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**An Exploration of Brain Injury: From the  
Dependent Child to the Brain Injury  
Survivor**

**by**

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Thesis submitted in partial fulfilment of the requirements for the degree of  
Doctorate of Clinical Psychology

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&

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## **LIST OF ABBREVIATIONS**

ABI	Acquired Brain Injury
BASC	Behaviour Assessment for Children
BSRM	British Society of Rehabilitation
CAMHS	Community and Adolescent Mental Health Service
CBT	Cognitive Behavioural Therapy
CGT	Constructivist Grounded Theory
CIF	Child Information Form
DARE	Database of Abstracts of Reviews of Effects
DOH	Department of Health
GCS	Glasgow Coma Scale
GT	Grounded Theory
IPA	Interpretative Phenomenological Analysis
MFG	Multi Family Group
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
PCA	Principal Component Analysis
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSS	Post-Traumatic Stress Symptoms
RTA	Road Traffic Accident
TBI	Traumatic Brain Injury
UK	United Kingdom

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## **DECLARATION**

This thesis has been written for submission as a partial fulfilment for the requirements for the Universities of Coventry and Warwick Clinical Psychology Doctorate Programme.

This thesis is the candidate's own work, carried out under the supervision of Dr. Eve Knight, Dr. Tom Patterson, & Dr. Julia Cook. Authorship of published papers will be shared with supervisors. This thesis has not been submitted for a degree at any other institutions.

The thesis chapters will be prepared for submission according to the criteria of the following journals:

Chapter 1: The Literature Review 'The Impact of Parental Brain Injury on Children: A Critical Review' was prepared for submission to the journal of Neuro Rehabilitation (see Appendix 1 for guidelines).

Chapter 2: Empirical Paper 'Mutual Support and Identity following Traumatic Brain Injury: A Grounded Theory Study' was prepared for submission to the journal of Qualitative Health Research (see Appendix 1 for guidelines).

## CHAPTER SUMMARY

CHAPTER ONE: The literature review critically evaluates research that has explored the psychological impact of parental acquired brain injury (ABI) on children. The review identifies a number of factors that affect the psychological well-being of children, including both adverse and protective factors. Evidence from the studies reviewed indicates that children are vulnerable to experiencing a range of emotional and behavioural difficulties following parental ABI. Clinical implications of the review findings are discussed, and directions for future research considered.

CHAPTER TWO: The empirical paper aimed to explore the role of mutual support in Traumatic Brain Injury (TBI) survivors' reformation of their identity among individuals attending a mutual support group. Using a Grounded Theory approach, a model of the participants experience was developed. The core category reflected how participants regained a sense of self through *getting to know the "new" me*. Five conceptual categories were identified in relation to identity formation: *pre-injury self*, *comparison with others*; *accessing the social world of brain injury*; *purpose and self-efficacy*; and *acceptance of the post-injury self*. The findings highlight a potentially important role for mutual support in identity reformation following TBI and implications for brain injury rehabilitation programmes are discussed.

CHAPTER THREE: The third paper presents my personal and professional reflections of the research process and how my views have changed over the course of training. To illustrate these changes, elements of the grounded theory model proposed in the empirical paper (Chapter 2) have been applied to my own experiences. It is hoped that this approach will evidence my experience and exploration of *getting to know the scientist-practitioner*.

# **Chapter I: Literature Review**

## **The Impact of Parental Acquired Brain Injury on Children: A Critical Review of the Literature**

Word count: 8190 (excluding tables, figures, footnotes and references).

Abstract: 162

Target Journal: Neuro Rehabilitation: An Interdisciplinary Journal (see Appendix 1 for author guidelines) Amendments will be made prior to submission for publication.

## **1.0. ABSTRACT**

**Aim:** The present literature review set out to critically evaluate the existing empirical evidence regarding the psychological impact that parental acquired brain injury (ABI) has on the child.

**Method:** The databases PsychInfo, EBSCO and Ovid Medline were searched. These search engines enabled thorough searches of AMED, Embase, ASSIA, ERIC, PsychArticles, FRANCIS, E-Journals, Education Research Complete and CINAHL. Eleven articles met the inclusion criteria for the review.

**Results:** Empirical findings regarding the psychological impact that parental ABI has on the child broadly translated into the following themes: Relationship between the injured parent and the child; relationship between uninjured parent and the child; family disruption and compromised parenting and protective factors.

**Conclusions:** Overall, the studies comprising the present review suggest that parental ABI does impact on a child's psychological well-being. Evidence indicates that children are vulnerable to experiencing emotional and behavioural difficulties following ABI and this should be a focus in national guidelines and clinical practice.

*Keywords:* ABI, Parent, Children, Psychological, Impact, Review.

## **1.1. INTRODUCTION**

Providers of Neuro Rehabilitation services are becoming increasingly aware of the importance of providing support to the entire family of the brain-injured person. As a result of this, a large amount of attention has been given to the study of the needs of family members (e.g., Brooks, 1991; Ergh, Rapport, Coleman, & Hanks, 2002; Hanks, Rapport, & Vangel, 2007) and in particular, the needs of spousal and parental caregivers with regard to burden, stress and adjustment (e.g., Hammond, Davis, Whitstone, Philbrick, & Hirsch, 2012; Ennis, Jaffe, Mangione-Smith, Konodi, MacKenzie, & Rivara, 2014). However, only a relatively small number of those studies have focused on the impact of parental brain injury on the child.

### **1.1.1. Definitions, Incidence, Prevalence and Outcome of Acquired Brain Injury**

The British Society of Rehabilitation Medicine (BSRM) defines Acquired Brain Injury (ABI) as, “...*an inclusive category that embraces acute (rapid onset) brain injury of any cause*” (2003, p.7). ABI is an umbrella term, which refers to all types of traumatic brain injury and also includes vascular disease, brain tumours, stroke, meningitis, anoxia, encephalitis, and hydrocephalus and largely affects adults of working age (BSRM, 2003). Traumatic Brain Injury (TBI) is usually viewed as a subset of ABI and specifically refers to an injury to the brain caused by external force after birth, such as a fall, assault or motor vehicle

accident. Injuries to the brain that are present at birth such as cerebral palsy or those which occur later in life and progressive in nature, such as Parkinson's disease or Alzheimer's disease do not usually fall under the umbrella of ABI. The remainder of this paper will adopt the definition ABI as given above and will focus on the effects of ABIs, including those caused by a traumatic event.

Headway, the UK's national brain injury association, state that in England and Wales, 1.4 million cases of ABI each year are assessed within Emergency departments. It is estimated that around 10% of these are moderate or severe brain injuries causing significant and long-term disability. Over half a million people living in the UK suffer from a disability resulting from an ABI (Headway, 2013). Incidence rates are particularly high in males under the age of 30 and many of these individuals will have children (McGregor & Pentland, 1997).

Niemela, Kinnunen, Paananen, Hakko, Merikukka, Karttunen, Gissler, & Rasanen (2014) conducted a retrospective population based study on a sample of 1532 children who had a parent with an ABI. Overall, 22.5% of those who had a parent with an ABI were treated in specialised psychiatric care. This study provides a useful estimate of the prevalence of mental health difficulties in children affected by ABI at the population level. Moreover, although the paper does not tell us about the proportion of cases where parental ABI contributed to the child's mental health problems; the findings do suggest that parental brain injury can have a significant impact on the psychological well-being of the children.

The UK's National Service Framework for Long Term Conditions (Department Of Health (DOH, 2005) advises that services need to examine the needs of children in families where a parent has a disability. The effects of ABI are often complex and result in long term difficulties for parents with speech and language, motor/physical abilities, behaviour, cognitive functioning, social skills and personality changes (Howes, 2005). ABI has a vast range of sequelae and has the potential to impact on almost any aspect of parenting, with likely consequences for children (Ducharme, 1999; 2000).

### **1.1.2. Family Impact of ABI**

Families play a pivotal role in caring for loved ones who have suffered an ABI. The behavioural, cognitive and emotional changes following an ABI are likely to have a substantial impact on the entire family and their way of life (Brooks, 1991; Florian & Katz, 1991; Kreutzer, Marwitz, & Kepler, 1992). Brain injury affects not only the person with the injury; family members also face significant adjustments such as diminished social interaction, social isolation, loneliness, and the challenge of adapting to and coping with personality changes in their loved one. They may also have to manage difficult feelings of their own such as frustration, loss, guilt, grief, blame, depression and anxiety (Livingston et al., 2010; Ponsford et al., 2003; Kreuter et al., 2009; Webster, 1999; Christensen, 1997; Evans, 2003; Lefebvre, 2005).

