mother's carer because she would feel like she had been replaced as her mother's friend. There was a definite sense of a loss of emotional support with Nicole no longer confiding in anyone, as she did not want others to see her cry.

Nicole became quite tearful early on in the interview and apologised for being upset. I could tell that she felt uncomfortable crying in front of me but I got a sense that she had not had anyone to talk to about how she was feeling. The interview lasted approximately 45 minutes. It was my last interview and after a lengthy period of recruitment I was looking forward to it finishing. Additionally I had travelled a long distance to meet with her and I think I was anxious to get the journey done. I wondered if a combination of these things meant that I did not probe her as much as I had others in previous interviews. She was the oldest participant I saw and initially I thought she seemed the most independent but as the interview progressed I felt she was just as reliant on her mother as the others I had interviewed. I wondered about the impact of the brain injury happening just as she started a new job and at a stage in her life where she would be more independent. I got a sense that this made things more difficult and that she wanted to be the child being looked after again. It felt like she had lost her best friend. She also seemed like she was still at the very early stages of adjusting to what had happened to her and her family. She seemed to be relying on the hope that everything would go back to normal and was not really using many other coping strategies. This made me sad because I was aware that in reality things might not be the same again.

### Emerging themes

In this section I will provide a detailed discussion about the emerging themes that were identified as part of the analysis. Three master themes were identified:

1. Loss
2. Distress
3. Coping

Within these there were a number of subordinate themes with satellite themes associated with them. These are illustrated in Figure 1 and will be discussed in more detail throughout

this section. I will provide quotations from each of the participants to evidence the themes and to provide context.

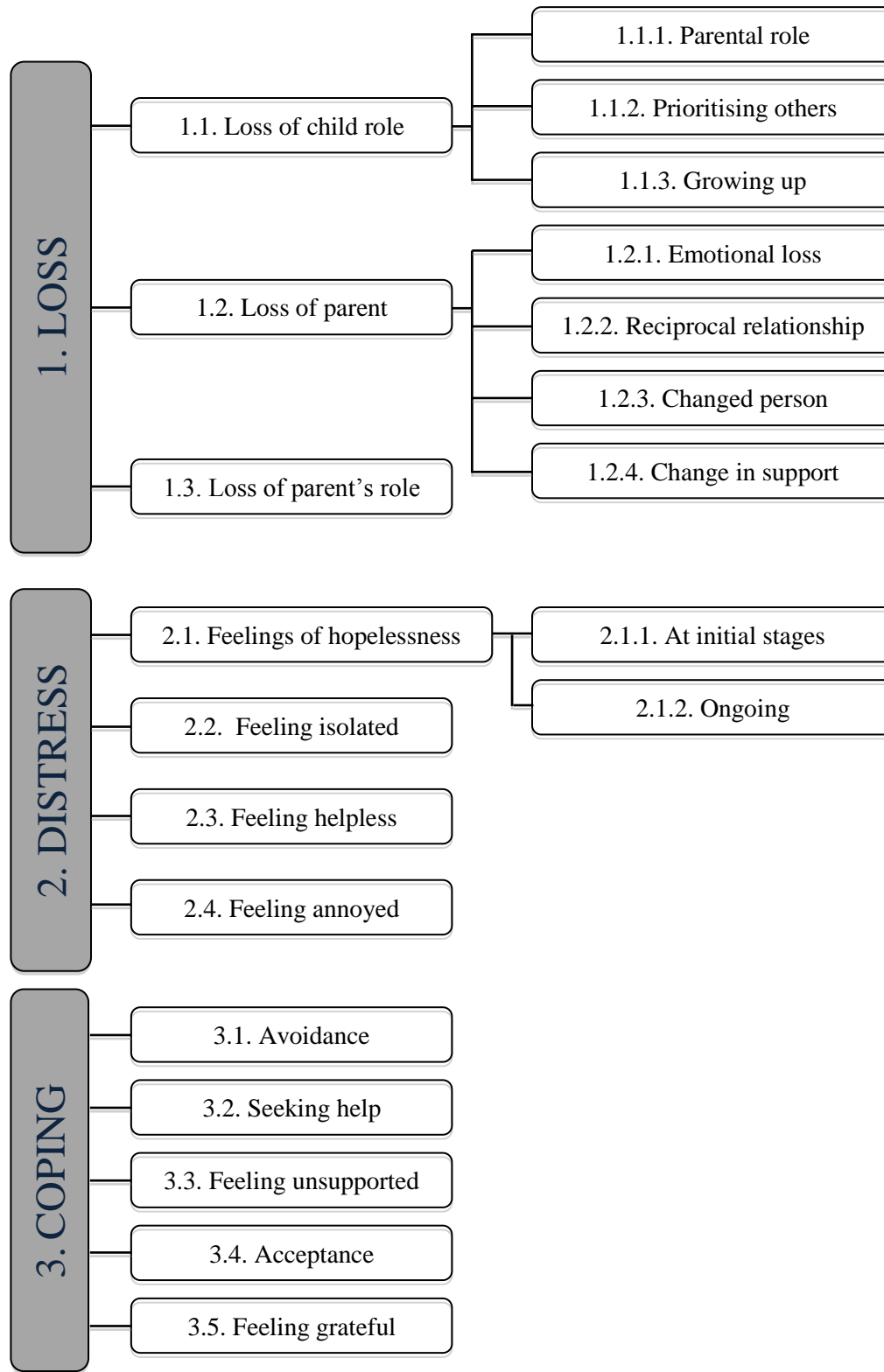


Figure 1: Overview of emerging themes



## *1. Loss*

There were universal themes of loss for each of the participants. Each described feeling that they had lost their parent with ABI but also their role within the family and support they had received previously. They reported a number of positive outcomes as a consequence of their losses such as feeling closer to other family members.

### *1.1. Loss of the child role.*

Each of the participants described feeling that their role within the family had changed. This included taking on more parental responsibility and feeling like they had grown up as a result of their parent's ABI. Whilst in some ways this was viewed positively, there was a sense that they had lost their role as the child within the family, due to a change in responsibilities.

#### *1.1.1. Parental role.*

All five participants described taking on more parental responsibility within the family following their parent's ABI. This occurred in a number of different ways. Four of the participants thought they had taken on a caring role with the parent.

**“I feel like I have to do more stuff for her like she in't, she can't really walk, well she can walk but she'd just a bit slow and like 'cause she'd been like laid down in hospital for such a long time like her arms and that are like she can only like reach and like not upright so you have to do stuff like brush her hair for her and stuff like that she can't reach.” Charlotte**

Charlotte felt that she was doing small tasks for her mother and initially minimised the role she was playing. However as the interview progressed it became clear that she felt she was taking on these roles at the expense of her own childhood.

**“I don't wanna sound nasty but erm I don't know sometimes I just feel like it should be her looking after me. I know like she's been in hospital but like I don't know I don't want to do that stuff for her.” Charlotte**

**“I’d do it ‘cause she’d do it for me but well, that she does, that she did it for me but like erm you know when you just dun’t really wanna do summat but you do it anyway ‘cause it makes them happy. I’d do it just ‘cause of that.” Charlotte**

It was clear that Charlotte felt a sense of obligation to take on the caring role because her mother had looked after her in the past. However, there was some recognition that this was not how a parent-child relationship should be and that she did not want this change in their roles.

Jessica highlighted the impact her need to care for her father had on childhood activities such as school.

**“But school is really really really annoying ‘cause like if I’m there late it’s for good reason because I wanna see dad get out of door first and see how he’s walking.” Jessica**

She viewed herself as a carer for her father and took responsibility for making sure he was all right and got to where he needed to be.

**“I’m really really really protective over him. I just don’t want owt to happen to him anymore.” Jessica**

She experienced some anxiety with regards to her father since his ABI and took on the protective role he had previously taken on for her. Nicole also felt that she was taking on a parental role for her mother and experienced some anxiety associated with this.

**“I feel like I’m having to look after her.” Nicole**

She worried about the impact it could have on their relationship because she had to take on more responsibility for her mother.

**“I want to still like have a good relationship with her but when she is like this I feel like I’m constantly moaning at her and I don’t want her to start hating me for it.” Nicole**

For three of the participants the parental role also involved providing emotional support for the parent. Sarah described hypothesising what her father may be thinking and adapted her behaviour to make things easier for him.

**“It’s just little things like that but you’re still going with him you know and sometimes if he, if he’s doing stuff on his own then we try and be with him so he dun’t feel like lonely or anything.” Sarah**

She described taking on an emotionally supportive role with her father, trying to make him feel better about the situation. Charlotte found herself trying to comfort her mother but finding it difficult to cope with her being unhappy.

**“It upsets me quite a bit knowing that she’s not happy. But I try like erm tell her like just to, that it’ll be alright and stuff’ll get better do you know what I mean but like erm I still know she’s not happy.” Charlotte**

Both Nicole and Sarah hid their emotions because they did not want to make their parents upset. Previously they had experienced their parent providing them with emotional support in this form.

**I don’t want to upset her, I don’t want to give her anything to worry about.” Nicole**

Part of this emotionally supportive role resulted in participants feeling like they had to change the way they were for the parent. Charlotte described feeling like she was putting on an act with her mother. There was a sense that this was at the expense of how she was feeling.

**“Erm [pause] I feel like I’m putting on an act sort of it you get me like ‘cause sometimes when I’m not happy I have to pretend I am so I can’t say.” Charlotte**

Nicola and Sarah had similar experiences in their interactions.

**“Like I try and watch what I’m saying now when I’m speaking to her.” Nicole**

**“Erm, well to start with it were a bit like, you were really conscious of what you were doing like the tv was turned down or if we were in the car we didn’t have the music on and we had to talk quietly or if me and [sister] were arguing then we tried to stop”**

**Sarah**

Taking on more parental responsibility was not restricted to the relationship with the parent with ABI but was also identified with the other parent. Three of the participants reported that they tried to become more helpful, seemingly taking on some of the roles previously occupied by the parent with ABI.

Both Molly and Sarah described helping their mothers, Sarah providing emotional support to her mother and being proud of this role.

**“I think that helped mum having someone else to talk to while dad were away.” Sarah**

**“Just help my mum loads more, erm talk my sister straight when she’s been horrible to my mum. Say there’s no need for the way you speak to her.” Molly**

Both Nicole and Sarah talked about doing more practical tasks such as housework to help their uninjured parent.

**“Aye, I need to do all the cleaning ‘cause my dad doesn’t touch the cleaning.” Nicole**

**“Erm it felt quite like happy to help out mum. Even stuff just like siding the dinner plates or just chopping up the carrots or something for the tea then it made her life a bit more easier than it wa.” Sarah**

There was a sense of them feeling that they were looking after the other parent whilst the parent with ABI was not there. For the participants who were older siblings this supportive role extended to their younger siblings. This appeared to be regardless of the age of the participant. Charlotte described feeling like she had taken on some of her mother’s responsibilities with her younger sister, and taking pride in this, and likewise Sarah felt proud of being a role model for her sister:

**“I feel like I’ve got a lot more responsibility with our [name] ‘cause like I had to tell her about periods and do you know what I mean she’d just gone to high school so like she comes to me to talk now instead of my mum.” Charlotte**

**“When I look after our [sister] . . . I know I’ve done summat good for her if you get me.” Charlotte**

**“Er, well I felt like, I felt quite special actually erm, you know, having to be like a role model for my sister.” Sarah**

Molly felt that she had to take on a more authoritarian role with her younger sister. She felt this was important because she wanted her sister to learn from her mistakes.

**“I don’t want her to go down the road I went down ‘cause I regret that so much.”  
Molly**

As a result of these changes in their relationships with their siblings two participants felt that they were closer. Charlotte qualified this as arguing less with her younger sister.

**“Well, when we lived together we used to argue and we didn’t really get along and then since like we’ve been apart when we do see each other we like we’re really good with each other so we like don’t argue.” Charlotte**

Sarah thought she spent more time with her sister and this had made them closer.

**“Well, we’ve always been close erm but now we’ve got like. Well we have separate bedrooms now but erm, I think we are closer. We do a lot of stuff together.” Sarah**

### *1.1.2. Prioritising others.*

All five participants described having to make changes for other members of the family. This involved giving up their own plans. There were feelings of guilt about wanting things for themselves such as support and external activities. This guilt resulted in them

minimising the distress caused by these changes by trying to make the best of their new plans.

Nicole felt guilty about seeking support from her father. When she was with her mother she would minimise their relationship so that her mother did not feel jealous.

**“I tell her something me and my dad have done and she gets a bit jealous and that’s when I start to feel guilty. My dad’s relationships so good now and like ‘cause she’s stuck up there and she doesn’t get to be here and have a normal relationship and that’s what makes me feel guilty.” Nicole**

She reported putting her own plans on hold so that she could support her mother. There was her sense that she thought that her mother was more important than her.

**“I’d feel like guilty or whatever not seeing her through the good and the bad times so I don’t really like plan anything.” Nicole**

Charlotte talked about having to give up activities that she enjoyed but not challenging this because she felt unable to justify continuing them.

**“I never argued with me auntie so like if she asked me why and I said “‘cause I’ve got art” she’d have said summat like “well your mum’s more important” or summat so I just like thought well I’ll just not go to art.” Charlotte**

There was a sense that she felt guilty prioritising something she enjoyed over her mother because she worried about what people would think. Molly had learnt to be more protective of herself but this made her feel guilty.

**“I know that sounds mean but I couldn’t live with him here, I can just about bear seeing him on a Sunday with the way he is but I couldn’t have him living here ‘cause it would just be a nightmare ‘cause you’d have to watch him everywhere he went.” Molly**

Three participants reported no longer wanting to leave home because they did not feel they could leave their parents.

**“I was gonna go to uni but . . . I don’t think I could go because of my mum and my dad, I couldn’t leave them.” Molly**

**“I’m not really gonna go to college . . . I just don’t want to leave home.” Jessica**

They wanted to look after their parents. There was a sense that they could not be left on their own in case something happened to them, like a parent with a young child.

Charlotte thought she would no longer be able to go to university because she would have to care for her mother.

**“Then like say if ‘cause I wanted to go to uni I don’t know I’d be able to like go there and stuff like so my mum’s not like on her own.” Charlotte**

Despite being tearful as she talked about this she minimised her distress and reported adapting to her new plans. It felt like Charlotte did not want to appear like she was blaming anyone for her having to change her future.

### *1.1.3. Growing up.*

Three of the participants reported feeling that they had grown up as a result of their parent’s ABI. This involved them coping better and having more responsibility. They viewed this positively.

Charlotte and Sarah both discussed their increased responsibility for their sisters and for themselves:

**“Like I’ve grown up a lot as well.” Charlotte**

**“We do a lot of stuff together. ‘Cause I’m older now we can like say just walk into town together or and then my mum will come and pick us up and then we’ll come back.” Sarah**

Molly particularly felt that she had grown up since her father's heart attack. She associated growing up with acceptance about the future and about her father. She also appeared to take pride in making positive changes in her life following her initial difficulty coping with what had happened to her father.

**“I have I’ve changed I’ve grew up, sorted my life out, realised that my dad’s never coming home and he’s never gonna be the same again.” Molly**

### *1.2. Loss of parent.*

Each of the participants described feeling like they had lost their parent. This included changes in their personality and social interaction. This loss was not restricted to the parent with ABI but also included perceived changes in support from the other parent.

#### *1.2.1. Emotional loss.*

All participants described feeling as though they had lost the emotional support of the parent with ABI. They reported not feeling they could talk to them anymore or rely on them for emotional support.

Nicole talked about feeling that she had lost a friend and confidante in her mother.

**“It’s heartbreaking ’cause she was my pal and I could tell her anything.” Nicole**

She reported feeling like she had lost her support because her mother could no longer be trusted to keep things private and not seeking support elsewhere. She was tearful as she talked about this loss that left her feeling lonely.

**“There’s not much to talk about there because you cannot really tell her things ‘cause if you let her into something private then she would just tell anybody ‘cause she doesn’t realise that you’re not meant to say things to other people.” Nicole**

Charlotte also felt that she could no longer seek support from her mother.



**“Erm, well I feel like I can’t talk to her about everything now and like basically only stuff we talk about is stuff that’s not important like well school.” Charlotte**

Being unable to live with her mother also played a role in this loss of support. Whilst other people in the family supported her, there was a sense that her mother played a special role and was irreplaceable.

**Erm, well I like talking to our [name] but I’d rather have me mam ‘cause like it’s, it’s different like you know that she actually cares about everything you saying ‘cause she’s your mam and like even though I know our [name] does care but it’s just a different sort of caring really in’t it.” Charlotte**

Sarah also found the experience of her father being an inpatient meant she had lost his emotional support with his absence being a reminder that there was a problem.

**“Erm I felt like, like there were something missing type thing ‘cause before that he were always like supportive and pushing you to do stuff but when he won’t there it were strange feeling like not to like look round and not see your dad like clapping or cheering you on.” Sarah**

Jessica described feeling ignored by her father.

**“I feel really ignored when he dun’t speak to me.” Jessica**

There was a sense that she was blaming towards him and felt the loss of emotional warmth previously experienced from her father. Four of the participants described a similar loss of emotional warmth from the parent, and as experiencing them as cold or distant. Molly reported feeling that her father did not care, and that she wanted to be comforted by him, but had had to come to terms with him not being there for her.

**“He looks at you like a blank piece of paper.” Molly**

**“I just wanted my dad home and I wanted him to tell me everything was going to be all right. And that he was gonna stay with me.” Molly**

Charlotte described a similar experience, feeling that her mother no longer cared about how she felt.

**“Like sometimes when we talk . . . it’s like she han’t got any emotions like she don’t care, if you get me.” Charlotte**

Nicole described feeling annoyed that her mother responded negatively and did not regulate her emotions.

**“If she doesn’t get what you’re meaning then she gets angry, that annoys her instead of just saying can you explain that, I didn’t get it she gets angry and then she says oh shut up and she’s dead rude about it. But erm that can be annoying as well.” Nicole**

#### *1.2.2. Reciprocal relationship.*

Four of the participants described a change in the social relationship with the parent with ABI. The adolescent was much more in control of communication. They now initiated it because the parent did not and at times they avoided it. They spent less time with the parent, which impacted on the reciprocal nature of the relationship.

Nicole commented that her mother’s ABI had meant that their communicative relationship had changed. She had difficulty talking to her mother as she couldn’t be trusted to keep things private due to her disinhibition.

**“There’s not much to talk about there because you cannot really tell her things ‘cause if you let her into something private then she would just tell anybody ‘cause she doesn’t realise that you’re not meant to say things to other people.” Nicole**

Whilst it appeared Nicole was not blaming her mother for this change, there was a sense that she had lost her normal social interaction with her. Jessica described having initiate conversation and showed some distress at her father no longer making an effort to speak to her.

**“Well he dun’t speak a lot at all. Like today when I got home from school ‘cause today I wa cooking . . . and . . . I gived him some and he said thanks but he never says hi or owt now.” Jessica**

Molly felt she had to initiate conversation and this was difficult because she did not know what to say.

**“He won’t say anything. You’ve got to speak to him you know if you want to, but you can’t really.” Molly**

There was a sense that she avoided talking to him because it was too difficult. This resulted in a deterioration in their relationship; Charlotte described a similar feeling:

**“Isn’t really a relationship if I’m honest, ‘cause you don’t know what to say to him.” Molly**

**“It’s just pointless making conversation sometimes but mostly when she’s tired.” Charlotte**

Jessica’s reciprocal relationship was affected by her feeling that her father no longer spent time with her.

**“We just don’t do what we used to do anymore . . . he used to just take me out loads of times . . . and . . . he used to help me with my homework but he dun’t now.” Jessica**

**“He’s been really lazy and he used to be proper active but now he dun’t, he just goes straight to bed and I always just go on laptop now and watch telly and all my dad [does] is go upstairs” Jessica**

Her use of the word lazy suggests she is angry with her father for not spending time with her. It feels like she believes he is making an active choice to isolate himself from her, which makes her feel more rejected. Nicole felt that the house was empty without her mother and she missed the social relationship they previously shared.

**“It’s just too quiet without her. It’s just boring, not having her here and that.” Nicole**

Nicole described having a close relationship with her mother and her absence made Nicole appear more dependent on her. Not every participant described a loss in their social interactions with their parent. Whilst Sarah was tearful when she discussed being apart from her father, feeling that they had lost time together, she chose to view the consequences positively, stating that she now spent more time with her father and the family as a whole. Whilst there were initial problems in the reciprocal relationship, she felt they were now closer.

**“Erm it were a bit of a shock to start with and I think he felt that he missed as well on it so we tried to do a lot more to sort of make up for that like now so yeah.” Sarah**

### *1.2.3. Changed person.*

Three of the participants described experiencing their parent as different. This was particularly difficult because they looked the same, so others thought everything was fine, but they acted differently.

Jessica felt this had had a large impact on her life and was tearful when discussing this.

**“Everything in my life has changed, especially with my dad.” Jessica**

Molly described no longer having a relationship with her father because he had changed so much.

**“So it’s hard to have a relationship with someone that isn’t really your dad anymore ‘cause he doesn’t know you and sometimes I feel like I’m talking to a complete stranger. Because he’s just not the same person any more.” Molly**

Nicole described being embarrassed by the changes in her mother.

**“Her manners have just like went completely away ‘cause she doesn't say thanks to things or like she just changed completely like that and she’s just quite rude” Nicole**

There was some difficulty making sense of the changes in their parents. Nicole discussed her expectations of someone with an ABI. She described her mother looking the same but acting differently.

**“It’s weird. It’s so different because like she just looks the same, she just looks normal until she speaks and then she’ll just say something.” Nicole**

There was a sense that this was difficult because others do not understand that there is something wrong and her mother is not just being rude. Molly had a similar experience with her father.

**“Erm when you look at him you wouldn’t think anything’s wrong because he can still move perfectly fine.” Molly**

The physical normality made it more difficult to come to terms with her father being an inpatient and not able to return home.

**“But knowing that he’s in a place like that where there’s people there that can’t move, it’s just not right looking at him in there he should be like, I can’t even say where he should be ‘cause I don’t know where he should be.” Molly**

Molly seemed to have difficulty making sense of the changes in her father because the cognitive problems were not visible. It seemed harder to understand what her father’s needs are.

#### *1.2.4. Change in support.*

Every participant described feeling closer to the other parent as a consequence of the ABI. Some felt closer to their family as a whole. Charlotte described rebuilding a relationship with her father that had previously been difficult.

**“Now I’ve started talking to me dad so on plus side like things have got better.”**

**Charlotte**

She viewed this change positively. Sarah felt similarly.

**“Erm well again we’ve been a lot closer ‘cause it were like mum being sort of like a single parent for a bit so we were, we were always with mum.” Sarah**

She viewed her mother positively for coping and felt that they were much closer because they had coped with the difficult situation together. Molly also described feeling closer to her mother because she felt they could talk about anything now.

**“Mine and my mum’s relationship has gone so much stronger ‘cause we can talk about anything now and I mean anything in the world.” Molly**

Nicole experienced the same change in relationship with her father.

**“Like I’m a lot closer to him. I always could speak to him but I don’t know like I’d rather speak to him now, I feel comfortable telling him things like that’s good.” Nicole**

Jessica reported her mother taking on some of the roles her father had previously occupied.

**“Like normally when we go to [place] my mum’s just in there cooking tea but she dun’t now, she takes me out ‘cause my dad goes to bed.” Jessica**

It seemed as though her mother was trying to make things easier for her. These changes in relationships extended to the entire family unit for three of the participants.

**“I’ve become a lot closer to all me family.” Charlotte**

Sarah repeatedly discussed her family being closer now. It seemed important for her to find positives in the situation.

**“Erm, it’s ok but I like I suppose in a way it was erm, it was kind of like good because it brought all of us closer together and now we like treasure like moment, like special moments well not, ‘cause he’s not gonna die or anything, but it’s nice to feel like special things like that.” Sarah**

There was a sense that they had to celebrate time together because her father could have died. Jessica talked about being much more aware of her family and an increased desire to care for them.

**“Really it’s a change ‘cause I normally just got on with my life but now what happened to my dad I just like care about them now.” Jessica**

Whilst participants did describe better relationships with their family, three of them also described a deterioration in these relationships. Jessica noticed that she argued with her mother more.

**“We’ve fallen out loads of times. Like if we have an argument I’ll just cut out of it and go upstairs and when she tries to talk to me I just ignore her and then the next day I come and she starts again so I just ignore her again and it never works.” Jessica**

She felt that her mother did not listen to her.

**“I don’t really talk to my mum that much about it ‘cause really she in’t gonna listen anymore.” Jessica**

She seemed resigned to not being supported by her mother and this extended to the rest of her family.

**“Really feels like all family’s split apart in middle. I used to be proper backed up but now I don’t.” Jessica**

She felt unwanted and isolated within the family. Molly noticed a deterioration in her relationship with her mother but took responsibility for that change.

**“Lost a bit of a relationship with my mum ‘cause I was just such a cow really.” Molly**

Nicole described having difficulty coming to terms with the changes in her relationships.

**“I don’t want to be too close to him ‘cause that’s what I was like with my mum . . . but then I feel guilty that me and my dad are getting on so well.” Nicole**

She felt guilty for the change in her relationship and felt the need to minimise the positive aspects of her relationship with her father so her mother would not be jealous. She felt stuck in the middle of her family as her father and sister argued at home.

**“So I feel like I’m the mum, trying to calm everybody down all the time.” Nicole**

Charlotte felt different from others in her family in her coping strategy.

**“Like the doctors come in and I started crying and me auntie wan’t there, it were just me, my grandma and granddad and erm me grandma told me to stop crying so I just like I felt right out of place and stuff. I can’t remember how I felt, it were just like I were quite shocked. Like ‘cause they don’t show any emotion whatsoever.” Charlotte**

As a result of this experience she avoided showing emotion in front of her family and thought she should cope independently.

Overall there appeared to be some conflicting feelings amongst the participants about how they felt within their family. Whilst they appeared to have strengthened relationships in a number of adult ways, there is a sense that they have lost the support they would have previously received as a child. They appeared to take on the responsibility for the loss of this support and this caused some distress.

### *1.3. Loss of parent’s role.*

Three of the participants described a loss of the parent’s role within the family. This involved the loss of the security they previously provided. They reported feeling that the parent could no longer be trusted.



Molly did not think her father could come home because he would have to be watched constantly within the house and could not be trusted alone. However, conversely, she wanted her father home to protect her and keep her safe but she was distressed because he could no longer provide that security as he could not be trusted. Charlotte had the same fear for the future.

**“And he’s never coming home ‘cause he’s not safe and him not being here I don’t feel safe ‘cause he was like he helped me through so much and he was always there and you get so used to someone being there and then he stops.” Molly**

**“When she comes home . . . if we all move back in with each other like . . . we wouldn’t be able to go out and stuff like . . . in case she like run a bath and forgot she’d run it and like she might flood the house.” Charlotte**

There was a sense that her mother would not be able to provide physical security as she once had. As though she was not safe. This loss of security for Charlotte extended to physically no longer having a home.

**“Well, it isn’t that I don’t wanna live with me auntie, it’s just not my house if you get me.” Charlotte**

She had lost the basic security of having a place she could call a home, something previously provided by her mother. Jessica felt protective of her father and did not feel secure that he would be able to get to where he needed to be. As a result she sacrificed, receiving punishments at school to ensure he did what he needed to.

**“I’m late ‘cause I wanted to see how he goes and make sure he gets there.” Jessica**

Both Jessica and Molly experienced changes in their financial situation since their parent’s ABI. Jessica thought her family was being exploited and that her father was no longer there to protect them against this.

**“And like my brother [name], ‘cause my dad has a bank account dun’t he with loads of money in it and erm . . . my brother always takes card and that and I keep on telling my mum but she dun’t listen.” Jessica**

Molly contributed to improving the financial situation following her father’s heart attack.

**“We weren’t very good with money erm so we had to like start selling things to get more money. Like selling things that we didn’t need like this back room used to be just full of absolute crap and we just sold loads of stuff. We got quite a bit of money for it and now that I’m working it sort of helps, and I get EMA as well” Molly**

She had not needed to contribute financially previously because her father had provided this security. She seemed to take pride in being able to contribute.

## *2. Distress*

There were universal experiences of distress described by each participant. They described feeling hopeless, isolated and helpless. They also felt annoyed about their situation.

### *2.1. Feelings of hopelessness.*

Each participant described feelings of hopelessness. This was associated with high levels of distress and a belief that things would not get better.

#### *2.1.1. At initial stages.*

Each participant described feelings of hopelessness at the initial stages of their parent’s injury.

Jessica described high levels of distress. She frequently talked about feeling like her life was over. This experience was shared by Molly.

**“I felt like I wa going to die without him.” Jessica**

**“I felt like my whole world had fell on top of me erm I just didn’t know what to do.”**

**Molly**

**“Refused to do my work, ripped it up in front of the teacher erm, and just got myself excluded all the time or sent to the quiet room or the STR.” Molly**

There was a sense that this distress was related to her grieving for the perceived loss of her father.

**“So I just, when weeks and weeks had gone by and sort of started taking things of my dad’s to bed like t-shirts, slept in his bed on his side, drank out of his cup, cleaned his bike and just like done stuff that he’d do just to keep myself close to him.” Molly**

Sarah was unable to sleep at the initial stages. She found it difficult to comprehend what had happened.

**“Cause I were like a bit older I were sort of like a bit worried so that night I didn’t, I din’t sleep much until like my grandma says explained what were happening erm but it sorta, it didn’t sink in as much.” Sarah**

Nicole ruminated over finding her mother.

**“It hurt, I hated seeing it and I keep getting the image of her in my head. I just don’t know I felt, I just can’t even explain it. It was horrible. I was heartbroken.” Nicole**

### *2.1.2. Ongoing.*

These feelings of hopelessness remained in each of the participants at the time of interview. Jessica felt she contained this distress at home but noticed it was impacting on school.

**“Really my life has just fallen apart. It’s just really really hard going to school and that nowt’s really really going to change in future and that and sometimes I do get upset in class and I do have to go out and that.” Jessica**

Molly talked about the constant reminders of the changes in her father and the distress associated with this.

**“There’s pictures of him around, it just hurts looking at them, at how we used to be ‘cause like I can’t even remember how he used to be. I remember bits but I can’t remember a lot so it does hurt.” Molly**

She became protective of herself; she remained distressed by the situation with her father but regulated how often she saw her father to ensure her distress was manageable.