ABI often causes a permanent upheaval to the family system. Many studies have identified the impact that diminished motor, cognitive and functional abilities following ABI have on the family unit and these effects appear to increase in line with the severity of these sequelae (Wood, 1997, Hoffman, 2001). In relation to this, Sinnakaruppan & Williams (2001) conducted a review of the needs of family members in a caregiving role and identified that provision of emotional support was one of the most frequent unmet needs among participants. However, this study did not include children as carers in their sample.

### **1.1.3. Impact of ABI on Relationships**

Research findings suggest that the nature and quality of relationships between family members prior to the brain injury influences how well they will cope with adjusting to inevitable changes (Golombok, 2000). Significant levels of stress and change can lead carers to feel overwhelmed and experience carer burden (Webster et al., 1999), with some studies identifying elevated levels of stress and strain among married couples following acquired physical disability, including ABI (Lyons et al., 2005; Dues et al., 1999).

Following ABI the individual may face multiple losses (e.g., job, income, physical abilities) and experience a number of psychosocial difficulties (e.g., depression, anxiety, social isolation, financial difficulties), all of which can place pressure on relationships within the family. Studies that have explored the impact of ABI on the social lives of affected individuals found that they were less likely

to engage in socialising (Gomez-Hernandez et al., 1997; Zencius et al., 1999) and that they had fewer friends and social contacts relative to their peers (Dawson & Chipman, 1995; Finest et al., 1995). These findings were identified using both qualitative (e.g., semi structured interviews) and quantitative (e.g., Quality of Life Questionnaire, Social Functioning Exam) measures involving the ABI survivor and family members. Sadness at the loss of intimate relationships and difficulty forming new relationships has also been reported in those with ABI as well as changes in family relationships (Bamford, 2007; Lezak, 1986).

The frontal lobes of the brain are commonly affected by ABI and are likely to result in impaired executive function, which can impact greatly on relationships. Executive function is an umbrella term for a number of abilities, including self-awareness, social behaviour, inhibition of inappropriate behaviour, and control of emotions (Headway, 2015). The frontal lobes play a central role in social cognition, the capacity to attend to, recognise and interpret interpersonal cues that guide social behaviour. This has the potential to impact on an individual's emotional awareness and ability to form bonds with others.

Changes in personality are associated with deficits in executive functioning and are common in ABI (e.g., irritable, aggressive, lack of initiation/motivation), and in addition to the effects these changes may have on adult family members, they can also have a substantial negative impact on child functioning (Maritz & Sachs, 1995; Urbach & Culbert, 1991). More generally, damage to the frontal lobes can therefore result in significant behaviour change (e.g., inappropriate

sexualised or aggressive behaviour). Hora & Sousa (2005) reported that family members found behavioural changes the most difficult to cope with, particularly if the survivor had an explosive temper, depression, anxiety, aggressiveness, increased dependency and/or memory difficulties. A considerable amount of research has studied the impact of ABI on spousal carers and how this affects the relationship (Howes et al., 2005; Jumisko et al., 2005). Of particular concern to partners were the loss of emotional support and companionship and experiencing a loss of affection, which may result in marital difficulties (O'Carroll et al., 1991; Webster et al., 1999).

The influence of parental brain injury on children has been studied sporadically over the past 25 years and the long-term consequences for those children remain unclear. Being confronted with parental brain injury can be very threatening to the child's view of others and the world and may result in adverse emotional and psychological sequelae, such as shock, confusion, sadness, frustration and feelings of uncertainty or loss with respect to the outcome of the injury (Butera-Prinzi et al., 2004; Katzlberger & Oder, 2000; Webster et al., 1999). Daily routine and family dynamics are likely to change and may leave the child feeling vulnerable, potentially destabilising a *secure base* from which to explore the world (Davies & Cummings, 1994; Fishman & Meyers, 2000; Hakvoort et al., 2010). It is also likely that the uninjured parent, if present, may be less emotionally available as they are faced with multiple stressors impacting on their own mental health and/or parenting abilities (Butera-Prinzi et al., 2004; Charles et al., 2007).

A child's emotional and behavioural well-being has been found to be at risk if there is marital conflict within the home and this is particularly evident within ABI populations (Davies & Cummings, 1994; Fishman & Meyers, 2000; Hakvoort et al., 2010; Hammond et al., 2011). It is surprising that, given the substantial research focus on the needs of relatives as carers, there have been very few studies of the impact of parental ABI on children. Among the relatively few studies in this area, Urbach et al. (1994) identified children of ABI parents as a 'high-risk' group for behavioural and emotional difficulties, including running away, dropping out of school, lack of social competency and difficulties with peer relationships. Findings from other studies support this observation (e.g., Lezak, 1978; Hansell, 1990).

In a similar vein, studies on the developmental impact on children with a parent with disabilities other than ABI, including parental psychiatric difficulties, physical disabilities and multiple sclerosis, emphasise an elevated risk of psychosocial difficulties and childhood psychopathology thus highlighting the importance of considering this in children of parents with an ABI (Freidmann, Katz-Leavy, Manderscheid, & Sondheimer, 1996; Garley, Gallop & Johnston, 1997).

## **1.2. Rationale**

The BSRM (2003) rehabilitation guidelines suggest that rehabilitation services should be alert to the likely strain on families/carers and, in particular, the needs of children in the family. However, little guidance is suggested as to how this would be implemented in services and although on the BSRM agenda, little progress has been made in this area since the original statement of guidelines in 2003. The present review therefore provides a timely examination of the literature.

To ensure a comprehensive literature review it was deemed important to include literature exploring any type of ABI as opposed to limiting the scope of the search to TBI. It was felt that the specific nature of the injury (e.g., traumatic, stroke, hypoxia) was not a main concern of this review but rather the psychological impact on children following parental ABI (e.g., emotional, relational or psychosocial consequences) on children was of high importance. Given the likelihood of many ABI survivors falling within child-rearing age and the possible adverse psychological and psychosocial consequences for children, it is appropriate that this literature is reviewed.

## **1.3. Aim**

The aim of the current review is to critically evaluate the current literature on the psychological impact of parental ABI on the child.

It is hoped that through reviewing current literature in this area, the present paper will be able to provide an overview and critique of empirical findings on the psychological impact of children who are affected by parental ABI as well as to make clinical and research recommendations relevant to clinicians working in the field of brain injury rehabilitation. In addition, the National Institute of Health and Clinical Excellence (NICE, 2007) recommend that children should be included in the rehabilitation of the parent as they are likely to experience high levels of stress due to the significant changes, thus, findings from the present review may potentially be of benefit to service providers by informing policy development around the support needs of children. Due to the paucity of literature in this area it was deemed appropriate to review both qualitative and quantitative research. In addition, excluding research based on one methodology is often considered bad practice due to eliminating potentially valid findings (Dixon-Woods et al., 2007).

## **2.0. METHOD**

### **2.1. Search strategies**

Search terms were informed by the question “What is known about the psychological impact of acquired brain injury on children?” A number of different search terms were identified from published research and synonyms were chosen for different components of the question.

Table 1. Search terms based on the review question.

Concept	1. ABI	2. Parent	3. Child	4. Psychological
Search term	ABI	Parent	Child	Psychological
Additional Variations	ABI*	Parent*	Child*	Psychol*
	TBI		Care*	Psychol* Effect*
	TBI*		Youth	Psychol* Impact
	Head Injury		You*	Emotional Well being
	Head Injur*		Adolescent	Emotion*
	Brain Injury		Adoles*	Mental health
	Brain Injur*			

*Note.* Terms taken from concepts 1, 2, 3 and 4 were combined using the Boolean operator “and”. \* represents truncation to capture variation in the terminology

## 2.2. Data Sources

The Cochrane Database of Systematic Reviews and the Centre for Reviews and Dissemination (DARE) were searched initially to determine whether this review would be an original contribution to the literature regarding parental brain injury and the psychological impact on children.

Search terms identified were entered into PsychInfo, EBSCO and Ovid Medline, between December 2014 and April 4<sup>th</sup> 2015. These search engines enabled thorough searches of AMED, Embase, ASSIA, ERIC, PsychArticles, FRANCIS, E-Journals, Education Research Complete and CINAHL. These search engines provide psychological and psychiatric articles and were deemed appropriate given the nature and focus of the review. To ensure consistency across searches, each database was searched by keyword only. Hand searches of reference lists of accessed articles were also carried out.