**“Erm, it doesn’t feel right to be honest ‘cause I shouldn’t be saying that about my dad but I can’t see him when he’s like that, it’s just the worst feeling anyone could go through.” Molly**

Nicole described ruminating over the past.

**“I depress myself even more like sit and look at pictures.” Nicole**

Charlotte tried to contain her distress.

**“But now like I could cry about it all the time I don’t.” Charlotte**

Sarah did not directly report distress and it seemed important for her to appear like everything was positive within the family. However, she was tearful throughout the interview, suggesting some ongoing distress.

## *2.2. Feeling isolated.*

There were feelings of isolation amongst the participants. They felt alone and that they had no one to turn to who understood what they were experiencing. They experienced a loss of friendships and a loss of support from siblings.

Molly reported feeling alone.

**“It just felt like I had no one.” Molly**

She described feeling that others had not experienced what she was going through and thus did not understand.

**“Just didn’t feel like I was getting the support I needed ‘cause no one in my year has got a dad like mine, you know what I mean.” Molly**

There were times where this was so overwhelming that she did not feel able to get out of bed.

**“I just, I was just one time I refused to get out my bed, I was just like I’m not going, I didn’t want to socialise with anyone. I didn’t want to socialise with my mates I’ve got now, I was just that upset and it hurt.” Molly**

As reported previously Charlotte stated that she felt alone and out of place within the family because they did not express negative emotions in front of her. Nicole isolated herself at home ruminating over pictures from the past. Jessica felt rejected by her family and therefore alone. She felt she had lost support from her siblings. Charlotte experienced a loss of this support also because they were no longer living together.

**“It’s quite hard like we can’t both live together ‘cause there’s like not enough room or like she won’t want to come live down here and stuff and like it has affected me quite a bit because like I’ve always been used to having her there.” Charlotte**

This added to the sense of isolation. Molly noted similar changes in their relationship.

**“Mine and my sister’s relationship is bad but it’s nothing like, we try and be nice to each other but there’s always that one thing in the way and I don’t know what it is.”**

**Molly**

Jessica reported losing friendships since her father's injury.

**“Really upsetting but I’ve told her that erm he’s really well now and that and then she still never comes round.” Jessica**

There was a sense that she thought her friends were avoiding the house because of her father. Molly described rejecting friends at the initial stages because of her distress. This left her feeling more alone.

**“So I lost quite a few people ‘cause it wasn’t like people I was close to anyway it was like just mates, not my mates I’ve got now, it was just like mates and they were like do you know what you can just do one ‘cause the way you’re speaking to people’s unreal.” Molly**

Charlotte no longer spent as much time with her friends despite them being an important source of support to her. She talked about being unable to spend as much time with her friends due to the feeling of obligation to her mother:

**“Erm well I used to go out all the time and like now I have to have a lot of time for my mum. I don’t see my mates as much and I used to like go to an art class on a Tuesday that I can’t go to now ‘cause I go see mum.” Charlotte**

### *2.3. Feeling helpless.*

Four of the participants described feeling distressed at being unable to fix or change the situation.

**“It does, it hurts a lot knowing that he’s like that and you can’t do anything about it. You just don’t know what to do.” Molly**

Molly felt lost because she was able to change the situation.

**“I don’t want her to be, I just want her to be back to normal.” Nicole**

Nicole felt that she could not change things either and just wanted things to return to the way they were before. Jessica's belief that nothing was going to change resulted in her not confiding in people.

**“I just don't wanna tell em about it 'cause there in't really no point 'cause they can't do owt.” Jessica**

Sarah described feeling dependent on her father's mood. At times she thought he did not trust her and there was nothing she could do about it.

**“Sometimes it's like oh that's ok but other times I feel like that he dun't have that he dun't trust me I know he does but it just feels like he doesn't want me to go out.” Sarah**

#### *2.4. Feeling annoyed.*

Three participants described feeling annoyed with their parent with ABI and the changes they had had to make. There was a sense that they thought they should not feel that way.

Charlotte was angry that she might have to sacrifice her life plans to look after her mother.

**“I don't know, like I can't think of word but it's make me quite angry that I'd have to do a lot of stuff 'cause I don't want to do it. I want to go out and I want to have fun, I don't want to be like 24/7 looking after me mam.” Charlotte**

Sarah described some frustration about her father's apparent lack of trust in her.

**“Say like a normal dad, yeah they'll be protective but they'd probably say “oh yeah, it's ok. So long as I know where you're going” but he seems to get a bit more stressed about the situation. But yeah I get annoyed sometimes 'cause it's like “why can't it happen?” but erm I, I don't mind really.” Sarah**

She minimised her annoyance in this situation but her use of the word “normal” suggested that she viewed this as a negative change. Nicole described annoyance at the negative changes in her mother also.

**“If she doesn’t get what you’re meaning then she gets angry, that annoys her instead of just saying can you explain that, I didn’t get it she gets angry and then she says oh shut up and she’s dead rude about it. But erm that can be annoying as well.” Nicole**

### *3. Coping*

Each of the participants described different strategies for coping with the loss and distress associated with their parent’s ABI and the changes experienced as a result.

#### *3.1. Avoidance.*

There was a universal theme of avoidance as a coping strategy. This involved using distractions, trying to get on with things and not talking to people about their family. There was a sense that this was because the situation was too difficult to address but also because they were seeking normality while everything around them appeared to be changing.

Charlotte talked about using distractions to avoid thinking about what was happening.

**“Erm well he’s got this new house that he’s like doing so we’ll go round and like plaster walls and stuff and just like talk and then takes me out like shopping quite a bit.” Charlotte**

A number of participants talked about just wanting to get out of the house to avoid the situation.

**“I just didn’t want to be like here in this house, I just want to constantly be out with everyone ‘cause everything in this house is just my dad.” Molly**



**“When I’m not near my mum I don’t want to deal with it so I just try and forget about it which is impossible but I just try my best.” Nicole**

Sarah described having a room at her grandma’s house as a space away from home.

**“We had it decorated so it made it look a bit more livelier and everything so it felt sort of like a second home, a home away from home type thing but it’s still quite nice to go up there you know, so yeah.” Sarah**

Avoiding rumination over the changes at home was important for them to be able to get on with things and feel able to get away from the difficulties.

**“Like, I’m alright with it like, I just like brush it off my shoulders do you know when I want stuff like that.” Charlotte**

Molly found that getting on with things allowed her to think about her father less which reduced some of her distress.

**“I’m either working or college work and little things distract me so I try my best just to blank everything out.” Molly**

Sarah found this an important coping strategy also. She thought being younger helped because she was not fully aware of what was happening.

**“Because, ‘cause I was younger then it, I just sort of kinda got on with it and erm yeah.” Sarah**

Getting on with things did not mean that they were able to entirely avoid what was happening.

**“I was always like thinking about things but I never really let it get in the way of anything that was going on ‘cause my dad wouldn’t want me to sit at home and worry about everything.” Sarah**

It was important to Sarah that she did what she thought her father would want. A key part of avoiding the situation was not talking to people about what was happening and how they felt. Jessica described not wanting to talk to people.

**“I just don’t really, I don’t like telling people. The only person I really talk to is [name] and she like asks me questions and that like you do and that and erm and she asks me if I want, she asks me if I want her to tell what I said to her to my mum but I always say no ‘cause I don’t want her knowing this stuff and that.” Jessica**

There was a sense that she was protective of her family and did not want external people to know about them.

Nicole was also avoidant of talking about how she was feeling.

**“I try deal with anything other than anything when I’m with my mum, I just hate talking about it.” Nicole**

She had lost the person she would have gone to for support when her mother was hospitalised. She was uncomfortable crying in front of others and apologised throughout the interview for crying. There was a sense she avoided talking about it because she knew that she would be tearful if she did.

Molly felt unable to talk to her family because she was protective of their emotions.

**“I don’t want to speak to my mum ‘cause I’ll upset her and our [name]’s 13, she’ll be 14 this year, but she’s not grown up enough do you know what I mean.” Molly**

It seemed avoidance of talking about her family was a strategy employed by others in her family also.

**“We don’t speak much about how my dad is. If we go and see him, we go and see him, but we don’t really speak much about it ‘cause I understand more and I’ll get myself upset and If I see my mum cry, I’ll cry, and our [name]’s just sat there like, I don’t know, she doesn’t seem as bothered.” Molly**

Participants avoided talking to their friends also. Sarah did not want people to pity her.

**“Erm, I don’t like people feeling sorry for me. Erm I can’t, you know, I like to just think about it once and then sorta move on you know ‘cause it’ll always like be there that unless I don’t have to talk about it then I try not to.” Sarah**

Nicole thought her friends provided her with normality so did not talk to them about it so that she could protect this.

**“I feel like it’s cutting in even my friends. Like that’s when I have my normal time because they don’t pester me. Erm, but I don’t know. It’s better when I’m with my friends ‘cause I don’t think about it as much” Nicole**

Avoidance as a coping strategy meant they were not addressing their distress but it allowed them to engage in activities that were not related to the difficult situation with their parent and provided them with some of their previous normality.

### *3.2. Seeking help.*

Participants did report seeking help from others when they felt they needed it. This was at the later stages of their experiences. It involved talking to people but in some cases utilising professional supports such as school.

Sarah realised that she felt better when she spoke to people.

**“Erm to start with yeah. I didn’t like talking about it ‘cause erm I sort of felt upset but then my grandma sort of helped me to realise that erm there’s not just like your dad that you can talk to, there’s always like me or my mum.” Sarah**

Jessica found it important to talk to people who had been through difficult situations themselves.

**“I: So what has really helped you?”**

**J: Well talking to other people about it and like going there for support to do and just meeting new friends with other, with bad like things in their family as well.” Jessica**

She found professional support particularly helpful although she still found it difficult to talk to people, but had a close confiding relationship in school:

**“It’s really helping but I just don’t really like to talk to people there. Like in meetings we talk about family and every time when it comes to me talking I go very quiet.”**

**Jessica**

**“Like I used to talk to this girl at school called Mrs [name] . . . erm I used, she used to asked me how’s my dad and that and I’d tell her everything about it and erm we used to just talk about it and like there wa a girl here, coming here from school about my dad and that and saying I can talk to her.” Jessica**

Charlotte utilised professional support in order to feel more skilled at managing her emotions.

**“I used to go to CAMHS do you know what that is that thing where you talk to people and like I got really really stressed and like me hair started falling out and stuff I don’t really know why but it just did and er so I kept going and erm, erm I sort of learned how to like do it all myself like.” Charlotte**

Molly found talking to her friends an important source of support.

**“She’s been there for like through everything and she’s never judged do you know what I mean. It’s nice to have mates that like listen to you and like.” Molly**

### *3.3. Feeling unsupported.*

Four of the participants described feeling unsupported by professionals or friends. Molly and Jessica felt that school did not understand what they were experiencing, or having

to do at home. Molly would have liked some regular time set aside by teachers where she could talk about what was happening in private.

**“Erm, the teachers just didn’t really help. They’d only come to me, they’d only like see me when I was upset where my friends were there every day asking me how I am every day.” Molly**

**“But school is really really really annoying ‘cause like if I’m there late it’s for good reason because I wanna see dad get out of door first and see how he’s walking.” Jessica**

Nicole felt unsupported by professionals at the hospital.

**“The doctor in there wasn’t very like helpful. He just came out with it and then he was like looking at me and not even saying like “are you ok?” or nothing or sorry.” Nicole**

Three of the participants felt unsupported by friends. Jessica thought her closest friend no longer saw her because of what had happened.

**“Because like [name] in’t the same, like she dun’t come around anymore and that ‘cause of it happening but normally when my dad wan’t like this she used to come round loads of times but I think she just dun’t want to see him the way he is.” Jessica**

Molly described pushing friends away because of her difficulty coping. Charlotte was unable to spend as much time with them so could no longer access their support as easily.

#### *3.4. Acceptance.*

There were varying levels of acceptance of the changes amongst the participants. Molly felt that as she had got older she had accepted her father was not coming home but it was still difficult for her.

**“Now that I’ve got older I understand but it’s more upsetting. It’s never gonna be how it used to be.” Molly**

Seeing her father was a constant reminder of the changes. Jessica was beginning to realise that things would not return to the way they were previously.

**“Mum said it’s gonna get all better soon, but it won’t.” Jessica**

There was a sense that she felt helpless in this situation but had accepted that she could not change it. Nicole, however, was not at a stage of acceptance, still hoping that things would return to normal.

**“I just try to convince myself that everything is going to be better and that she will be back to normal and that she’ll be home soon.” Nicole**

She was interviewed the closest to her mother’s injury so this may explain her lack of acceptance at that stage.

### *3.5. Feeling grateful.*

Participants initially feared their parent dying. When their parent did not die they felt they should be grateful that things were not worse. Despite this there was an increased awareness of their parent’s mortality. There was a sense that this could not distress them because things could have been worse.

Charlotte, Nicole and Molly described the initial distress and fear that their parent would die.

**“Yeah ‘cause I didn’t think she were gonna survive ‘cause no one else did.” Charlotte**

**“I just like fell to the floor ‘cause obviously you hear brain and right away you think she’s going to die.” Nicole**

**“‘Cause I jumped and thought that’s it my dad’s do you know gonna pass away and he never.” Molly**

Molly and Jessica still thought about their fathers dying.

**“If he passed away, touch wood that he doesn’t, I don’t think I’d look at the future.”**

**Molly**

**“When he passes away I’m gonna be like really really upset and my life will proper fall apart like proper badly.” Jessica**

However, these fears were minimised because there was a need to feel grateful that things were not worse. Molly discussed the positive aspects of her father’s heart attack.

**“I cried at that ‘cause it just reminded me of my dad ‘cause my dad was lucky. He’d just got out the van going to [place] but he’s forgot his little disc thing to get through so he’s come back to the yard, got out and had a heart attack. I’m glad he didn’t have it when he was driving ‘cause I would have lost him.” Molly**

Sarah described a similar feeling of gratitude.

**“But when he went into like the rehab centre and you saw all the other people you’d think how lucky you are to have a dad that can still walk and talk and do everything else that a normal person can.” Sarah**

Seeing other people with ABIs allowed her to see that not only did her father not die but also the injury could have been worse. She used this thought to cope when she was feeling upset about what was happening.

## DISCUSSION

This study aimed to examine adolescents' experiences of loss after parental ABI and the sense they make of these experiences. These two processes were not distinct, and throughout, participants described the process of sense making as being part of the experience and as such they will be presented together below. Loss was a dominant emerging theme for the participants. The interview aimed to elicit change in order to investigate loss. There were descriptions of multiple losses including loss of a parent and their role, in addition to the adolescent's role as a child in the family. One important finding was that there was a degree of resilience within these adolescents, who positively reframed a number of aspects of the losses. In addition to these losses, the participants described feelings of distress including feelings of helplessness, hopelessness, isolation and annoyance. Coping was another dominant theme with strategies such as avoidance and help seeking, from professionals as well as family and friends, being utilised.