### **2.3. Selection Criteria**

Articles were identified and retrieved through databases and selected based on their eligibility according to their predetermined inclusion and exclusion criteria.

#### **2.3.1. Inclusion Criteria**

Studies were included if they:

- (i) Had been published in a peer reviewed journal
- (ii) Included participants that had suffered an ABI and were parents
- (iii) Indicated that the children either had a mean age of below 18 years old or that the majority of children in the study were under the age of 18.

- (iv) Provided an indication of the psychological or emotional well-being, mental health, or adjustment of children affected by parental brain injury.

### **2.3.2. Exclusion Criteria**

Studies were excluded if they:

- (i) Did not focus on the psychological impact on children
- (ii) Were published as a book chapter, letter, discussion piece, case study or were unpublished studies or conference proceedings
- (iii) Were not available in English

## **2.4. Systematic search results – study selection**

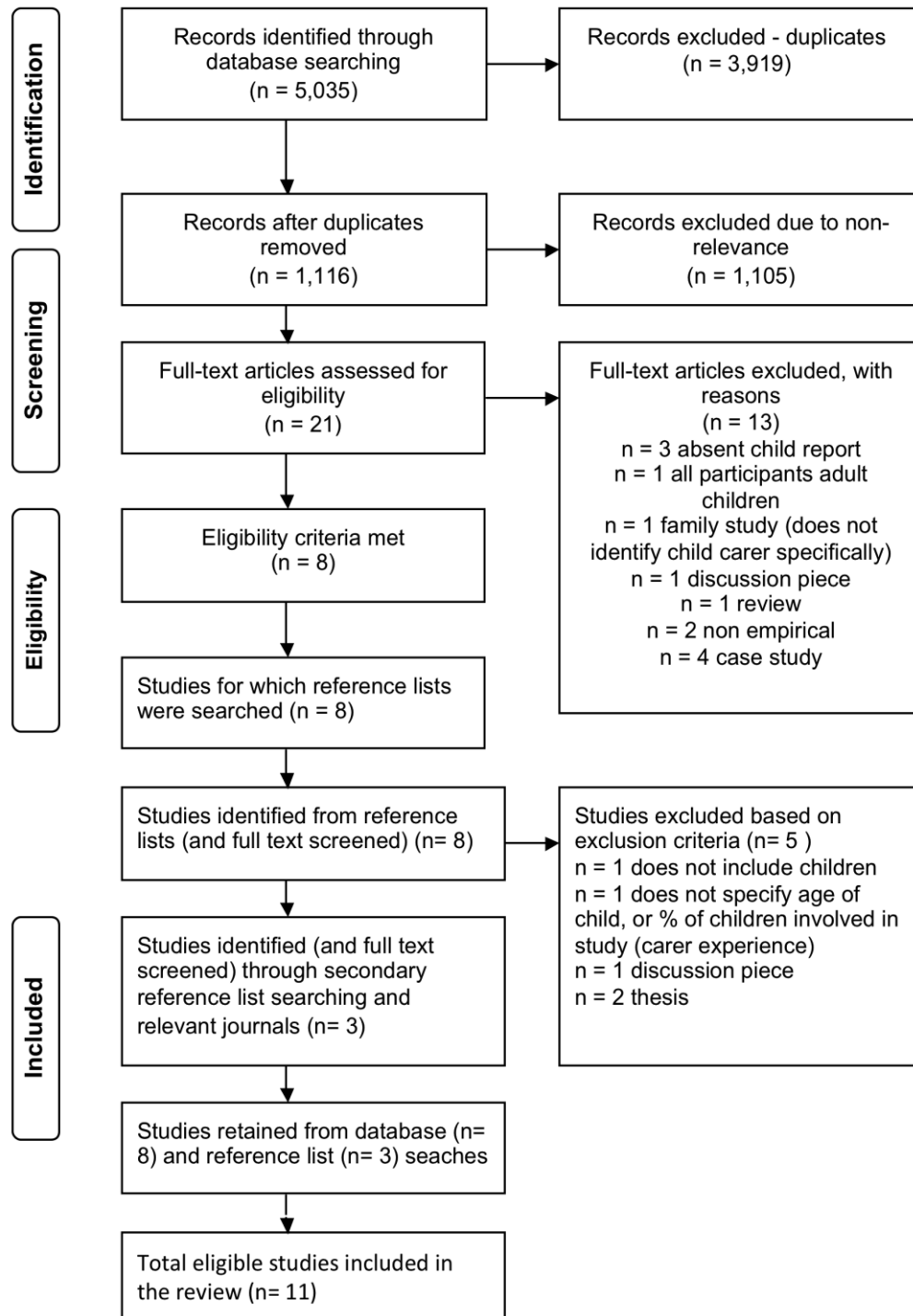
### **2.4.1. Phase 1**

5,035 articles were retrieved through specified databases. These were saved to RefWorks interface and all duplicates were removed. 1,116 articles remained. Titles and abstracts were screened using the inclusion and exclusion criteria and this resulted in 21 potential suitable articles. Full text articles were reviewed and 8 articles met the selection criteria.

#### **2.4.2. Phase 2**

The reference lists of the 8 articles were searched by hand and scanned for additional papers. This process revealed a further 8 potential articles. Hand searches of secondary reference lists were carried out and 3 additional results were found. Once exclusion criteria were applied once again the total number of articles suitable for inclusion was 11.

The study selection process is detailed in Figure 1, in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) group guidance (Liberatie et al., 2009).



*Figure 1:* Flow diagram based on PRISMA presenting the study selection process

## **2.5. Data Extraction**

Once studies were identified, a method of data extraction was used based on the Population, Phenomenon of Interest/Intervention, Context, Outcome, Study design framework (PICOS; Joanna Briggs Institute, 2008, see Appendix B). This ensured that relevant information was accurately and consistently obtained and allowed for the generation of dominant themes across the studies reviewed. Table 2 identifies key data extracted.

### **2.5.1. Assessment of Quality**

To assess the quality of research in the present study, a quality assessment framework was used. This allowed information about each study, such as the population, aim and rationale, methodology and analysis to be evaluated and given a quality rating. Currently, a number of frameworks that offer a clear and comprehensive guide to assessing both quantitative and qualitative literature exist (e.g., Downs & Black, 1998; Sanderson et al., 2007).

Due to the present study assessing both qualitative and quantitative literature, the framework by Caldwell et al. (2005) was used as it is designed to assess quality of research with a focus on health and considers both types of methodology, and therefore deemed to be the most appropriate (see Appendix C).

The literature was considered against each quality criterion and rated as: 0 criterion not met; 1 criterion partially met; or 2 criterion met. Total number of ratings was then summed and converted to a percentage score. Percentage scores for each individual study are included in Table 2.

All papers in the present study were assessed based on their quality (see Appendix D) and to ensure a comprehensive review, no studies were excluded based on a poor quality rating, rather, the assessment was used to assess the quality of the evidence when amalgamating findings and to make relative judgments as to the methodological rigour and robustness of findings across studies.

## **2.6. Data Extraction and Synthesis**

Literature on the synthesis of quantitative evidence is well developed but there is a lack of research relating to qualitative synthesis (Dixon-Woods, Booth & Sutton, 2007). The present review identified both qualitative and quantitative research papers and it was important to establish a method that would integrate both types of evidence generated from the research question. The methods involved in synthesising qualitative research allow for a broader spectrum of evidence to be considered and have the benefit of allowing the structure of the review to develop naturally, rather than being imposed. In light of this, a qualitative approach to synthesis was adopted for both qualitative and quantitative studies.

Each paper was reviewed closely in relation to the research question of the present review and key findings are reported in Table 2. Themes were identified within the literature and these themes were then used as the foundation for the structure of the results section of the current paper.

#### **2.6.1. General Study Characteristics**

Characteristics of the reviewed literature can be found in Table 2.