### Loss

Each of the participants described a loss of their role as a child within the family unit. They all took on some parental responsibility, which included caring for the parent with ABI, providing support to the other parent and taking more responsibility for their siblings. The literature describes this process as Parentification. There are multiple definitions of this but the most commonly used is that of Boszormenyi-Nagy and Sparks (1973) who describe it as the expectation that the child will fill a parental role within the family. Girls are more likely to take on a parentified role than boys (Herer & Ofra, 2000; Peris et al, 2008). There was a sense of obligation amongst the participants with regards caring for the parent with ABI. They took on instrumental tasks, such as brushing their hair, ensuring they got to where they needed to be, and ensuring their safety. Additionally they provided emotional support by reassuring them and altering their behaviour to reduce stress for the parent. A number of participants described no longer sharing their feelings with the parent, and made sense of this as not wanting to burden them. Instrumental parentification is a less stressful role than emotional parentification (Hooper, 2007) and can have a positive effect on the family, stabilising them in a time of high stress (Moreno-Lopez, Holtum & Oddy, 2011). Tubbs and Boss (2000) confirmed the frequency of this process in the children of people with ABI but highlighted it as a stage of denial in their complicated grief



process. Indeed, the participants described a willingness to assume this role and minimised its impact because they knew their parent would have done these tasks for them. However, there was some acknowledgement that this was what is expected of a parent, not a child, and at times they described feeling resentful about their new role because they wanted to be cared for.

However, the parentified child can adapt well to this change in role and feel empowered by their new role (Bying-Hall, 2008). The participants did describe a new sense of maturity and pride from assisting their family. However, it has been argued that children need to be supported by the other parent in order to show this kind of resilience (Boszormenyi-Nagy & Sparks, 1973; Bying-Hall, 2008; Hurd, 2002; Maitz & Sachs, 1995; Thatsum et al, 2008). There were mixed feelings with regards the support they had received from the uninjured parent. A number of participants described it as a reversal of this role, providing the parent with additional support. Again, this involved both instrumental and emotional tasks. They viewed this role with warmth, all describing having a closer relationship with their uninjured parent. They may have observed their parent with a 'halo' effect, feeling that they were doing well in spite of all the difficulties. They may become the uninjured parent's ally, feeling grown up and assuming the partner role previously occupied by the other parent (Earley & Cushway, 2002). The participants' reluctance to leave home may have been associated with this. Harris and Stuart (2006) reported participants felt guilty about leaving the uninjured parent alone to care for the parent with ABI. This support must be monitored, however, because the child drawn into supporting the uninjured parent may view the other parent with increasing negativity due to the strain they are putting on the 'stressed' parent (Florin & Katz, 1991; Peris et al, 2008; Uysal et al, 1998). Despite the positive feelings discussed, there were descriptions of feeling unsupported and increased arguing with the uninjured parent, which led to feelings of loneliness and isolation. In accordance with Pessar et al (1993) Jessica particularly described less positive parenting from her mother. It may be that in order for these individuals to feel properly supported in their parentified role they need to look for support outside the immediate family unit.

Participants who had younger siblings described closer relationships with their siblings. Older siblings are more likely to take on parentified roles than younger siblings (Herer & Ofra, 2000; Tucker, McHale & Crouter, 2001; Voorpostel et al, 2007). When there is an absence or reduction in parental support it is common for sibling relationships to

be strengthened (Bank & Kahn, 1982; Jacobs & Sillars, 2012; Milevsky, 2005). Participants described pride in providing instrumental and emotional support to their siblings. They gave advice but also modelled what they perceived as appropriate behaviours. This role reduces stress for younger siblings but may result in increased stress for older siblings (Jacobs & Sillars, 2012). Sarah and Charlotte described feeling closer to their sisters but Molly reported increased stress in her sibling relationship because she did not understand her sister but she felt responsible for her. Jacobs and Sillars (2012) reported that this role is important for younger siblings because it promotes cognitive reappraisal with the older sibling, suggesting alternative ways of viewing things. It provided participants with a sense of self-worth, that they had done something good both for their sibling and the uninjured parent. It is interesting however, that the younger siblings did not describe a better relationship with their siblings. There are a number of possible explanations for this. Bying-Hall (2008) reported that the process of parentification should be managed carefully as without the support of a parent the younger children may become resentful of the 'bossy' older sibling. It may be that Nicole and Jessica felt resentful of this change in role. Alternatively people who described difficult previous relationships with their siblings experienced increased anxiety as a result of increased sibling contact rather than supported (East & Rook, 1992). Nicole and Jessica's previous relationships may have been characterised as difficult and conflict continued. Nicole described arguing with her sister and having a previous alliance with her mother. Jessica too described a difficult relationship with her siblings prior to her father's assault.

One aspect of this loss of child role was prioritising others within the family. All participants had to make changes that involved giving up their own plans. Boszormenyi-Nagy & Sparks (1973) argued that while this is an important process for adolescents, it should not cause excessive burden on the child. When the child's own needs are not met due to the needs of the parent and other family members they learn to suppress their own feelings and to prioritise others (Romano, 1976). They learn to anticipate the needs of others as a way of being accepted and may become adults who believe that their own feelings are not as important as others (Winnicott, 1965, cited by DiCaccavo, 2006). There was a sense of guilt for desiring things for themselves, whether it was support or time for themselves. Charlotte described worrying about what others would think if she prioritised herself. She wanted to be seen as the 'good' child who loved her mother and as a result sacrificed her own desire to be a child. Similarly Nicole did not want people to see her

upset so she avoided talking about her feelings, to assume this role of the mature child who was looking after everyone. This may also explain Sarah's reluctance to engage in the negative consequences of her father's ABI. She frequently talked about not wanting her father to feel guilty and therefore not asking for things she desired. This would have resulted in her being viewed positively within the family and perhaps even praised for coping so well. Thus reinforcing the perception that they must care for others.

Earley and Cushway (2002) highlighted the role Erikson's stage theory of psychosocial ego development (1959) may play in the parentification of these adolescents. They highlighted the importance of children passing through each stage of development, including initiative versus guilt and industry versus inferiority. If the adolescent cannot master the demands placed upon them they may end up feeling inferior and guilty and as a result inadequate. Thus they may attempt to maintain this role to appear competent and helpful. This is supported by the avoidant coping strategies described by each of the participants. They did not want to burden other people with their emotions but the result was feeling isolated. Thatsum et al (2008) reported that children who reported parentification expressed that they did not want to talk about their feelings. Whilst this is considered initially positive and part of normal development, if too much burden is placed on the child who cannot master the tasks, they may be left with internalising problems (Earley & Cushway, 2006; Harris & Stuart, 2006).

Each of the participants described a loss of the parent with ABI. They all experienced the parent as different. Jessica, Nicole and Molly described particular distress with regards these changes. It was difficult to come to terms with the fact the parent looked the same but acted differently. This is supported by the literature, which indicates that cognitive changes are often the most difficult for families to cope with (Ergh et al, 2002). These changes were particularly difficult to make sense of because the parent looked the same. However, it was generally not the behaviours themselves that were distressing but the loss of who the parent used to be. This provides further evidence for the theory of ambiguous loss (Boss, 1999), where the individual is physically present but psychologically absent. Molly described her father as a complete stranger at times. Participants were continually reminded of these changes by the presence of the parent and the additional support they had to provide. Molly found these changes so distressing she reduced the

frequency of visiting her father, in some ways rejecting the 'new version' of him. Four of the participants described ruminating on how the parent used to be.

There were changes in the relationship between the parent with ABI and the adolescent. Four of the participants described experiencing their parent as showing less emotional warmth. They described feeling ignored and that their parent no longer cared about how they felt. This supports Pessar et al's (1993) finding that families report a deterioration in the relationship between the parent with ABI and the child. In addition to actual changes in warmth the parentification of the child may play a role. Earley and Cushway (2006) reported that parentified children often describe a lack of closeness and warmth with their parents as a result of their change in role. Whilst there was a sense that they knew changes in the relationship were connected to the ABI, it appeared that they felt somewhat rejected by the parent. This feeling was supported by the changes in the reciprocity of the relationship. Three of the participants felt their parent no longer initiated conversation with them, resulting in the adolescent having to control interactions. This stemmed feelings of rejection and avoidance of these interactions. The relationship was further affected by loss of time spent together. The adolescent felt the parent could not or did not want to spend time with them, which left them feeling isolated.

The loss of the parent resulted in a loss of emotional support from the parent with ABI, the uninjured parent and the family as a whole. As previously reported participants suppressed their own feelings so they did not burden their already stressed parent but they described similar experiences with the family as a whole. Whilst three participants stated they felt closer to their family, two of those same individuals also said they felt more distant from them. Charlotte was previously supported emotionally by her mother; without this, she relied on extended family members for support, which made her feel closer to them. However, she experienced feeling out of place being tearful in front of her family and felt obligated to change or suppress her own emotional reaction. She thought this was strange but understood the suppression of emotion as generationally appropriate and adapted her response to please her family. As a result she did not have an appropriate emotional support. Jessica described her father as the lynchpin of her family. Whilst she cared more for her family and felt closer to them, she felt they had fallen apart without her father. This left her feeling isolated and that no one understood her. It is important for psychological

wellbeing that individuals feel supported after a trauma such as this (Ribbens McCarthy, 2007).

Three participants described a loss of security as a result of their parent's ABI. In accordance with Butera-Prinzi and Perlesz's (2004) study, Molly and Jessica described changes in their financial situation. There was some evidence that there were difficulties prior to their fathers' ABIs but that this had either worsened or was more evident to them now because they were expected to assist. Charlotte described this loss of security differently, as her mother becoming an inpatient had resulted in her no longer feeling she had a home because she had been forced to live with relatives. Whilst she was grateful for their support, there was a sense that this had left her feeling even less supported and more out of place. The parent no longer being perceived as 'safe' further compounded this loss of security. They could not be trusted to be left alone and had to be watched. They were almost viewed as dangerous by participants no longer trusted to provide the support a well-adjusted child expects from their parent.

#### Distress

Each participant described feelings of distress in response to their parent's ABI. This included feelings of hopelessness, isolation, helplessness and annoyance. These feelings are often associated with grief after bereavement (Christ, Siegel & Christ, 2002). Whilst the feelings of hopelessness were described most intensely at the initial acute phase of their parent's injury, they were still ongoing at the time of interview. When considering this in relation to ambiguous loss this is not surprising. Boss (1999) proposed that when an individual experiences ambiguous loss the grief process is ongoing because they are constantly reminded of the changes in their loved one. This was evident in the participants, particularly Molly who found it too distressing to see the changes more frequently than once a week. Adolescent grief processes should be considered differently from adults who experience a sustained period of these emotions then move on. Adolescents typically experience these emotions for a much briefer length of time, returning to relative normality quickly but returning to the feelings of distress regularly throughout their development (Christ, Siegel & Christ, 2002; Ribbens McCarthy, 2007). At times, rather than accept the loss of their previous parent, adolescents may become overly attached to the memory of their parent previously, idealising them and preventing the adolescent from coming to terms

with the finality of the situation (Harris, 1991). This is perhaps magnified in this sample who do not share the finality of a child whose parent dies; they continue to have hope that things can return to the way they were previously and thus maintain this attachment to the previous parent. This was evident particularly with Molly and Jessica. Molly started taking her father's belongings to bed to feel close to him and the way he was prior to his ABI. Jessica ruminated on and idealised the way her father was before, telling numerous stories about the positive times they had spent together despite obvious difficulties within the family. Age and time post-injury did not appear to play a role in diminishing these feelings as Molly was amongst the oldest in the group and was the longest post-injury.

The apparent parentification of a number of the adolescents may have also played a role in these apparent feelings of distress. There is evidence to suggest that parentified adolescents experience higher levels of depression than their non-caring counterparts (Williams & Francis, 2010). These individuals can often feel isolated although it is unclear if this is directly associated with parentification or the experience as a whole (Bying-Hall, 2008; Harris & Stuart, 2006; Moreno-Lopez et al, 2011). At times of increased stress adolescents highlight the importance of peers as companionship is considered a key support (Jacobs & Sillars, 2012; Maybery et al, 2005). However, in this sample a number of participants described a loss of peer support. They felt that their friends would not understand their situation and did not want to be pitied. Additionally they had less time to spend with friends due to increased responsibilities within the family. This contributed heavily to the feelings of isolation described. Molly described the importance of being able to speak to her friends and not feel judged by them. These adolescents are at a time in their lives where friendships are much less stable and low levels of support may go unnoticed, so maintaining friendships should be particularly encouraged in order for them to receive peer support from outside the home (Maybery et al, 2005; Moreno-Lopez, 2011; Scholte, van Lieschout, & van Aken, 2001).

The Family Experiential Model of Recovery (FEM) was designed as a clinical tool to help families understand their experiences in response to ABI within the family (Klonoff & Koberstein, 2010). It depicts the whole rehabilitation and recovery process. This model provides a visual representation at different stages and provides an excellent depiction of the experiences of distress shown by the participants. It frames experiences as falling in the 'coping zone' of expected behaviour and the 'warning zone', which is an indication of

difficulties within the family. The initial feelings of hopelessness and questioning why this had happened to them described by each of the participants were viewed as normal coping behaviours. Family members are then expected to move into the early stages of adjustment where they facilitate the needs of their loved one and sacrifice their own personal needs. This again was experienced by each of the participants although at times they moved back and forth from the warning zone where they felt overwhelmed and avoidant.

Klonoff and Koberstein (2010) propose that the next stage is that of seeking help as the reality of the situation becomes clear. Whilst the participants were aware of the benefits of seeking help they fell into the warning zone of avoiding this and ultimately feeling reluctant and hopeless. The fourth stage was that of awareness where the individual begins to accept the uncertainty of the future. None of the participants appeared to be coping at this stage of the process. They displayed denial about the future and were left feeling alone and helpless. Even Molly, who stated that she accepted that her father was never coming home, still expressed high levels of distress at this possibility. It is clear that time post injury does not impact on the stage of recovery. Sarah reported low levels of distress but was tearful throughout the interview. She may have been experiencing denial at this awareness stage of the model. The next stages are acceptance, realism and future. Whilst some participants were taking tentative steps towards acceptance, it was clear that they were not completely at these stages. The FEM provides a good clinical framework for illustrating the stages at which individual family members are at in the experience and appears to fit the story of these participants experience well. However, it further highlights the difficulties the participants were still experiencing.

### Coping

Coping emerged as a dominant theme for the participants. Coping is traditionally conceptualised as problem-focused or emotion-focused. Problem-focused coping involves the individual acting on the source of the stress to reduce or change it. Parentification was a good example of a problem-focused coping strategy because it allowed the adolescents to engage in instrumental tasks that reduced stress within the home. When employing emotion-focused coping strategies the individual attempted to regulate their emotional stress (Compas, Malcarne & Fondacaro, 1988). The use of emotion-focused coping is thought to increase with age with problem-focused coping being predominant during early adolescence

(Thatsum et al, 2008). The participants all described a number of problem-focused coping strategies.

In light of the limited research available on the coping strategies of children with parents with ABI, the literature on young carers can be utilised. These adolescents report similar experiences of parentification with 81% reporting worries about the health of the person they are caring for (Cree, 2003). Kartalova-O'Doherty and Doherty (2008) reported three types of coping strategies utilised by young carers. The first was "active behavioural" where the individuals sought help, were open about their parents' illness and took control. The second was "active cognitive" where they accepted their caring role as a family duty, thought positively about the situation and coped on a day by day basis. The final strategy was "avoidant" where the adolescent avoided discussions about their parents' illness, denied what was happening and spent as much time away from the home as possible. The avoidant and behavioural strategies were most likely to help the individuals in the short term. There was evidence of similar approaches in the participants in this study.