Table 2. Summary of study characteristics\*

Author(s) and Year of Publication and Quality Rating	Aims/Objectives	Sample	Design & Measures Used	Key Findings
Butera-Prinzi et al., (2004)  89%	To explore the child's experience of having a father with ABI	N = 4  Age range 7-12 years	Qualitative:  Phenomenological Approach	- Children were negatively impacted and at risk of emotional and behavioural difficulties  - Children reported profound grief, social isolation, fear of family disintegration, violence  - Children demonstrated resilience and reported positive outcomes, such as having greater independence due to parents having other responsibilities.
Charles et al., (2007)  89%	To explore multifamily group work (MFG) intervention with families with a parent with an ABI and impact on the child.	N = 9  Age range 7-13 years	Mixed Methods - Intervention  Qualitative: Thematic Analysis of MFG sessions  Quantitative: Within Subjects  Comprehensive ranges of validated assessments were used.	- Parents reported generally reduced levels of personal distress after MFG sessions but continuing high levels of mental and family dysfunction.  - Children were generally reported to be 'well-functioning' based on the BASC.  - Children showed reduced feelings of shame and isolation. Reported benefit of provision of mutual support, increased understanding, sharing diff experiences, moving from blame to compassion
Ducharme et al., (2002)  86%	To assess intervention of errorless compliance training for parents with an ABI for improving child compliance.	N = 8  Age range 2-7 years	Intervention  Quantitative: Multiple base line across subjects design  Measure of self-esteem and child compliance also completed.	- Prior to intervention: Parents: showed low self-esteem Children: Lack of compliance  - Post intervention: Parents: Increased parent self-esteem. Children: Generalised and durable increases were observed in child compliance after treatment.

Author(s) and Year of Publication and Quality Rating	Aims/Objectives	Sample	Design & Measures Used	Key Findings
Kieffer-Kristensen et al.,(2011)  92%	To relate illness and family factors to emotional and behavioural problems in school age children (7-14yrs) of parents with ABI and their spouses.	N=35 Age range 7-14 years  1 ABI Group 1 Diabetes Comparison Group	Quantitative: Cross Sectional Between Subjects	- 46% of children in ABI group met the clinical diagnostic criteria for PTSD total score to 10% in the diabetes group.  - Significant elevations on the externalising, internalising ^ total scores when compared to the normative sample.
Kieffer-Kristensen et al., (2013a)  86%	To listen and learn from children showing high levels of post-traumatic stress symptoms after parental ABI	N=35 Age range 7-14 years	Quantitative: Cross Sectional Within Subjects  A comprehensive range of validated assessments were used.	- ABI families – the children’s emotional functioning depends upon family factors and primarily on the level of parental stress in the healthy parent  - The family stress variables in the healthy parent were significantly related to post traumatic stress symptoms and emotional and behavioural problems in the children.
Kieffer-Kristensen et al., (2013b)  83%	To examine post-traumatic stress symptoms (PSS) and psychosocial functioning in children with a parent with an ABI	N=14 Age range 7-14 years	Qualitative:  Phenomenological Approach	- Themes identified Fear of losing the parent Distress and estrangement Chores and responsibilities Hidden loss Coping and support  - Children experienced several losses during different stages in their parent’s illness and that these losses were often suppressed or neglected both by the children and the parents so as to protect the ill parent.
Moreno-Lopez et al., (2011)  78%	To explore the experiences of adolescent offspring following parental moderate – severe ABI	N=9 Age range 13-20 years  Siblings were included	Qualitative: Grounded Theory	- Adolescents appeared to go through a process of re-evaluation of life priorities, sense of fragility, and increase in appreciation of family needs.  - Alternative parental figures and peer friendships appeared to play a central role for participants.

Author(s) and Year of Publication and Quality Rating	Aims/Objectives	Sample	Design & Measures Used	Key Findings
Pessar et al., (1992)  64%	Effect of parental brain injury and subsequent disabilities on the children.	N= 24 (Made up of family units)  Age range 2-23 years	Quantitative: Cross Sectional Within subjects  A comprehensive range of validated assessments was used.	<ul style="list-style-type: none"> <li>- 22/24 families reported negative changes in children's behaviour since the injury</li> <li>- In 10 of the families, significant and problematic changes occurred</li> <li>- Types of problems involved poor relationship with injured parent, acting out behaviour and emotional problems</li> <li>- Correlates of poor outcomes for the children were Injured parents gender</li> <li>- Compromised parenting performance of the injured parent</li> <li>- Compromised parenting performance of the uninjured parent and depressed in the uninjured parent.</li> </ul>
Stanescu et al., (2011)  86%	<p>Examining the interrelation between family functioning and children's mental health in families with a brain injured parent.</p> <p>Investigate predictive power of family functioning for children's psychological well-being.</p>	N=46 (Made up of family units)  Age range 11-18 years	<p>Quantitative: Cross Sectional Between Subjects</p> <p>Comprehensive ranges of validated assessments were used.</p>	<ul style="list-style-type: none"> <li>- Family dysfunction as a whole positively correlates with psychological symptoms of adolescents; four sub dimensions of family functioning predicted children problems, namely affective responsiveness, affective involvement and roles and communication.</li> </ul>

Author(s) and Year of Publication and Quality Rating	Aims/Objectives	Sample	Design & Measures Used	Key Findings
Stanescu et al., (2013)  53%	To identify main coping strategies used by adolescents with TBI parent.	N = 5  Age range 14 - 17 years  2 girls, 3 boys.	Qualitative:  Interpretative phenomenological approach	<ul style="list-style-type: none"> <li>- Emotional regulation and social support are associated particularly in girls.</li> <li>- Boys tend to not seek help in solving problems or share their feelings.</li> <li>- Coping styles used cover closeness (e.g., emotional balancing, search for social support, taking over responsibilities) and avoidance strategies; distraction, trivialising events, internalisation.</li> <li>- Externalise of grievances occurs in this age group, ranging up to conflicted outbreaks towards parents.</li> <li>- Identification with the parent perceived as stronger and as closer to the child is a powerful coping mechanism.</li> </ul>
Uysal et al., (1998)  81%	The effects of parental TBI on children and the effects of parental TBI on levels of depression for all family members.	N = 32 (Made up of family units)  Age range 7-18	Quantitative: Cross Sectional Between subjects  Comprehensive ranges of validated assessments were used.	<ul style="list-style-type: none"> <li>- Parents with TBI reported less goal setting, less encouragement of skill development, less emphasis on obedience to rules and orderliness, less promotion of work values, less nurturing and lower levels of active involvement to their children.</li> <li>- Spouses of individuals with TBI reported fewer feelings of warmth, love and acceptance towards their children.</li> <li>- No differences in the frequency of behaviour problems were found between parents with TBI and children of parents without TBI.</li> <li>- Parents with TBI and their children experienced more symptoms of depression relative to respective comparison groups.</li> </ul>

\* A comprehensive table of study characteristics including strengths and weaknesses can be found in Appendix E.

### **3.0. RESULTS**

Due to the focus being on the impact of parental brain injury on children, only findings related to psychological impact on children are reported in detail.

Findings from the studies reviewed broadly generated the following themes: Relationship between the injured parent and the child; relationship between uninjured parent and the child; family disruption and compromised parenting and finally protective factors. The research findings reviewed will be presented firstly to consider the quality, strengths and weaknesses of the whole body of literature and then secondly, specific findings from the studies will be discussed in line with the themes identified.

#### **3.1. Review of Studies**

In total, 4 qualitative studies, 6 quantitative and 1 mixed methods study were identified. With regard to quality, the mean score for qualitative research was 25.36 out of a maximum possible score of 36 (79%) with a range of 19-32, while the mean for quantitative research was 29.85 out of a maximum possible score of 36 (81%) with a range of 29-33. It may be that quality ratings differed on the grounds of the different epistemologies that these methods adopt. In addition, the lack of quality frameworks that adequately explore and/or combine both research methodologies may have resulted in differences in quality ratings within the present review.

A number of strengths across studies were identified. A total of 8 studies, both qualitative and quantitative, involved the child directly in the study either through direct interviews or the use of self-report measures. Including the child's perspective in studies is advantageous to understanding the impact ABI has on the child. In addition, the age range of children across studies ranges from 2-23 years, covering a substantial range and thus including participants at different stages of their development.

Several weaknesses were found across studies and are reflected in the quality ratings. Firstly, all 11 studies used relatively small samples, limiting generalisability to the wider population. Secondly, only two of the studies in the present review included control groups. Control groups allow the researcher to test, compare and measure findings relative participants from other populations, thus strengthening the reliability and validity of the study as a whole. Thirdly, in some cases the definition of ABI and/or TBI was not explicitly stated and was therefore unclear. Furthermore, in some samples the majority of participants were individuals with a TBI, limiting the ability to draw inferences from those studies that could be confidently generalised to the wider ABI population. Finally, none of the studies reported taking into account whether the children had experienced additional traumatic events or mental health difficulties post parental ABI and it has therefore not been possible to assess whether or not additional trauma may have been a confounding factor in any of the studies reviewed.

### **3.2. Relationship between the child and the injured parent**

Four of the papers explored aspects of the relationship between the injured parent and the child that had an impact on the child's psychological well-being.

Pessar, Coad, Linn & Willer (1993) conducted a cross sectional quantitative study involving families where the child was born prior to the onset of the ABI. They reported negative changes in children's behaviour including poor relationship with the injured parent. The Child Information Form (CIF) was administered to uninjured parents and principal component analysis (PCA) of the items describing the child, injured parent and the uninjured parent was conducted. Relationship problems between the child and injured parent were found to be the most prevalent problem area and were present in 10 out of 24 families. Relationship problems identified included being less loving toward the injured parent, not wanting to spend time with the injured parent and avoiding taking friends home. Interestingly, in 9 out of the 10 families where relationship difficulties between the child and injured parent were found, the injured parent was the father. This may pose questions around whether the gender of the parent with the ABI is a factor when considering the psychological impact on the child.

The relatively small sample size (n=24) makes it difficult to draw generalisable conclusions regarding possible gender differences due to the small number of mothers with ABI in the sample. In addition, the authors note that the use of the

uninjured parent as the primary source of information may introduce a reporting bias, particularly if the uninjured parent is depressed due to significant life changes as a result of the ABI. Principal component analysis (PCA) was used to analyse findings. While this is a useful tool for reducing a number of observed variables into a smaller number of artificial variables that explain most of the variance in the data set, this method is subject to criticism where there are fewer than 100 participants in the sample. This raises questions about the appropriateness of the use of PCA in this study and could potentially lead to a type one error and false rejection of the null hypothesis (Gorsuch, 1983; MacCallum et al., 1999). Given these limitations, the Pessar et al. (1993) study received a relatively low quality rating (Table 2).

Ducharme and Davidson (2002) received a relatively high quality rating for their multiple base line subjects' design study that evaluated treatment effects of errorless compliance training<sup>1</sup>. Positive changes were reported in compliance of the children aged 2-7 years, with fewer signs of oppositional behaviour present post-intervention. In addition, injured parent self-esteem increased over the course of the intervention, which may lead to a more positive interaction between the child and the injured parent. Ducharme et al. (2002) carried out rudimentary analysis of parent-child relationship behaviours of 4 participating children based on observation of video recordings of parent-child interactions. They observed a significant increase in behaviours such as increased warmth towards the child, as well as an increase in loving and encouraging comments which may facilitate

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<sup>1</sup> Errorless compliance training (Ducharme, 1996; Ducharme et al., 1994) is an intervention developed to provide ABI parents with a strategy for improving child behaviour without coercive or constraining consequences.

restoration of the parent-child bond (Ducharme & Rushford, 2001). This intervention-based study is useful when considering how to facilitate the repair of the child-parent relationship post ABI where children are showing significant behavioural difficulties. However, it is possible that the child participants' behaviour may have been influenced to some degree if they were aware of being video recorded.

Charles et al. (2007) conducted a high quality (Table 2) mixed method within subject's study involving 6 families, totalling 9 children. Three parents in the group acquired their brain injury before the child was born and 3 parents suffered the brain injury after the child was born. A number of quantitative measures were administered to the injured and uninjured parent, alongside child self-report. Qualitative data was obtained through Multi Family Group (MFG)<sup>2</sup> work. MFG sessions were audiotaped and analysed using thematic analysis.

Children expressed a sense of loss of their relationship with the injured parent, similarly to that described in the Pessar et al. (1993) study above. Children in the Pessar et al. (1993) study appeared to present as more avoidant (e.g., avoid spending time with injured parent and/or avoid bringing friends home) in response to parental ABI. In the Charles et al. (2007) study, it was identified that children presented as more distressed and unsettled where the ABI had occurred after the child was born, as they had had a particular relationship with their parent prior to the ABI. In addition, these authors stated that children found it

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<sup>2</sup> Multi Family Group (MFG). Bringing together therapeutic group processes with a unique focus on the family multidimensional system. It holds a strong psycho-educational and problem solving focus (Charles et al., 2007).

difficult to manage conflicting feelings such as anger and resentment, as well as having loving and compassionate feelings towards the injured parent. Charles et al. (2007) did not indicate whether there were additional children born before or after the brain injury in the family unit. It may be advantageous to explore birth order effects to see if there are behavioural or psychological differences between siblings where one child was born prior to brain injury onset and those born after.

However, it is important to consider that Charles et al. (2007) recruited a sample of parents who were in points of crisis around their relationship with their children, which had led to them accessing support and attending the MFG. As part of their assessment, the children completed the Behaviour Assessment for Children (BASC) and were generally reported to be ‘well-functioning’; however, the study does not report the basis on which ‘well-functioning’ was defined or determined. Nevertheless, the BASC is a well-rounded assessment and is multidimensional, including reports from the child, parent and teacher thus gaining a comprehensive picture of the child’s functioning (Reynolds & Kamphaus, 1992).

Kieffer-Kristensen & Johansen (2013b) explored the difficulties faced by 14 children with an ABI parent using interpretative phenomenological analysis (IPA). They identified that parental ABI and subsequent changes in family dynamics affected all children in their study. The six themes that were identified from the analysis were: fear of losing the parent, distress and estrangement, chores and responsibilities, hidden loss, coping and support. The themes of

‘hidden loss’ & ‘chores and responsibilities’ suggest that there was a change in the parent-child relationship and perhaps placed the child in a more responsible position. The theme of *hidden loss* revealed the children missing the old parent and remembering them as being more active, fun, relaxed and supportive. *Chores and responsibilities* identified children taking on more practical chores in the home (e.g., cooking, cleaning, buying food) and spending less quality time with the injured parent. In addition, older children took on responsibility for younger children, particularly when they perceived the injured parent to be struggling physically and/or emotionally. Most children in this study identified significant changes in the injured parent (e.g., cognitive, emotional and behavioural) and described that they found it painful to think of these changes and spoke of missing the ‘old parent’. Children spoke of the injured parent becoming tired more easily post injury and experienced them as being more irritable and angry. The findings bear similarities to the Pessar et al. (1993) study; children in both studies made a conscious effort to hide their feelings of loss and grief. Attempting to interpret this finding, Pessar and colleagues suggest that this may be the child’s way of protecting the injured parent. However, the studies differ considerably with regards to quality ratings; the Pessar et al. (1992) study was deemed to be of lower methodological quality (64%) than the Charles et al. (2007) study (89%; Table 2).

Although the findings are interesting, a limitation of the Kieffer-Kristensen et al. (2013b) study was that the length of interviews varied considerably and the younger children had trouble articulating their views. This may have been as a

result of the child's stage of development and lacking the emotional language to discuss the difficulties they may have been facing. The implications of this may be that younger children's needs are bypassed and will need closer observation by the uninjured parent to determine emotional and behavioural changes. Secondly, the participants all had elevated post-traumatic stress symptoms (PSS) due to change in the injured parent and family disruption and do not tell us about the experience of children who do not show these symptoms.

### **3.3. Relationship between the child and the uninjured parent**

Four studies in the present review focused on the relationship between the child and uninjured parent following parental ABI and all scored highly with regards to methodological quality (Table 2). Butera-Prinzi et al. (2004) employed an interpretative phenomenological qualitative approach with children aged 7-14 years and identified 10 themes<sup>3</sup>. The theme 'relationship with their mothers' identified children feeling empathy for the uninjured parent, describing them as '*stressed*', '*unhappy*' and '*angry*' and reported that they were smoking more, isolating themselves and not experiencing enjoyment in activities since the spouses ABI. The children in this study also worried about the uninjured parent's emotional state and feared they would lose them and would consciously not depend on them for fear they would 'burden' them.