All five participants described avoidance as an important problem-focused coping strategy. Thinking about what was happening was overwhelming and distressing, so participants used distractions. Avoidance did not entirely remove their distress but it reduced it considerably. Thatsum et al (2008) found that adolescent use of distraction could be adaptive and in this sample it allowed them to get back to their everyday lives. Harris and Stuart (2006) reported high frequencies of avoidance also. Finding some normality within a stressful situation was important to the participants. This is echoed in the literature on young carers who reported that spending as much time as possible away from the family home was an important method of reducing stress (Earley, Cushway & Cassidy, 2007; Kartalova O'Doherty & Doherty, 2008). Moreno-Lopez et al (2011) highlighted the role friends play in providing a space for individuals to feel as though things had not changed. This may contribute to explaining why a number of the participants reported not talking to friends about the difficulties at home. In a number of ways this avoidance was a protective factor for the participants. It allowed them to go to school, to have positive times with friends and reduced some of the feelings of distress. However, Ribbens McCarthy (2007) warned that this could result in their overwhelming feelings not being acknowledged and them feeling like they do not have appropriate places to share them. Indeed a number of participants did report feeling isolated and not understood. Their distress may go unnoticed



and unaddressed. This may have been the case with Sarah, who reported only positive reactions during the interview, but cried throughout, clearly distressed but unable or unwilling to discuss this distress. There was also a sense that she felt she could not be upset because her father would not want that, and she did not want to burden him further. Thus she may have felt she had to suppress her feelings to protect him.

Each of the participants described seeking help in some form. The most commonly utilised source of support was friends. This is commonly cited in the literature as a key support (Moreno-Lopez et al, 2011, Thatsum et al, 2008). Molly highlighted this as an opportunity for emotion-focused coping where she could talk about how she was feeling. She thought this was because she would not be judged. There was a sense that it was less burdening to friends than family. She was the only participant to comment on sharing her feelings with friends. This may have been due to her age and stage of development in comparison to the other participants. However, Sarah did report talking to her family after some time. She was encouraged to do so and learned that this was acceptable with certain individuals. She avoided sharing with friends because she did not want them to pity her. There was a sense that a number of them thought talking would be helpful but that it would be too difficult. Schotle et al. (2001) reported low levels of support from friends were associated with adjustment problems and low level peer support may go unnoticed. This is of concern as three participants reported a loss of friendships. Two of them positively reframed this as an opportunity to learn whom they could trust. However, Jessica reported high levels of distress due to the change in her relationships. She blamed the breakdown on her friend's avoidance of her father, which resulted in her trying to persuade them he was 'back to normal,' which she did not believe herself. In addition to the distress caused, this removed an emotion-focused source of support for her.

There were varying reports of the participants' experience of professional support. Jessica stated that school had been supportive initially. She was provided with a designated person to speak to at school, which she found helpful. However, as she progressed through school this person did not move with her and she thought she did not have anyone to talk to. She blamed school for not understanding that her difficulties continued and not maintaining this support. Similarly Molly thought she was not provided with enough support by school because they did not understand what was happening. There was a sense that school could have done more. This was of concern as it has been suggested that teachers can provide an

important source of support (Moreno-Lopez et al., 2011). Other professional support included counselling, previous contact with mental health services and a group for carers. The latter two supports were rated positively. It gave them the skills to cope independently but also provided them with an opportunity to meet others with similar problems. This left them feeling less isolated. Counselling was not popular amongst participants. It may be that this was viewed as emotion-focused coping, which was just too overwhelming for participants to actively engage in. Molly reported not wanting to talk to a stranger but she would talk to friends. It could be hypothesised that professional support would have exposed the difficulties she was experiencing and that this would have burdened her mother further. In contrast talking to friends can be done with relative privacy.

Feeling grateful was an emotion-focused coping mechanism for the participants. They initially experienced high levels of distress at their parent's injury because they feared they would die. Following their survival they were more aware of their parent's mortality but coped with this by feeling grateful that it was not worse; they could have died or been physically disabled. This understanding allowed them to focus on the positive aspects of their parent's injury and provide some relief. This feeling of gratefulness is dominant in the ambiguous loss literature. In contrast to participants' positive meaning making, Osborne and Coyle (2002) reported that this makes it more difficult to admit to feeling a sense of loss and to therefore address this loss. There was a sense of duty underpinning the feelings of gratefulness; that the adolescents thought they ought to feel positive about the situation because their parent was still alive. This may have created an internal conflict for the adolescents who wanted to grieve the loss of their former parent but felt guilty if they were not seen to be grateful that things were not worse. This may have been the case for Sarah. However, perhaps this should not be pathologised in her. She reported this as a positive way of coping; she was doing well at school and reported no concerns.

The participants reported varying levels of acceptance. Molly, the furthest post-injury, reported accepting that her father was not going to come home. This was a difficult process for her but she thought she had had to do this to reduce her own distress. This may have reduced her feelings of guilt about not supporting her father more and visiting him more regularly. However, acceptance had allowed her to grow up and view her future more positively. Nicole seemed to have particular difficulty accepting the changes in her mother. She held a strong sense of hope that she would return to normal. Kean (2010) reported that

hope was important in better outcomes in individuals with ABI. In order to maintain this, families need to remain positive around them. Accepting that her mother would not return to normal would have caused high levels of distress for Nicole and perhaps reduced her ability to support her mother. However, continued unrealistic hope would inhibit her from grieving for the loss of the mother she knew and coming to terms with her as a changed person (Dupuis, 2002). At the initial stages acceptance does not play a key role in the family recovery (Klonoff & Koberstein, 2010). However, this should be monitored as the parent's recovery progresses.

### Clinical Implications

There were a variety of experiences amongst the participants. The individuality of every ABI, every family and every family member means that every adolescent has a unique experience. It is important to note that there can be no rigid formulation that allows us to predict how they will respond. Families require thorough assessment and flexibility from professional services. Adolescents need to be directly included in this assessment where possible, as parents may not be aware of their current needs. Whilst individuals experience multiple losses, they also report a number of positives and resilience in a time of high stress. These positives should be encouraged.

All participants reported distress in relation to their current situation. They felt unable or unwilling to share this distress with others for fear of burdening their already stressed family. This may result in parents being unaware of the difficulties their child is experiencing. They had less opportunity to spend time with friends and as such lost an important source of support. They also avoided the overwhelming nature of their distress in an attempt to return to normality. This avoidance was adaptive to some extent and they should be encouraged to have positive time independent of the family. The adolescent grief process should be viewed differently to the grief process as experienced by adults, and tailored, age-appropriate support should be provided when needed as they may not feel able to disclose distress until later stages of their parent's recovery. As such, they should be approached at stages after initial assessment of the patient and family, as part of the rehabilitation support provided to the family as a whole. Assessments are often carried out while the adolescents are at school, which prevents their involvement in the process. There must be a degree of flexibility in services to ensure their involvement. Support can be

offered by clinical psychology services within rehabilitation services as they have existing knowledge about the family set-up. Where there are concerns about adolescents, referrals to Child and Adolescent Mental Health Services should be facilitated by the rehabilitation services in order to provide specialist intervention and best meet their needs.

However, as participants did not highly rate direct engagement with professional services, an important role for clinicians may be the coordination of informal support systems. Families should be assisted in encouraging the maintenance of time spent with friends. This provides distraction where necessary but also an opportunity to talk. Sibling support was viewed positively and this should be encouraged where relationships were previously stable. School can play an important role in support, but this should be managed in collaboration with the child. Teachers would benefit from education regarding the ABI and the ongoing impact of this, highlighting that the child may continue to require support some time post injury. This should be consistent, as the adolescent has to adapt to other change in school such as change of year. It may be best offered by school-based counsellors through the Targeted Mental Health in Schools Project (Department for Children, Schools and Families, 2008) as they can be supported within their own environment by people who know them. This may increase the likelihood of the adolescent engaging.

A number of participants described feeling isolated as a result of their parent's injury. They felt others did not understand them and they could not identify with others. They may benefit from the opportunity to meet others who have gone through similar experiences. This may be in the form of a group. Alternatively they would benefit from access to a resource giving examples of the experiences of others. This would reduce feelings of isolation and may encourage them to discuss their distress.

The process of parentification of adolescents within the families should be monitored. A degree of increased responsibility was considered valuable as it provided an opportunity for problem-focused coping and gave them pride. However, the level of support they are providing and the resentment caused by the loss of their own child role could be unnoticed within the family. This change in role should not be at the expense of the adolescent's relationships within the family, which can be negatively affected as a result of parentification. Standardised assessment of parentification should be carried out where there is evidence of some role reversal in the family. This is vital as the overly parentified

child can present with depression and relationship difficulties in adulthood, which leads to further accessing of services. Input at this stage may serve to prevent further input in adulthood. Services would benefit from increased links with young carer organisations, which would allow the adolescents to meet people in similar circumstances but also learn appropriate ways of managing their responsibilities.

### Strengths and Limitations

In order to consider the implications of this study the strengths and limitations should be considered. One of the major strengths was that adolescents had the opportunity to share their experiences independent of their family. They were able to give a voice to their experiences and reported that it was important to them to be able to help others in similar situations. By conducting the interviews privately without family members present, they were able to discuss a number of issues that they have felt unable to share in the presence of their family. This was further facilitated by allowing them to choose the location of the interviews to ensure privacy. This discussion highlighted this to the parent also, further increasing the provision of privacy. Whilst the study aimed to look at loss, and this was a major theme identified, the nature of the interview elicited their perceptions of change and produced a number of positive outcomes from a high stress situation. This indicated that adolescents have the ability to be resilient in potentially traumatic situations.

The nature of IPA facilitated the production of rich, detailed interviews that provided an insight into the variety of experiences of adolescents with a parent with ABI, an area that continues to be under-researched. These experiences were unique to the individuals and as such cannot be generalised to larger populations. However, they can provide professionals with some insight, and highlight issues to be considered when working with these families. Willig (2001) questioned the ability of individuals to convey the nuances of their experience accurately. This might have been particularly difficult with the sample of adolescents who may have had relatively restricted emotional language. Indeed a number of them did appear to have difficulties expressing themselves, frequently saying, "I don't know" or stating that they did not know how to describe the experience. Emotional issues may have impeded the clear expression of their experiences. This was particularly evident where participants described only positive changes but displayed distress non-verbally by becoming tearful throughout the interview. This is likely to have

impacted on the analysis as it was focused on the verbal aspects of the interview and not the non-verbal cues. In an attempt to overcome some of these difficulties information about the experience of the interview was included in the detailed pen portraits and observations were incorporated where appropriate throughout the explanations of the themes.

The participants may have found it difficult to speak to a stranger. I was an unfamiliar, professional adult linked to health services asking them to express themselves openly about a difficult experience. Molly commented that she had not utilised professional health service support because she did not like the idea of talking to a stranger yet this was what she was asked to do as part of the interview process. This may have impacted on their ability to provide an open narrative about their experience. Some of the interviews were relatively short in comparison to others. Lack of rapport may have impacted on their ability to share. However, this was not obvious during the process. These factors may have impacted on the richness of the interviews and therefore the analysis process. Positive as well as negative experiences were reported, which suggests that the adolescents felt comfortable with the process.

One of the criticisms of IPA is that there are no formal guidelines for the incorporation of research reflexivity and the researchers beliefs into the research (Willig, 2001). There are no explicit guidelines as to how this may affect the analysis. This is particularly relevant in this case given my previous experiences. However, Smith argues that IPA should be used as guidance and not as a rigid step-by-step tool for analysis. Throughout the study and the analysis I have paid attention to my experiences, keeping a research log and using a number of quality control measures to ensure that the themes are reflective of the transcripts.

One of the major limitations with this study is the diversity of the sample. There were no male participants. As the literature suggests there may be gender differences in experiences and it would have been beneficial to capture these. It may be that the nature of the study, encouraging the participants to talk about their experiences, appeals less to male adolescents than females. There is evidence to suggest females are more likely to verbalise their emotional response than males (Schulman, 1993). Additionally, all the participants were white girls, which further reduced the diversity of the sample. The middle age range of adolescence, 15 and 16 year olds, was not included. This may be coincidental; however, for

future studies facilitating the inclusion of these people would be beneficial. This would be particularly useful as at this age adolescents are experiencing increasing demands at school with formal examinations and this may impact on their experiences. Finally each of the participants described their parents having cognitive problems rather than physical impairment following their ABI. Cognitive changes have been highlighted as particularly difficult for families to cope with and as such adolescents of parents with physical difficulties may have had different experiences. Whilst there was a lack of diversity in the sample, this allowed for a degree of homogeneity, which perhaps explains the degree of continuity in the themes identified.

The identification process for participants should be considered also. In order to find people who were willing to consent I think staff may have identified people who either had very positive experiences with BIRT and thus would be keen to help or those whose family members were concerned about. This may have led to a selection bias in the participants included. Families who were not engaging positively with services were potentially not approached because it was not thought they would agree or they could not be contacted. This may have resulted in a potentially vulnerable group being excluded.

### Personal Reflections

The process of this thesis has given me a number of opportunities to reflect on my experience of having a father with ABI. I was 13 when he was hit by a car while riding a bicycle. His severe head injury resulted in him being in hospital for a prolonged period. My mother had to spend long periods of time with him in hospital so my younger sisters and I were cared for by both sets of grandparents. We eventually moved areas to be closer to family support and my father returned to our family home with 24-hour care until he died approximately five years ago. I chose to include my school essay in the introduction because it allowed me to have a direct comparison of my experience with those of the participants. There are clear descriptions of distress and a sense of loss throughout. I also reported experiencing my father as a different person much like a number of the participants. My father could not communicate and I think this was how I experienced him differently. Throughout the interviews I wondered how I would have responded to changes in his personality. I think I would have found this more difficult because for me there was always a sense that my dad was still in there, he just could not get out. I remained hopeful

about things returning to the way they had been previously even six months post injury. Despite the distress there was a sense that I was trying to identify positives such as the improvements my father was making. There were a number of similarities between our experiences and quality control was an important aspect of this to ensure that I was not merely representing my own experiences. I was pleased it was evidenced in the literature to provide further credibility to the research.

In retrospect I did identify with some of the participants more than others. I was surprised by how difficult I had found my first interview with Charlotte. I realised we were the same age, the oldest in the family and had similar coping strategies. She did not want other people to know she was finding it difficult because she wanted people to think she was strong. I remember feeling similarly and I think my awareness of the importance of this perception to me may have stopped me probing this more. Whilst I was prepared how to respond, I was surprised that each participant had become tearful. I think this was because I had learned to talk about my father without becoming tearful. This was the first time I questioned my coping strategy at the time.

I found the parentification literature particularly interesting, particularly given the prevalence of parentified children who enter into the clinical psychology profession (Nikcevic, Kramdisova-Advani & Spada, 2007). I chose this research due to my own interests. I remember I was not offered professional support and in retrospect I thought this seemed odd. I do not think I would have accepted support if it had been offered but it made me question if the children of people with an ABI were forgotten. I remembered my sister being offered an appointment with a “nice lady” who took her for ice cream. I later discovered this was a clinical psychologist within the service. My sister was another reason I was interested. Our family often talked about her being a ‘daddy’s girl’ and how my fathers’ ABI had impacted on her the most, yet she had just one contact with services.