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<sup>3</sup> Themes identified: Onset of Illness, Living with Physical and Psychological Changes, Loss and Grief, Increased Violence, Relationship with Mothers, Absence of Social Support, Teacher and Professional Support, Fears of Family disintegration and financial hardship, Signs of emotional trauma and Positive Coping

With a similar focus, Kieffer-Kristensen, Siersman & Teasdale (2013a) conducted a quantitative, within subjects, cross sectional study with 35 seven to fourteen year olds. They found that children's emotional functioning depends upon family factors and largely on the level of parental stress in the uninjured parent. Stress in the uninjured parent was positively and significantly associated with the child's PSS and emotional and behavioural problems in children. Kieffer-Kristensen et al. (2013a) used the Danish version of The Symptom Check-List-90-Revised (Achenbach et al., 1991) to determine the uninjured parents symptoms of depression, anxiety and aggression. This measure is well established; more than 1,000 studies have demonstrated reliability, validity and utility of the instrument (Smith et al., 2003).

Interestingly, the study found no significant relationships between the injured parent's characteristics, parental depression, marital adjustment, and the children's presentation. This contrasts with findings from other similar studies (Charles et al., 2007; Kieffer-Kristensen & Johansen, 2013b). In attempting to account for this finding, Kieffer-Kristensen et al. (2013a) suggest that the absence of relationships between these variables may be due to children accepting that the injured parent is absent emotionally and unstable due to their injury, and that they rely on the uninjured parent for support. This explanation is in line with observations elsewhere that support from the uninjured parent may have positive influences on the child's ability to adapt to new changes (Moreno-Lopez, Holttum and Oddy, 2011; Pessar et al., 1993).

The findings of the Kieffer-Kristensen et al. (2013a) study are certainly interesting, though it should be borne in mind that the study relied on a volunteer non-referred sample and that all study participants were from two parent families, which may be misrepresentative of this population given marital conflict following ABI (Webster et al., 1999).

Overall the literature suggests that the relationship between the child and the uninjured parent plays a significant role in the behavioural and emotional well-being of the child post ABI. Thus far, relationships have been discussed with regard to the injured and uninjured parent in relation to the child. The literature reviewed here also demonstrates that these relationships play out as part of a family system and there appear to be other factors such as family disruption and compromised parenting that has the potential to impact on the emotional and behavioural presentation of the child.

### **3.4. Family Disruption and Compromised Parenting**

Five studies identified that ABI can cause substantial disruption within a family system. Butera-Prinzi et al., (2004) found that children were negatively affected and at risk of emotional and behavioural difficulties following parental ABI. Children reported substantial levels of grief, social isolation, fear of family disintegration and violence. Family disintegration was identified as a fear of the children in this study, with particular fears reported around financial position and lifestyle changes. Similarly, Charles et al., (2007) in their study, found that

children had to adapt not only to their parents physical and psychological changes but also to a different family life and that the children's fears presented themselves in behaviours such as withdrawal, silence, hyperactivity and lack of compliance.

Children also reported an increase of violence within the family following parental ABI (Butera-Prinzi et al., 2004). Findings from this small qualitative study identified that all children in this study (n=4) had either been physically abused by their fathers following ABI or had witnessed violence between family members and suffered vicarious trauma as a consequence. This study looked solely at fathers with an ABI and the findings might usefully be built upon with a future study exploring the perspective of children with injured mothers.

Violence within the families post ABI was also explored by Charles et al. (2007), who identified that families were reluctant to share information about violence and it wasn't until group cohesion and trust developed within treatment that this emerged. Charles et al. (2007) found that five out of six families had witnessed violence from the parent with ABI toward their children and in two families the children had retaliated with violence (e.g., swearing, hitting, biting and spitting). Interestingly, the parents in this study rated their children as 'well-functioning' with no significant adjustment difficulties. However, group discussion regarding violence and personality changes revealed parents discussing the serious impact that the violence had had on their children, suggesting discrepancies across methodologies.

Uysal et al. (1998) used a comprehensive battery of formal measures<sup>4</sup> to evaluate the parenting skills of parents with brain injuries and their spouses with children between 7 and 18 years of age. Injured parents reported a general reduction in their parenting abilities (e.g., less goal setting, less encouragement, fewer boundaries, and less nurturing). Uninjured parents identified fewer feelings of warmth, love and acceptance towards their children.

An identified strength of this study is the inclusion of the child's perspective, with children describing both parents as being less actively involved in parenting roles. A further strength is the use of a comparison group that consisted of 16 families where no parent had a TBI. Parents with TBI and their children were found to experience more symptoms of low mood relative to the comparison group. No differences were identified in the frequency of behaviour problems between children of parents with TBI and children of parents without TBI, though it is possible that this could be due to the length of time of which the family had had to adjust to changes, with the average time since onset of injury being 9 years.

The sample used in this study challenges its strength; it may over represent those families with desirable outcomes by virtue of selection bias, particularly

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<sup>4</sup> Parents Battery: Parent Behaviour Form, Parent Practices Questionnaire (Strayhorn et al, 1988), Parenting Dimensions Inventory (Slater et al, 1987) Beck Depression Inventory (Beck et al, 1988;1961)  
Behaviours of their children: Children's problem checklist, Behaviour Rating Profile  
Children's Battery: Behaviour Rating Profile (Schincka, 1985), Children's Depression Inventory (Kovacs, 1985) Parent Behaviour Form (Brown, 1990)

given that separated or divorced or parents not living with their children were excluded from the study and these limitations are reflected in the quality score (Table 2).

### **3.5. Protective Factors**

Several protective factors were deemed important to the children in four of the studies including autonomy and resilience, positive factors inside the family and factors outside of the family.

Butera-Prinzi et al. (2004) found that the children in their study showed resilience when confronted with parental ABI, noting positive outcomes such as developing greater independence in the context of having more responsibilities. Kieffer-Kristensen et al. (2013b) similarly found that children took on greater responsibility within the home including taking on different household chores. Similarly, Moreno-Lopez et al. (2011) also found that eight adolescents in their study took on new roles and responsibilities in the family that involved acquiring new skills related to their parent's ABI.

In addition, Butera-Prinzi et al. (2004) reported several factors that the children identified as helping them through the catastrophic changes, namely the availability and flexibility of a compassionate person at the time of the injury, the presence of a consistent significant person (e.g., mother or grandmother), being able to share concerns and feelings with friends and family and maintaining

relationships with people outside of the family and engaging in activities. Two of the four children in this study reported certain changes following parental ABI as positive such as being able to spend more time with the injured parent and older siblings having greater responsibility, altering the family dynamic.

Moreno-Lopez et al. (2011) also found that friendships played a fundamental part in children's lives after onset of parental ABI in their grounded theory (GT) study with nine adolescents aged 13 – 20 years. Availability of friends and their support was felt to be an essential feature of true friendship, for example the perception that friends could be relied upon if and when needed. Friendships were seen as a vital source of reciprocal support and security for all adolescents. However, this study received a lower quality rating (Table 2) due to lack of generalisability, vague methodological procedures with regards to GT and relatively brief conclusion.

The study by Stanescu & Romer (2013) which received a relatively low quality score, carried out IPA of 20 counselling sessions with two girls and three boys, aged between 14 and 17 years, exploring how they cope having a parent with a brain injury. They noted gender differences in coping styles between children. Girls were reported to express their emotions (e.g., crying, needing to communicate and be listened to), whereas boys tended to not seek help from others or express their feelings. Generally, coping styles used involved *closeness* strategies (e.g., seeking social support, gathering information and problem

solving, taking over household duties and parentification<sup>5</sup>), but also avoidance strategies (e.g., distraction, blocking out traumatic event, internalising difficulties and resignation) that were also identified in children by Pessar et al. (1993) and Charles et al. (2007). In addition, children perceived being closer to and having a stronger relationship with the injured parent and found this to be a powerful coping mechanism. The relatively small sample and lack of demographic information in this study limits the generalisability of these interesting findings and points to a need for further large-scale studies with a similar focus.

## **4. 0. DISCUSSION**

### **4.1. Discussion of findings**

The aim of the present review was to critically evaluate empirical literature that has sought to investigate the impact of parental ABI on the child. The findings will now be discussed and conclusions offered alongside consideration of clinical implications of the findings and recommendations for future research.

Relationship difficulties between the child and injured parent were found to be a prevalent problem area. Changes in the injured parent (e.g., cognitive, emotional and behavioural) appeared to impact on the child's psychological well-being as evidenced through findings of behavioural (e.g., oppositional, avoidant) difficulties and emotional difficulties (e.g., unsettled and distressed) and

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<sup>5</sup> Parentification is the process of role reversal whereby a child is obliged to act like a parent to his or her own parent (Stanescu et al. 2013).

relationship difficulties in children (Pessar et al., 1993; Ducharme et al., 2002; Charles et al., 2007; Kieffer-Kristensen et al., 2013b). This resonates with findings from the research literature on children of parents with cancer, where it is well documented that having an ill parent can have a significant impact on children's psychological functioning and their relationship with the ill parent (Compas et al., 1996; Birenbaum et al., 1999; Romer, 2007).

A tentative link was also made in a few of the studies reviewed here between parental stress in the uninjured parent and children's emotional functioning (Butera-Prinzi et al., 2004; Kieffer-Kristensen et al., 2013a; Charles et al., 2007; Kierffer-Kristensen et al., 2013b). Stress in the uninjured parent was associated with the level of children's PSS and emotional and behavioural problems (Kieffer-Kristensen et al., 2013a). It is likely that when a family is presented with parental ABI, the injured parent is preoccupied with adjusting to changes resulting from the ABI whilst the uninjured parent is preoccupied with caring for their partner. Thus, it is probable that both parents become less attuned to their child's emotional needs resulting in the child being vulnerable to feeling endangered and neglected (Kobak, 1999).

Family disruption (Butera-Prinzi et al., 2004; Charles et al., 2007) and compromised parenting (Uysal et al., 1998) following an ABI has the potential to impact on the child's well-being. Violence from the injured parent towards children was identified in the present review as a factor that contributes to a child's behavioural and emotional well-being (Butera-Prinzi et al., 2004; Charles

et al., 2007). It is well documented that physical violence has a great impact on a child's development. For example, if a child's environment is consumed by fear and violence it is possible that the normal milestones of growing up are likely to be adversely affected (Margolin & Gordis, 2000). Similarly, marital conflict has been found to be a risk factor for behavioural problems in children and has been significantly associated with elevated externalising and internalising behaviours. This is in line with findings for children with a parent with ABI reported in the present review (Marshall & Watt, 1999; Pessar et al., 1994; Charles et al., 2007; Stanescu and Romer 2013).

Protective factors were identified within the literature in relation to children finding positive aspects of parental TBI including autonomy and resilience, positive factors inside and outside of the family (Butera-Prinzi et al., 2004; Kieffer-Kristensen et al., 2013b; Moreno-Lopez et al., 2011; Stanescu & Romer, 2013). Children identified people outside of the immediate family as helping them through the catastrophic changes they faced post ABI. Grandparents and friends of such children were found to be a source of reciprocal support and security and an outlet for children needing to share their concerns (Butera-Prinzi et al., 2004; Moreno-Lopez et al., 2011).

Gender differences between children were also found in relation to coping strategies, however the empirical literature around this is scarce and thus findings at this stage can only be considered preliminary and perhaps speculative (Stanescu & Romer, 2013). The use of avoidance among children was also a

common finding and potentially indicative of being unable to face painful and traumatic emotions in relation to their parents' ABI (Pessar et al., 1993; Charles et al., 2007; Stanescu & Romer, 2013). Avoidance is a common strategy used by children when faced with surmountable levels of stress or threat and can act as a protective factor in being able to continue with their everyday lives. Research tells us that often the child's best option for psychologically surviving is to dissociate or shut off the experience from his/her consciousness (Perry et al., 1995).

#### **4.2. Clinical Implications**

The current review indicates that clinical practitioners are more likely to hear reports of children's difficulties from parents rather than the children themselves. Therefore it is important that practitioners consider working within a systemic framework that includes direct work with children as well as the parents.

Charles et al. (2007) stated that it takes time to build rapport and relationships with parents before they disclose the most upsetting outcomes of parental ABI (e.g., violence). This should be borne in mind by clinical staff working in this area when assessing risk for violence either directly to children or more widely within the family.

In addition, as Charles et al. (2007) allude to, the use of formal measures such as the BASC do not always accurately capture the difficulties faced and only

through building relationships with families are individuals able to reveal the reality of living with the consequences of an ABI. Thus, formal measures should be used only as one part of a comprehensive multi-disciplinary assessment involving the entire family.

The wide range of psychological and relational consequences for children of a parent with ABI highlighted in the present review, points to a need for practitioners to prepare families for all potential outcomes of ABI and alert them to these difficulties early on in the rehabilitation process and make them aware that severity of difficulties may not surface until they are at home. For example, community rehabilitation teams may need to encourage open discussion, build relationships and encourage normalisation with the entire family to prevent difficulties reaching crisis point.

Finally, NICE (2007) and BSRM (2003) guidance for head injury is useful when considering the whole context but little information is provided with relation to support for families and children. A small sub-section of the NICE (2007) guidance explains that staff should share information with children and introduce them to the long-term complex changes in their parent and provide literature around support groups. Given the behavioural and emotional difficulties identified in the present review, this guidance is somewhat limited and fails to address the range of adverse effects that ABI can have on children or how the needs of those children can be best met by services. The present review demonstrates the need to consider the psychological well-being of the child

within current guidance in a manner that is both thorough and considerate of the system around the child.

#### **4. 3. Limitations**

There were a number of limitations to the present literature review. Firstly, seven of the studies reviewed recruited participants who were already attending support services. Therefore the experiences of people not accessing services is under-represented would be beneficial to explore in future research. In addition, the use of cross sectional methods in the majority of studies reviewed indicates a need for caution regarding the extrapolation of findings to all children with a parent with ABI.

A further limitation was that the majority of the reviewed studies had relatively small sample sizes and two studies included several children over the age of 18. However, it was felt that the findings within these studies reflected the psychological impact of parental brain injury on children as the majority were less than 18 years of age.

Finally, another limitation identified was that the research was heavily reliant on the views of the injured and uninjured parents. A number of factors may account for this. The process of gaining ethics where children are directly involved can be considerable and time consuming and may put off busy practitioners.

#### **4.4. Future research directions**

Future research would benefit from practitioners building links with families to explore the experiences of the child in more depth and from their perspective. It would also be of interest to gather the experiences and reflections of adults who experienced parental brain injury as a child. It may be that their retrospective accounts could benefit children in similar circumstances and inform clinical practice.

In addition, the gender of the injured parent was not specifically looked at within any of the studies reviewed and this would benefit from further exploration given that the mother is often the primary caregiver. Further, the current study addressed the psychological impact on children of parents with ABI so perhaps the next step with regards to future research may be to identify the needs and potential interventions for children in more depth.

#### **4.5. Conclusion**

The aim of the present literature review was to systematically evaluate the research regarding parental ABI and the psychological impact this has on the child. Overall, the studies comprising the present review suggest that parental ABI does impact on a child's psychological well-being through altered relationships with the injured and uninjured parent, family disruption, compromised parenting and protective factors. It is evident that children are

vulnerable to experiencing emotional and behavioural difficulties following ABI and this should be a primary focus in national guidelines and clinical practice. Clinician's should bear in mind that ABI 'patients' may also be mothers and fathers of children and in instances where psychological difficulties are present in parents, the likelihood of this impacting on the emotional well-being of the child is high and need for family intervention should be assessed for.

## 5.0. REFERENCES

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## **Chapter II: Empirical Paper**

### **Mutual Support and Identity following Traumatic Brain Injury: A Grounded Theory Study**

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Abstract: 169

Target Journal: Qualitative Health Research (see Appendix 1 for author guidelines). Amendments will be made prior to submission for publication.

## 1.0. ABSTRACT

Loss of identity within Traumatic Brain Injury (TBI) has been of interest for many years to clinicians and researchers working in this area, yet there has been little research that has included TBI survivors' views on how mutual support impacts on their identity reformation post TBI. The present study interviewed 8 adults who were attending a brain injury mutual support group. Using a Grounded Theory approach, a model of the participants experience was developed. The core category reflected how participants regained a sense of self through *Getting to know the "new" me*. This encompassed five conceptual categories: *Pre-Injury Self*, *Comparison with others*; *Accessing the Social World of Brain Injury*; *Purpose and Self Efficacy*; and *Acceptance of the Post-Injury Self*. Clinical implications regarding the benefits and disadvantages of TBI survivors attending mutual support groups as a means to facilitate identity reformation are discussed. Future research focusing on understanding the experience of TBI survivors who do not engage in mutual support is indicated.