The process of doing the research was harder than I had anticipated. I found it difficult as a clinician to interview adolescents who demonstrated high levels of distress and feel unable to work therapeutically with them to attempt to reduce it. When they described their isolation and people not understanding I wanted to tell them about my experiences but did not want to over-step my boundaries as a researcher. Keeping a diary of these experiences and discussing these issues in supervision were key processes for me. Despite



these difficulties I was invested in the research and am honoured to be able to contribute to this growing area of literature and important aspect of services.

### Conclusion

This study aimed to provide a rich, in-depth analysis of the experiences of adolescents who have a parent with an ABI. These individuals remain relatively under-researched. Participants described a change in role within the family. They assumed more parental responsibility in all the relationships within the family unit. Whilst they reported pride and feeling more grown up due to this change, there was also a sense that they had lost a number of valued child roles. The literature suggests these role changes can have long-term implications into adulthood. They described loss of both parents but particularly the emotional support of the parent with an ABI. As a result of these losses they experienced high levels of distress that included feelings of isolation and hopelessness. Research suggests that this is particularly distressing because of the uncertainty of their situation. They have lost the 'previous' parent and are left with a 'new' parent for which they feel they should be grateful. The nature of their coping strategies suggested that these feelings could go relatively unnoticed by professionals and family members. They avoided how they felt about their parent as a protective coping strategy. They sought normality with their friends and found this by not sharing how they were feeling. Additionally they feared burdening the already stressed family. Whilst many describe this positively, they reported feeling better when they verbalised their distress and shared it with others.

It is clear that adolescents experience multiple losses but they often choose not to share these or the distress associated with them. Whilst this study cannot provide a definitive list of risk factors within this group, it serves to highlight the potential needs of this group in a time of high stress. Future research would benefit from the inclusion of male participants to investigate if there are gender differences in experiences. Further research is required within this population in order to evidence the creation of services that can meet the needs of the entire family and not solely the person with the ABI and their partner.

## REFERENCES

- Aldridge, J. & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy* 21, 303-320
- Bank, S.P. & Kahn, M.D. (1982). *The sibling bond*. New York: Basic Books
- Beach, D.L. (1997). Family Caregiving: The Positive Impact on Adolescent Relationships. *The Gerontologist* 37(2), 233-238
- Betz, G. & Thorngren, J.M. (2006). Ambiguous Loss and the Family Grieving Process. *The Family Journal: Counselling and Therapy for Couples and Families* 14(4), 359-365
- Blieszner, R., Roberto, K.A., Wilcox, K.L., Barham, E.J. & Winston, B.L. (2007). Dimensions of Ambiguous Loss in Couples Coping with Mild Cognitive Impairment. *Family Relations* 56, 196-209
- Boss, P. (1999). *Ambiguous Loss: Learning to Live with Unresolved Grief*. London: Harvard University Press
- Boss, P. (2004). Ambiguous Loss. In: F. Wash & M. Mcgoldrick (Eds.) *Living Beyond Loss: Death in the Family* (2<sup>nd</sup> Ed.) New York: Norton, p237-246
- Boss, P. (2007). Ambiguous Loss Theory: Challenges for Scholars and Practitioners. *Family Relations* 56, 105 – 111
- Boszormenyi-Nagy, I. & Spark, G.M. (1973). *Invisible Loyalties: Reciprocity In Intergenerational Family Therapy*. New York and London: Harper & Row
- Bowlby, J. (1969). *Attachment and loss, volume 1: attachment*. London: Hogarth Press
- Bowlby, J. (1973). *Attachment and loss, volume 2: separation: anxiety and anger*. London: Hogarth Press

- Bowlby, J. (1980). *Attachment and loss, volume 3: loss: sadness and depression*. London: Hogarth Press
- Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87-108
- Butera-Prinzi, F. & Perlesz, A. (2004). Through children's eye's: children's experience of living with a parent with an acquired brain injury. *Brain Injury*, 18(1), 83 – 101
- Byng-Hall, J. (2008). The significance of children fulfilling parental roles: implications for family therapy. *Journal of Family Therapy*, 20, 147 - 162
- Carnes & Quinn (2005). Family Adaptation to Brain Injury: Coping and Psychological Distress. *Families, Systems and Health* 23(2), 186-203
- Christ, G.H., Siegel, K. & Christ, A.E. (2002). Adolescent Grief: "It Never Really Hit Me... Until It Actually Happened." *Journal of American Medical Association*, 288(10), 1269 - 1278
- Compas, B.E., Malcarne, V.L. & Fondacaro, K.M. (1988). Coping With Stressful Events in Older Children and Young Adolescents. *Journal of Consulting and Clinical Psychology*, 56(3), 405 – 411
- Cree, V.E. (2003). Worries and problems of young carers: issues for mental health. *Child and Family Social Work*, 8(4), 301 – 309
- Department for Children, Schools and Families (2008). *Targeted Mental Health in Schools Project*. Retrieved 25 July 2012 from [www.education.gov.uk/publications/standard/\\_arc\\_SOP/Page11/DCSF-0](http://www.education.gov.uk/publications/standard/_arc_SOP/Page11/DCSF-0)
- Douglas, J. M. & Spellacy, F. J. (1996). Indicators of long-term family functioning following severe traumatic brain injury in adults. *Brain Injury*, 10, 819-840

- Dupuis, S.L. (2002). Understanding Ambiguous Loss in the Context of Dementia Care. *Journal of Gerontological Social Work*, 37(2), 93-115
- East, P.L. & Rook, K.S. (1992). Compensatory Patterns of Support Among Children's Peer Relationships: A Test Using School Friends, Non-school Friends and Siblings. *Developmental Psychology*, 28(1), 163 - 172
- Earley, L., & Cushway, D. (2002). The Parentified Child. *Clinical Child Psychology and Psychiatry*, 7(2), 163 – 178
- Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of care giving: a focus group study. *Counselling Psychology Quarterly*, 20(1), 69–80.
- Elliot, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229
- Ergh, T.C., Rapport, L.J., Coleman, R.D. & Hanks, R.A. (2002) Predictors of Caregiver and Family Functioning after Traumatic Brain Injury: Social Support Moderates Caregiver Distress. *Journal of Head Trauma Rehabilitation*, 17(2), 155-174
- Erikson, E.H. (1959) *Identity and the life cycle*. New York: International Universities Press.
- Fann, J.R., Burington, B., Leonetti, A., et al (2004). Psychiatric illness following traumatic brain injury in an adult health maintenance organization population. *Archives of General Psychiatry*, 61, 53 – 61
- Florian, V. & Katz, S. (1991). The Other Victims of Traumatic Brain Injury: Consequences for Family Members. *Neuropsychology*, 5(4), 267-279
- Fossey, E., Harvey, C., McDermott, F. & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36, 717-732

- Frank, J.B. (2008). Evidence for Grief as the Major Barrier Faced by Alzheimer Caregivers: A Qualitative Analysis. *American Journal of Alzheimer's Disease and other Dementias*, 22(6), 516-527
- Freud, S. (1917). Mourning and Melancholia. *Standard Edition*, 14, 243-258
- Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report*, 8(4), 597-607
- Gouvier, W.D., Prestholdt, P.H. & Warner, M.S. (1988) A survey of common misconceptions about head injury and recovery. *Archives of Clinical Neuropsychology*, 3, 331-343
- Grazioplene, R.S., Bender, C.M. & Puskar, K.R. (2007). The impact of parental cancer on the adolescent: An analysis of literature. *Psycho-Oncology*, 16, 127-137
- Guth, M. (1989). Head injury rehabilitation: The role of the family in TBI. Houston: HDI Publishers
- Harris, E.S. (1991). Adolescent Bereavement Following the Death of a Parent: An Exploratory Study. *Child Psychiatry and Human Development*, 21(4), 267 - 281
- Harris, D. & Stuart, A.D. (2006). Adolescents' experience of a parental traumatic brain injury. *Health Sa Gesondheid*, 11(4), 46 - 56
- Headway (2012). *What happens in a TBI?* Retrieved 22 May 2012 from [www.headway.org.uk/What-happens-in-a-TBI.aspx](http://www.headway.org.uk/What-happens-in-a-TBI.aspx)
- Herer, Y. & Ofra, M. (2000). Emotional and social adjustment of adolescents who show role-reversal in the family. *Megamot*, 40(3), 413-441
- Hooper, L.M., DeCoster, J., White, N. & Voltz, M.L. (2011). Characterizing the Magnitude of the Relation Between Self-Reported Childhood Parentification and Adult

- Psychopathology: A Meta-Analysis. *Journal of Clinical Psychology*, 67(10), 1028 – 1043
- Hurd, R. C. (2002). Sibling Support Systems in Childhood after a Parent Dies. *OMEGA*, 45(4), 299 – 320
- Jacobs, K. & Sillars, A. (2012). Sibling Support During Post-Divorce Adjustment: An Idiographic Analysis of Support Forms, Functions and Relationship Types. *Journal of Family Communication*, 12, 167-187
- Jorge, R.E. (2005). Neuropsychiatric consequences of traumatic brain injury: a review of recent findings. *Current opinion in Psychiatry*, 18, 289-299
- Jorge, R. E., Robinson, R. G., Starkstein, S. E., & Arndt, S. V. (1993). Depression and anxiety following traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 5, 369 –374
- Kartalova-O’Doherty, Y. & Doherty, D.T. (2008). Coping strategies and styles of family carers of persons with enduring mental illness: a mixed methods analysis. *Scandinavian Journal of Caring*, 22(1), 19-28
- Kean, S. (2010). The experience of ambiguous loss in families of brain injured ICU patients. *Nursing in Critical Care*, 15 (2), 66-75
- Kim, E. (2002). Agitation, aggression, and disinhibition syndromes after traumatic brain injury. *Neurological Rehabilitation*, 17, 297–310
- Klonoff, P.S. & Koberstein, E. (2010). Family Life. In Klonoff, P.S. *Psychotherapy after Brain Injury*. London: The Guildford Press, 150-171
- Kolakowsky-Hayer, S.A., Miner, K.D. & Kreutzer, J.S. (2001). Long-Term Life Quality and Family Needs After Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 16(4), 374-385

- Kreutzer, J.S., Kolakowsky-Hayner, S.A., Demm, S.R. & Meade, M.A. (2002). A Structured Approach to Family Intervention After Brain Injury. *Journal of Head Trauma Rehabilitation*, 17(4), 349-367
- Kreutzer, J.S., Sander, A.M. & Fernandez, C.C. (1997). Misperceptions, Mishaps and Pitfalls in Working with Families after Traumatic Brain Injury. *Journal of Head Trauma Research*, 12(6), 63-73
- Kreutzer, J.S., Sergio, C.D. & Berquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Journal of Head Injury Trauma*, 9(3), 104-115
- Kübler-Ross, E. (1973). *On Death and Dying*. London: Routledge
- Larson, M.J., Kaufman, D.A.S., Kellison, I.L., Schmalfuss, I.M. & Perlstein, W.M. (2009). Double Jeopardy! The Additive Consequences of Negative Affect on Performance-Monitoring Decrements Following Traumatic Brain Injury. *Neuropsychology*, 23(4), 433-444
- Lezak, M. (1978). Living with the characterologically altered brain-injured patient. *Journal of Clinical Psychiatry*, 39, 592-598
- Lezak, M. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, 10, 111-123
- Livingston, M.G., Brooks, D.N. & Bond, M.R. (1985). Three months after severe head injury: psychiatric and social impact on relatives. *Journal of Neurology, Neurosurgery and Psychiatry*, 48, 870-875
- Madill, A., Jordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualise and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20
- Maitz, E. (1990). The psychosocial sequelae of a severe closed head injury and their impact upon family systems. Unpublished doctoral dissertation, Temple University

- Maitz, E. A. & Sachs, P. P. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation*, 10, 1-11
- Malia, K., Powell, G. & Torode, S. (1995). Coping and psychosocial function after brain injury. *Brain Injury*, 9(6), 607-618
- Marsh N.V., Kersel D.A., Havill J.H., Sleigh J.W. (1998). Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury*, 12, 225–238
- Maybery, D., Ling, L., Szakacs, E. & Reupert, A. (2005). Children of a parent with a mental illness: perspectives on need. *Australian e-Journal for the Advancement of Mental Health*, 4(2), 1-11
- Milam, J.E., Ritt-Olsen, A. & Unger, J.B. (2004). Posttraumatic growth among adolescents. *Journal of Adolescent Research*, 19, 192-204
- Milevsky, A. (2005). Compensatory patterns of sibling support in emerging adulthood: Variations in loneliness, self-esteem, depression and life satisfaction. *Journal of Social and Personal Relationships*, 22(6), 743-755
- Miller, F. (1996). Grief Therapy for Relatives of Persons With Serious Mental Illness. *Psychiatric Services*, 47, 633-637
- Moreno-Lopez, A., Holttum, S. & Oddy, M. (2011). A grounded theory investigation of life experience and the role of social support for adolescent offspring after parental brain injury. *Brain Injury*, 25(12), 1221-1233
- National Institute for Health and Clinical Excellence (2007). Head injury: Triage, assessment, investigation and early management of head injury in infants, children and adults. *National Clinical Guideline Number 56*. London: National Institute for Clinical Excellence



- Nikcevic, A.V., Kramolisova-Advani, J. & Spada, M.M. (2007). Early Childhood Experiences and Current Emotional Distress: What Do They Tell Us About Aspiring Psychologists? *The Journal of Psychology*, 141(1), 25-34
- Osborne, J. & Coyle, A. (2002). Can parental responses to adult children with schizophrenia be conceptualized in terms of loss and grief? A case study analysis. *Counselling Psychology Quarterly* 15(4), 307-323
- Park, E., Bell, J.D. & Baker, A.J. (2008). Traumatic Brain Injury: Can the consequences be stopped? *Canadian Medical Association Journal*, 178(9), 1163-1170
- Peris, T.S., Goeke\_Morey, M.C., Cummings, E.M. & Emery, R.E. (2008). Marital Conflict and Support Seeking by Parents in Adolescence: Empirical Support for the Parentification Construct. *Journal of Family Psychology*, 22(3), 633-642
- Perlesz, A., Kinsella, G. & Crowe, S. (1999). Impact of Traumatic Brain Injury on the Family: A Critical Review. *Rehabilitation Psychology*, 44(1), 6-35
- Pessar, L.F., Coad, M.L., Linn, R.T. & Willer, B.S. (1993). The effects of parental traumatic brain injury on the behaviour of parents and children. *Brain Injury*, 7(3), 231-240
- Rees, R. (1988). How some families cope and why some families do not. *Journal of Head Trauma Rehabilitation* 3(3), 72-77
- Ribbens McCarthy, J. (2007). “They all look as if they’re coping, but I’m not”: the relational power/lessness of ‘youth’ in responding to experiences of bereavement. *Journal of Youth Studies*, 10(3), 285 - 303
- Romano, M.D. (1976). Preparing children for parental disability. *Social Work in Health Care*, 1, 309–315

- Rosenbaum, M. & Najenson, T. (1976). Changes in life patterns and symptoms of low mood as reported by wives of severe brain injured soldiers. *Journal of Consulting and Clinical Psychology*, 44, 881-888
- Sander, A.M. & Kreutzer, J.S. (1999). A wholistic approach to family assessment after brain injury. In: Rosenthal, M., Griffith, E.R., Kreutzer, J.S. & Pentland, B. (eds.) *Rehabilitation of the Adult and Child with Traumatic Brain Injury* (3rd ed). Philadelphia: FA Davis
- Scholte, R.H.J., van Lieschout, C.F.M. & van Aken, M.A.G. (2001). Perceived Relational Support in Adolescence: Dimensions, Configurations, and Adolescent Adjustment. *Journal of Research on Adolescence*, 11(1), 71-94
- Seaton, J.D. & David, C.O. (1990). Family role in substance abuse and TBI rehabilitation. *Journal of Head Trauma Rehabilitation*, 5, 41-46
- Shabad, P. (1989). Vicissitudes of psychic loss of a physically present parent. In Dietrich, D. & Shabad, P. (Eds) *The problem of loss and mourning* (110-126). Madison: International University Press
- Shulman, S. (1993). Close relationships and coping behavior in adolescence. *Journal of Adolescence* 3, 267-283
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage
- Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In Smith, J.A. (Ed.), *Qualitative Psychology: A Practical Guide to Methods*. London: Sage
- Springer, J.A., Farmer, J.E. & Bauman, D.E. (1997). Common Misconceptions about Traumatic Brain Injury Among Family Members of Rehabilitation Patients. *Journal of Head Trauma Rehabilitation*, 12(3), 41-50

- Tateno, A., Jorge, R.E. & Robinson, R.G. (2004). Pathological laughing and crying following traumatic brain injury. *Journal of Neuropsychiatry Clinical Neuroscience*, 16, 426–434
- Teasdale, G. and B. Jennett (1974). Assessment of coma and impaired consciousness: A practical scale. *Lancet* 2(7872), 81-84
- Thatsum, M., Johansen, M.B., Gubba, L., Olsen, L.B. & Rommer, G. (2008). Coping, Social Relations and Communication: A Qualitative Exploratory Study of Children of Parents with Cancer. *Clinical Child Psychology and Psychiatry*, 13(1), 123-138
- Tubbs, C.Y. & Boss, P. (2000). An Essay for Practitioners Dealing with Ambiguous Loss. *Family Relations*, 49, 285-286
- Tucker, C. J., McHale, S.M. & Crouter, A.C. (2001). Conditions of Sibling Support in Adolescence. *Journal of Family Psychology*, 15(2), 254-271
- Urbach, J.R. & Culbert, J.P. (1991). Head-injured parents and their children: psychosocial consequences of a traumatic syndrome. *Psychosomatics*, 32, 231-240
- Uysal, S., Hibbard, M.R., Robillard, D., Pappadopulos, E. & Jaffe, M. (1998). The Effect of Traumatic Brain Injury on Parenting and Child Behaviour. *Journal of Head Trauma Rehabilitation*, 13(6), 57–71
- Vaishnavi, S., Rao, V. & Fann, J.R. (2009). Neuropsychiatric Problems after Traumatic Brain Injury: Unravelling the Silent Epidemic. *Psychosomatics* 50(3), 198-205
- Voorpostel, M., van der Lippe, T., Dykstra, P.A. & Flap, H. (2007). Similar or Different? The Importance of Similarities and Differences for Support Between Siblings. *Journal of Family Issues*, 28(8), 1026-1053
- Williams, K. & Francis, S.E. (2010). Parentification and Psychological Adjustment: Locus of Control as a Moderating Variable. *Contemporary Family Therapy*, 32, 231-237

Willig, C. (2009). *Introducing Qualitative Research in Psychology (2<sup>nd</sup> Ed.)*. New York: Open University Press

Winnicott, D.W. (1965). *The family and individual development*. New York: Basic Books

Worden, J.W. (1991). *Grief counselling and grief therapy: a handbook for the mental health practitioner*. London: Routledge

## APPENDIX 1

### Literature Review Search Strategy

Two key databases were used in the literature review: Psychinfo and Medline. Multiple search terms were used as detailed below. No date restrictions were used. Each abstract was examined for relevance. Relevant articles were included in the literature review. The references section from each relevant article was examined for further pertinent literature.

| Search Term  | No. articles identified |         |
|--|-------------------------|---------|
|  | Psychinfo               | Medline |
| Head injury/Brain Injury/Acquired Brain Injury/Traumatic Brain Injury + Parent             | 255                     | 218     |
| Head injury/Brain Injury/Acquired Brain Injury/Traumatic Brain Injury + Family Functioning | 126                     | 95      |
| Head injury/Brain Injury/Acquired Brain Injury/Traumatic Brain Injury + Consequences       | 776                     | 1070    |
| Chronic Illness + Parent   | 478                     | 285     |
| Dementia + Parent  | 157                     | 197     |
| Ambiguous Loss   | 95                      | 17      |
| Ambiguous Loss + Head injury/Brain Injury/Acquired Brain Injury/Traumatic Brain Injury     | 4                       | 1       |

## APPENDIX 2

### Participant Information Sheet

Leeds Institute of Health Sciences  
Faculty of Medicine and Health

Charles Thackrah Building  
University of Leeds  
101 Clarendon Road  
Leeds LS2 9LJ

[www.leeds.ac.uk/lihs](http://www.leeds.ac.uk/lihs)



**UNIVERSITY OF LEEDS**

Participant Information Sheet v.4

---

### **Participant Information Sheet**

#### **The experience of having a parent who has suffered a brain injury**

Please read this information sheet carefully

We are asking you to take part in a study looking at the experiences of young people whose parent has had a traumatic brain injury.

Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you. So please read this leaflet carefully. Talk about it with your family and friends if you want to.

#### **Why is the study being done?**

We are interested in how having a parent with a traumatic brain injury affects young people. People know that brain injuries can affect the whole family, not just the person who is injured. We think it is important to know about how young people feel. We hope this will help plan how to help them better in the future. The study will not involve judging you or your family in anyway.

#### **Why have I been asked to take part?**

You are being asked to take part because you have a parent who has been involved with the Brain Injury Rehabilitation Trust. This is where the research is being done. People from 13 to 18 years old are being asked to take part.

#### **Do I have to take part?**

No. It is up to you. If you want to take part you and your parent or guardian will be asked to sign a form saying you are happy to take part. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. After the interview has been done you can still decide to withdraw within one month. If you stop or do not want to take part it will not affect your parent's or your family's work with the Brain Injury Rehabilitation Trust.

#### **What will happen to me if I take part?**

You will arrange a time to meet the main researcher, Jennifer Hadden and be interviewed. Jennifer will ask you questions about what has happened since your parent's injury and how you feel. This will last from about 45 minutes to an hour and a half.

**What will I be asked to do?**

You will be asked to meet with Jennifer Hadden to be interviewed once, although with your permission she might contact you again if we need more information. We will arrange a time and place that suits you best. The interview will be recorded with an audio recorder.

**What are the possible benefits of taking part?**

Some people like taking part in research so it can help other people like them in the future. Others find talking to a researcher about their experience helpful.

**What are the possible disadvantages of taking part?**

Some of the things we talk about might be difficult. Sometimes people get upset talking about their experiences. If this happens we can stop the interview if you want. You can choose not to answer questions if you want. You will be given advice on who you can contact if you want to talk about the things that have upset you again.

**Will anyone else know I'm doing this?**

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Your parents will not be informed of what you say. We will change your name on any information we send out so people don't know it is you. If we are worried about you and think you are not safe from yourself or someone else we have to tell someone. This might involve contacting social services but we will talk to you about what we are going to do.

**What will happen to the results of the research study?**

The research will be written up and may be printed in journals or presented at conferences. People will not be able to tell the information is about you. The tape recordings will be kept locked up for 3 years and then will be destroyed, along with any other information we have about you. You can choose a different name to be used in the write up of the study. You can have a summary of the study when it is finished.

**Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the University of Leeds Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

**Jennifer Hadden, Charles Thackrah Building, 101 Clarendon Road, Leeds, LS2 9LJ  
Tel: 0113 343 2732, [umjha@leeds.ac.uk](mailto:umjha@leeds.ac.uk)**

APPENDIX 3

Participant Consent Form

Leeds Institute of Health Sciences  
Faculty of Medicine and Health

Charles Thackrah Building  
University of Leeds  
101 Clarendon Road  
Leeds LS2 9LJ



**UNIVERSITY OF LEEDS**

[www.leeds.ac.uk/lihs](http://www.leeds.ac.uk/lihs)

Participant Consent Form v.2

---

**Consent Form**

*To be completed by the participant*

Project title:

The experience of having a parent who has suffered a brain injury

Please circle if you agree with the following:

- Have you read (or had read to you) information about this project? Yes/No
- Has somebody else explained this project to you? Yes/No
- Have you asked all the questions you want? Yes/No
- What is this project about? Yes/No
  
- Do you have to take part? Yes/No
- Is it ok to stop at anytime? Yes/No
- What are some of the disadvantages of taking part? Yes/No
  
- Are you happy to take part? Yes/No
- Would you like to receive a summary of the study? Yes/No

If you do want to take part, you can sign your name below

Your name \_\_\_\_\_



Date \_\_\_\_\_

The person who explained this project to you needs to sign too:

Print Name \_\_\_\_\_

Sign \_\_\_\_\_

Date \_\_\_\_\_

APPENDIX 4

Parent/Guardian Consent Form

Faculty of Medicine and Health

Charles Thackrah Building  
University of Leeds  
101 Clarendon Road  
Leeds LS2 9LJ

[www.leeds.ac.uk/lihs](http://www.leeds.ac.uk/lihs)



UNIVERSITY OF LEEDS

Parent/Guardian Consent Form v.2

---

**Consent Form**

*To be completed by the parent*

Project title:

The experience of having a parent who has suffered a brain injury

Your child has agreed to take part in the above study. We would like your consent for them to be involved as well.

Please circle if you agree with the following:

- Have you read (or had read to you) information about this project? Yes/No
- Have somebody else explained this project to you? Yes/No
- Do you understand what this project is about? Yes/No
- Have you asked all the questions you want? Yes/No
- Have you had all your questions answered in a way that you understand? Yes/No
- Do you understand it's OK for your child to stop taking part at any time? Yes/No
- Are you happy for your child to take part? Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you are happy for your child to take part, you can sign your name below

Your name \_\_\_\_\_

Date \_\_\_\_\_

The person who explained this project to you needs to sign too:

Print Name \_\_\_\_\_

Sign \_\_\_\_\_

Date \_\_\_\_\_

Thank you for your help

## APPENDIX 5

### Interview Guide

version 2

- Thank individual for agreeing to participate
- Ask for demographic information sheet
- Explain how long it will take
- Remind them of their right to withdraw and confidentiality
- State that they do not have to answer any questions and we can stop at anytime
- Ask if there are any questions before we begin
- Start tape

**I wanted to start by doing a family tree with you. This gives me an idea of the important people in your life and also makes sure I know who you are talking about during the interview.**

**Can you tell me a bit about your life at the moment?**

*Include support, education and social activity e.g. Who is living at home at the moment? Do you go to school? Tell me about your friends?*

**What was it like for you when your parent had their accident/injury?**

*How come?*

**What's it like being in your family at the moment?**

*Ask about relationships with individual family members*

**How's that different from before?**

*Ask about relationships with individual family members*

**How have things been with Mum/Dad (injured parent) been since the injury?**

*Example prompts: Is there anything different about the way they speak to you or others? How has the ABI affected the time you spend together? Ask about thoughts and feelings*

**How have things been with Mum/Dad (uninjured parent) been since the injury?**

*Example prompts: as above. Ask about thoughts and feelings*

**Can you give me any examples of things in your life you've had to change since your parent's accident/injury? How did that feel?**

*Example prompts: has it affected your friendships? Has it affected school? How about your jobs in the house? etc. Include social relationships, education, financial situation. Find specific examples.*

**How is it going to be in the future?**

*Example prompts: did you ever think about the future before? Have the changes at home affected this?*

**What do you think might be important for other people in your position to know?**

**Is there anything we haven't talked about that you think is important?**

**I'm wondering how you are before we stop.**

**What made you decide to take part?**

**In order to keep the information confidential I am going to get you to choose a pseudonym/other name. This means you will know what is your information but no one else will. What name would you like to use? Why did you choose that name?**

- Thank them for participation
- Ask permission to contact again if necessary
- Remind them of contact details
- Switch off tape
- Check recording

APPENDIX 6

Demographic Survey Form

Leeds Institute of Health Sciences  
Faculty of Medicine and Health

Charles Thackrah Building  
University of Leeds  
101 Clarendon Road  
Leeds LS2 9LJ



**UNIVERSITY OF LEEDS**

[www.leeds.ac.uk/lihs](http://www.leeds.ac.uk/lihs)

Demographic Survey Form

---

Participant code:

**Demographic Survey Form**

Please complete this and bring to your interview. Ask your family if you need help completing this.

Your age:

Gender: *(please circle)* Male/Female

How many brothers do you have?

How old are they?

How many sisters do you have?

How old are they?

Are you currently in education? *(please circle)* Yes/No

If yes where are you studying? *(please tick)*

School

College

University

Other *(please state)*

If no are you currently employed? *(please circle)*

Yes/No

If yes please state what your current occupation is:

Ethnicity: *(please tick)*

White       Mixed race       Chinese   
Black       Asian       Arab

Other: *(please state)*

Who lives in your house? *(please state)*

Parent's occupation:

What was your dad's job before the ABI?

What is your dad's job now?

What was your mum's job before the ABI?

What is your mum's job now?

Does your parent need extra support?

No

Yes, from family and friends

Yes, from professionals

If yes, how many hours per week?

Less than 6  6 to 10  11 to 15  16 to 20  over 21

**THANK YOU FOR COMPLETING THIS FORM**

**PLEASE RETURN TO JENNIFER HADDEN AT YOUR INTERVIEW**



## APPENDIX 7

### Ethical approval letter

Faculty of Medicine and Health  
Research Office

Room 10.110, Level 10  
Worsley Building  
Clarendon Way  
Leeds LS2 9NL

T (General Enquiries) +44 (0) 113 343 4361  
F +44 (0) 113 343 4373

Jennifer Hadden  
Academic Unit of Public Health  
Leeds Institute of Health Sciences  
University of Leeds  
Charles Thakrah Building  
101 Clarendon Road  
LEEDS LS2 9LJ



UNIVERSITY OF LEEDS

11 August 2011

Dear

**Re ref no: HSLTLM/10/032**

**Title: Experiences of loss in adolescents whose parents have traumatic brain injuries**

I am pleased to inform you that the above research application has been reviewed by the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee and following receipt of the amendments requested, I can confirm a favourable ethical opinion on the basis described in the application form, protocol and supporting documentation as submitted at date of this letter.

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics and Governance Administrator for further information ([r.e.desouza@leeds.ac.uk](mailto:r.e.desouza@leeds.ac.uk))

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I wish you every success with the project.

Yours sincerely

A handwritten signature in black ink that reads "Laura Stroud".

**Professor Alastair Hay/Mrs Laura Stroud/Dr David Jayne  
Chairs, LIHS/LIGHT/LIMM REC**

APPENDIX 8

BIRT ethical approval letter



Miss Jennifer Hadden  
Clinical Psychology Training Programme  
Leeds Institute of Health Sciences  
University of Leeds  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ

17<sup>th</sup> October 2011

Dear Jennifer

**Research Proposal: Experiences of loss in adolescents with a parent with traumatic brain injury**

Thank you for providing detail of the above proposal for scrutiny by a panel of our Ethics Committee.

I am pleased to confirm that the panel supports your proposal.

Yours sincerely,



Iain Mackrory-Jamieson  
Company Secretary

Direct Tel: 01444 237297  
E-mail: [Iain.Mackrory-Jamieson@TheDTGroup.org](mailto:Iain.Mackrory-Jamieson@TheDTGroup.org)

cc Prof Mike Oddy

APPENDIX 9

Sample analysed transcript page

CHARLOTTE

588 to explain it again and she wan't really bothered about it then after I'd Mum  
589 explained it twice (mm). So that like changes as well. uninterested  
↳ Not caring.

590 I:  
591 And how does that feel for you? ↳ interactions  
laboured

592 C:  
593 It annoys me sometimes (mm) I know she can't help it but I hate like  
594 saying it twice (mm hm) or like three times like repeating myself cos it  
595 gets annoying. Justifying Mum but  
still irritating

596 I:  
597 So do you feel like you have specific things that you talk about with her  
598 then and then?

599 C:  
600 Erm, well I feel like I can't talk to her about everything now and like  
601 basically only stuff we talk about is stuff that's not important like well superficial  
602 school like that's a big topic like she talks about that all time like every repetitive  
603 couple of minutes she'll ask me how school is and stuff like that and erm ↳ impersonal  
604 but like she just not, I don't know we don't have proper conversations like changed  
605 we used to like erm, I don't know I can't think of summat now but like, conversations  
606 she'll ask me if I've got a boyfriend or summat and then she'll forget she's Mum forgetting  
607 asked me so then she'll wonder why what we're talking about and stuff Stop talking  
608 so then I just like stop talking and she gets confused when I stop talking. Fed up?  
609 It's just pointless making conversation sometimes but mostly when she's  
610 tired. worse when tired. ↳ loss of emotional support  
↳ Mum's memory  
↳ Frustrating.

611 I:  
612 And does she get tired more easily now? ↳ False interactions

613 C:  
614 A lot more easily than like say we would (mm hm) cos like her brains  
615 working ten times harder erm so yeah. Justifying changes in  
Mum.  
↳ Trying not to blame?

APPENDIX 10

Initial emerging themes

| Theme                                      | Participant |   |   |   |   |
|--|-------------|---|---|---|---|
|  | C           | J | S | M | N |
| <b>Experience of parent with ABI</b>       |             |   |   |   |   |
| 1. Different person                        |             | • |   | • | • |
| 2. Parental role                           |             |   |   |   |   |
| 2.1. Carer                                 | •           | • |   |   | • |
| 2.2. Providing emotional support           | •           |   | • |   | • |
| 2.3. Feeling anxious                       | •           |   |   |   | • |
| 3. Change in relationship                  |             |   |   |   |   |
| 3.1. Change in social interaction          |             |   |   |   |   |
| 3.1.1. Initiating interactions             |             | • |   | • | • |
| 3.1.2. Avoiding interactions               | •           |   |   | • | • |
| 3.2. Loss of time spent together           |             | • | • |   | • |
| 3.3. Loss of emotional support             | •           |   | • | • | • |
| 3.4. Loss of emotional warmth              | •           | • |   | • | • |
| 3.5. Putting on an act                     | •           |   | • |   | • |
| 3.6. Loss of parental security             | •           | • |   | • |   |
| 4. Feelings of guilt                       | •           |   |   | • | • |
| 5. Feeling helpless                        |             | • | • | • | • |
| 6. Feeling annoyed                         | •           |   | • |   | • |
| 7. Feelings of distress                    |             |   |   |   |   |
| 7.1. At initial stages                     | •           | • | • | • | • |
| 7.2. Currently                             | •           | • |   | • | • |
| 8. Feeling lucky                           |             |   | • | • |   |
| 9. Thoughts of parent dying                |             |   |   |   |   |
| 9.1. At initial stages                     | •           |   |   | • | • |
| 9.2. Currently                             |             | • |   | • |   |
| 10. Predicting parents thoughts            | •           |   | • |   | • |
| 11. Making sense of cognitive problems     |             |   |   | • | • |
| 12. Acceptance                             |             | • |   | • | • |
| <b>Experience of the sibling</b>           |             |   |   |   |   |
| 1. Change in relationship                  |             |   |   |   |   |
| 1.1. Feeling closer                        | •           |   | • |   |   |
| 1.2. Loss of support                       | •           | • |   | • |   |
| 2. Being a role model                      | •           |   | • | • |   |
| <b>Experience of the other parent</b>      |             |   |   |   |   |
| 1. Change in relationship                  |             |   |   |   |   |
| 1.1. Feeling closer                        | •           | • | • | • | • |
| 1.2. Loss of emotional support             |             | • |   | • | • |
| 2. Feeling helpful                         |             |   | • | • | • |
| <b>Experience of the family as a whole</b> |             |   |   |   |   |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1. Change in relationship                  |   |   |   |   |   |
| 1.1. Feeling closer                        | • | • | • |   |   |
| 1.2. Loss of closeness                     | • | • |   |   | • |
| 2. Loss of security                        | • | • |   | • |   |
| Experience of self                         |   |   |   |   |   |
| 1. Growing up                              | • |   | • | • |   |
| 2. Feeling isolated                        | • | • |   | • | • |
| 3. Loss of friendships                     | • | • |   | • |   |
| 4. Changes to future plans                 |   |   |   |   |   |
| 4.1. Having to give up plans               | • | • |   | • | • |
| 4.2. Adapting to changes                   | • |   | • | • |   |
| Experience of coping                       |   |   |   |   |   |
| 1. Speaking to others about their emotions |   |   |   |   |   |
| 1.1. Talking                               |   | • | • |   |   |
| 1.2. Not talking                           | • | • | • | • | • |
| 2. Friends                                 | • |   |   | • | • |
| 3. Professional support                    |   |   |   |   |   |
| 3.1. Feeling supported                     | • | • |   |   |   |
| 3.2. Feeling unsupported                   |   | • |   | • | • |
| 4. Distraction                             | • | • | • | • | • |
| 5. Getting on with things                  | • |   | • | • |   |

*Table 2: Initial emerging themes and their prevalence*

APPENDIX 11

Prevalence of final emerging themes

| Master Theme                           | Subordinate Theme        | Satellite Theme                  | Contributing Themes                | C                                | J | S | M | N |   |
|--|--------------------------|----------------------------------|------------------------------------|----------------------------------|---|---|---|---|---|
| Loss                                   | Loss of child role       | Growing up                       | 1. Growing up                      | ●                                |   | ● | ● |   |   |
|  |                          | Parental role                    | 2.1. Carer                         | 2.1. Carer                       | ● | ● |   |   | ● |
|  |                          |                                  |                                    | 2.2. Providing emotional support | ● |   | ● |   | ● |
|  |                          |                                  |                                    | 2.3. Feeling anxious             | ● |   |   |   | ● |
|  |                          |                                  | 3.5. Putting on an act             | ●                                |   | ● |   | ● |   |
|  |                          |                                  | 10. Predicting parents thoughts    | ●                                |   | ● |   | ● |   |
|  |                          |                                  | 2. Feeling helpful to other parent |                                  |   | ● | ● | ● |   |
|  |                          | 2. Being a role model to sibling | 2. Being a role model to sibling   | ●                                |   | ● | ● |   |   |
|  |                          |                                  | 1.1. Feeling closer to sibling     | ●                                |   | ● |   |   |   |
|  |                          | Prioritising others              | 4. Feelings of guilt for wanting   | ●                                |   |   | ● | ● |   |
|  | 4.1. Giving up plans     |                                  | ●                                  | ●                                |   | ● | ● |   |   |
|  | 4.2. Adapting to changes |                                  | ●                                  |                                  | ● | ● |   |   |   |
|  | Loss of parent           | Emotional loss                   | 3.3. Loss of emotional support     | ●                                |   | ● | ● | ● |   |
|  |                          |                                  | 3.4. Loss of emotional warmth      | ●                                | ● |   | ● | ● |   |
|  |                          | Loss of reciprocal relationship  | 3.1.1. Initiating interactions     |                                  | ● |   | ● | ● |   |
|  |                          |                                  | 3.1.2. Avoiding interactions       | ●                                |   |   | ● | ● |   |
|  |                          | 3.2. Loss of time spent together |                                    | ●                                | ● |   | ● |   |   |
|  |                          | Changed person                   | 1. Different person                |                                  | ● |   | ● | ● |   |
| 11. Making sense of cognitive problems |                          |                                  |                                    |                                  |   | ● | ● |   |   |

|                       |                          |  |   |   |   |   |   |   |
|-----------------------|--------------------------|--|---|---|---|---|---|---|
|                       |                          | Change in support                            | 1.1. Feeling closer to other parent         | ● | ● | ● | ● | ● |
|                       |                          |  | 1.1. Feeling closer to the family unit      | ● | ● | ● |   |   |
|                       |                          |  | 1.2. Loss of emotional support other parent |   | ● |   | ● | ● |
|                       |                          |  | 1.2. Loss of closeness in family            | ● | ● |   |   | ● |
| Loss of parent's role | Loss of security         | 3.6. Loss of parental security               | ●   | ● |   | ● |   |   |
|                       |                          | 2. Loss of physical security                 | ●   | ● |   | ● |   |   |
| Distress              | Feelings of hopelessness | At initial stages                            | 7.1. Distress at initial stages             | ● | ● | ● | ● | ● |
|                       |                          | Ongoing                                      | 7.2. Current                                | ● | ● |   | ● | ● |
|                       | Feeling isolated         | n/a  | 2. Feeling isolated                         | ● | ● |   | ● | ● |
|                       |                          |  | 3. Loss of friendships                      | ● | ● |   | ● |   |
|                       | Feeling helpless         | n/a  | 1.2. Loss of sibling support                | ● | ● |   | ● |   |
|                       |                          |  | 5. Feeling helpless                         |   | ● | ● | ● | ● |
| Feeling annoyed       | n/a                      | 6. Feeling annoyed                           | ●   |   | ● |   | ● |   |
| Coping                | Avoidance                | n/a  | 4. Distraction                              | ● | ● | ● | ● | ● |
|                       |                          |  | 5. Getting on with things                   | ● |   | ● | ● |   |
|                       |                          |  | 1.2. Not talking                            | ● | ● | ● | ● | ● |
|                       |                          |  | 2. Friends                                  | ● |   |   | ● | ● |
|                       | Seeking help             | n/a  | 3.1. Feeling supported                      | ● | ● |   |   |   |
|                       |                          |  | 1.1. Talking                                |   | ● | ● |   |   |
|                       |                          |  | 2. Friends                                  | ● |   |   | ● | ● |
|                       | Feeling unsupported      | n/a  | 3.2. Feeling unsupported                    |   | ● |   | ● | ● |
|                       |                          |  | 3. Loss of friendships                      | ● | ● |   | ● |   |
|                       | Acceptance               | n/a  | Acceptance                                  |   | ● |   | ● | ● |
| Feeling grateful      | n/a                      | 9.1. Thoughts of parent dying initial stages |   |   | ● | ● |   |   |
|                       |                          | 9.2. Thoughts of parent dying currently      | ●   |   |   | ● | ● |   |
|                       |                          | 8. Feeling lucky                             |   | ● |   | ● |   |   |

Table 3: Organisation and Prevalence of final emerging themes

## APPENDIX 12

### Quality Control Measure

Below are the emerging themes with brief summaries. Please cut and paste each quote at the bottom into the theme that it best represents.

|  |
|--|
| 1. Loss  |
| 1.1. Loss of child role  |
| 1.1.1. Parental role: Role reversal where the child has assumed parental responsibility within the family. |
| 1.1.2. Prioritising others: Making changes for others in the family.                                       |
| 1.1.3. Growing up: Feeling that they have grown up and matured.  |
| 1.2. Loss of parent  |
| 1.2.1. Emotional loss: Loss of emotional support and warmth from the parent                                |
| 1.2.2. Reciprocal Relationship: Change in social relationship with parent                                  |
| 1.2.3. Changed person: Experiencing the parent as different from prior to their TBI                        |
| 1.2.4. Change in support: Changes in support from other parent, e.g. feeling closer                        |
| 1.3. Loss of parent's role: parent no longer able to provide security e.g. financial, safety               |
| 2. Distress  |
| 2.1. Feelings of Hopelessness: Belief that things would not get better.                                    |
| 2.1.1. At initial stages:  |
|  |



|   |
|---|
| 2.1.2. Ongoing:   |
| 2.2. Feeling isolated: Feeling alone and that no one understands.                                     |
| 2.3. Feeling helpless: Distress at being unable to fix or change the situation.                       |
| 2.4. Feeling annoyed: Feeling annoyed with the parent with TBI and the changes they have had to make. |
| 3. Coping   |
| 3.1. Avoidance: Using distractions and not talking to people.   |
| 3.2. Seeking help: Asking for help to cope from family, friends and professionals.                    |
| 3.3. Feeling unsupported: Feeling unsupported by friends and professionals.                           |
| 3.4. Acceptance: Coming to terms with the changes within the family.                                  |
| 3.5. Feeling grateful: Feeling that things could have been worse                                      |

*Table 4: Quality Control Measure*

1. "I felt like I wa going to die without him."
2. "It does, it hurts a lot knowing that he's like that and you can't do anything about it. You just don't know what to do."
3. "Like I've grown up a lot as well."
4. "It's weird. It's so different because like she just looks the same, she just looks normal until she speaks and then she'll just say something."
5. "I feel like I'm having to look after her."

6. "It just felt like I had no one."
7. "When I'm not near my mum I don't want to deal with it so I just try and forget about it is impossible but I just try my best."
8. "We weren't very good with money erm so we had to like start selling things to get more money. Like selling things that we didn't need  
]like this back room used to be just full of absolute crap and we just sold loads of stuff. We got quite a bit of money for it and now that I'm working it sort of helps, and I get EMA as well"
9. "But now like I could cry about it all the time I don't."
10. "I've become a lot closer to all me family."
11. "He won't say anything. You've got to speak to him you know if you want to, but you can't really."
12. "I: So what has really helped you?  
J: Well talking to other people about it and like going there for summat to do and just meeting new friends with other, with bad like things in their family as well."
13. "I don't know, like I can't think of word but it's make me quite angry that I'd have to do a lot of stuff 'cause I don't want to do it. I want to go out and I want to have fun, I don't want to be like 24/7 looking after me mam."
14. "Erm, the teachers just didn't really help. They'd only come to me, they'd only like see me when I was upset where my friends were there every day asking me how I am every day."
15. "I'd feel like guilty or whatever not seeing her through the good and the bad times so I don't really like plan anything."
16. "Like sometimes when we talk, it's like she han't got any emotions like she don't care, if you get me."
17. "Now that I've got older I understand but it's more upsetting. It's never gonna be how it used to be."
18. "But when he went into like the rehab centre and you saw all the other people you'd think how lucky you are to have a dad that can still walk and talk and do everything else that a normal person can."