*Keywords:* TBI; Identity; Mutual Support, Grounded Theory, Experience

## **1.1. INTRODUCTION**

### **1.1.2. Traumatic Brain Injury**

Traumatic Brain Injury (TBI) refers to damage to the brain caused by an external force to the head e.g., a traffic accident, sport accident, assault, fall or industrial accident (Vnadermeulen et al., 2003, Lafosse et al., 2006). TBI has become a public health concern and a socio-economic problem throughout the world (Roozenbeek et al., 2013). It is a leading cause of disability, particularly among young adults and the likelihood of long-term disability is high (Mass, 2008).

Annually in the United Kingdom (UK), 200,000 individuals are admitted to hospital with a head injury. Of these, one-fifth has evidence of damage to the brain (NICE, 2014). Death resulting directly from head injury is rare and it is reported that as few as 0.2% of all individuals attending emergency departments with a head injury in the UK die as a result of their injury (NICE, 2014). The cost of rehabilitation and community care for TBI in the UK in 2010 was approximately £4.1 billion (Gustavsson et al., 2011). However whilst the number of people surviving TBI due to medical advances is increasing, the degree of resultant impairment can be significant.

### **1.1.3. Consequences of Traumatic Brain Injury**

The Glasgow Coma Scale (GCS) is typically used to classify levels of severity (mild, moderate, or severe) and prognosis in TBI and is calculated by assessing motor and verbal response and eye opening (Teasdale et al., 1974). For those who have experienced a moderate to severe TBI, the neurological trauma can result in a distinctive mix of physical, cognitive and affective impairments, all of which can be associated with personal and social difficulties. Cognitive consequences may include poor memory and concentration, poor visual perception, reduced ability to process information, plan, organise and problem solve, and inflexible thinking (Degeneffe, 2001; O'Rance & Fortune, 2007). A person who has suffered a TBI may be unable to focus, pay attention or attend to more than one aspect of a task at a time. These issues may result in restlessness and being easily distracted.

Dikmen et al. (2009) conducted a systematic review to assess the relationship between brain injury and cognitive impairment six months or longer after onset of injury. The review found substantial evidence indicating a relationship between moderate and severe penetrating head injury and long-term cognitive impairments. Pre-morbid intelligence, amount of brain tissue lost and the area of brain damaged were found to be important indicators of this association. However, evidence was less conclusive with regard to mild TBI.

Given the potentially devastating consequences of a moderate or severe TBI, it is unsurprising that some large-scale research has been undertaken in this area. For example, Sigurdardottir et al. (2015) conducted a national multicentre cohort study of individuals with TBI in Norway over a period of two years. The aim was to determine the rates of cognitive impairment one year post-TBI and data was collected on a number of relevant variables such as, demographic characteristics, severity of injury, rehabilitation, and functional outcomes (assessed using cognitive measures). The study found that in the sample of 105 patients, 67% had a severe cognitive impairment. However, a restricted inclusion criterion was used in this study consisting of individuals who had a GCS score of 3 to 8 during the first 24 hours after injury, thus eliminating a large proportion of those that fall outside of this GCS score. Further, the elimination of these GCS scores prohibits the analysis of cognitive impairment in mild-moderate TBI. An additional limitation was the exclusion of people with substance misuse who are thought to have poorer outcomes than the included sample, due to psychological and cognitive difficulties. By excluding these individuals, the true outcome of impairment after TBI may have been underestimated.

Changes in behaviour due to cognitive function are also quite common following a TBI and can often lead to the individual displaying indifference, emotional lability, poor social judgment and disinhibition (Kendall & Terry, 1996; Levin, 1995; Prigiano, 1992). Due to such difficulties, many individuals fail to return to work or to maintain meaningful social relationships and may find it increasingly difficult to hold on to aspects of themselves that shaped who they were prior to

their TBI (Malia et al., 1995). Aggression is also often seen in individuals' post-TBI, with research data suggesting that 25-30% of survivors may be affected (Tateno et al., 2003; Baguley et al., 2006). This can be very distressing for both the TBI survivor and the family. It is often a distinct change from how the person presented prior to their injury and a huge amount of understanding and patience is needed from all involved to understand the loss of control and level of emotional lability.

After a head injury, one of the greatest changes that individuals are faced with is an awareness that a part of them has changed in some way (e.g., Gracey et al., 2008). They may not be able to engage in the same activities that they did previously or even remember who they were before their injury. Consequently, individuals with TBI find themselves in an on-going process of (re-) defining 'who they are' and (re-) constructing their sense of self (Muenchberger et al., 2008).

#### **1.1.4. Self-Identity**

The definition of 'self-identity' differs within the extant literature. Broadly, this term refers to individuals' understanding of their own abilities, qualities and inner sameness over time (Ownsworth, 2014). Often, these perceptions are constructed from roles and accomplishments, social bonds with others, and psychological and physical attributes (Tajfel & Turner, 1979). When considering the significant changes that may result from a moderate-severe brain injury it is

not surprising that people often feel as though they have changed as an individual as a result of their brain injury. A pertinent goal of rehabilitation is often to guide recovery and encourage individuals' adjustment to their physical difficulties, daily limitations and role changes (Wilson & Gracey, 2009). Within the context of the aforementioned cognitive, behavioural and social changes this can be a slow and difficult process for the individual and can impact on re-creating a sense of self.

### **1.2.1. Identity following TBI**

Thomas et al. (2014) conducted a systematic literature review of 110 studies to explore the concept of change in self-identity following a TBI. These authors present an integrative model of reported change in self-identity through the expression of a number of cognitive, psychological and social sequelae of TBI. Three potential levels of change were identified: “*(a) component parts (egocentric self, sociocentric self, and identity as shared with others); (b) integral processes (self-awareness and expression via meaningful occupation and narratives); and (c) whole-system disruption*” (p. 1033). It is suggested that a threat to any of these core constructs can lead to a sense of significant change. Within their review, Thomas et al. (2014) discuss the sociocentric self and propose that social identity refers to the sense of self that people derive from group membership including family groups, recreational groups, vocational groups and so on (Jetten, Haslam, & Haslam, 2012). What is not considered

within the sociocentric self is the impact of incorporating identity as shared with others who are in similar circumstances.

Qualitative research has focused on self-understanding following a TBI, with a particular emphasis on self-concept or self-esteem, which are constructs closely linked to self-identity (Ownsworth, 2014; Tyreman & Humphrey, 1984). Research has shown that change in self-identity is a pertinent factor for survivors of TBI as part of re-defining who they are as suggested by Muenchberger et al. (2008). These changes in identity can range from the individual having a sense that they were different, no longer feeling like the person they were pre-injury, to no longer feeling like a person at all (Levack et al., 2010). Furthermore, it has been suggested that this threat to and uncertainty about identity may provide contribute to poorer rehabilitation outcomes and higher rates of mental health difficulties following injury (Ylvisaker, McPherson, Kayes, & Pellett, 2008).

Cooper-Evans et al. (2008) found that TBI has a negative impact on global self-concept and self-esteem. Body image and physical self-concept (Howes et al., 2005), social identity and social self-concept (Gracey et al., 2008), emotional and behavioural self-concept (Wright & Telford, 1996), all appear to affect a person's self-identity following TBI. In addition, Levak et al. (2010) conducted a qualitative metasynthesis reviewing 26 articles and found that loss and reconstruction of self-identity was a key finding.

### 1.1.6. Mutual Support

A plethora of research about the stressors of TBI for the individual and family members is well documented and can lead to feelings of loss, grief, burden and guilt (Blais & Boisvert, 2005; Anderson et al., 2002; Kreutzer et al., 1997; Kreutzer et al., 1994). Other common difficulties include financial loss, role changes, depression and anxiety (Blais & Boisvert, 2005). Social support is a well-documented protective factor and can encourage feelings of normality (Barrera & Ainley, 1983). Literature identifies that there has been an increase of mutual support groups since the 1970s and that these groups are expanding more quickly than any other kind of voluntary organisation (Elsdon et al., 2000). UK Government and official NICE guidelines have stipulated the importance of access and referral to such support groups (DOH, 1994; NICE, 2004).

Mutual support groups have been defined as:

*“A self-help or mutual aid group is made of people who have personal experience of the same problem or life situation, either directly or through their family or friends. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are run by and for their members”* (Self-help Nottingham, 2000, p. 2).

Thomas et al. (2014) identify the importance of group membership within sociocentric self-concept and identify social identity as being a necessity in reformation of the self (Paterson and Stewart, 2002). Social identity refers to the

sense of self that individuals develop from group memberships such as family groups, recreational groups, vocational groups and so on (Jetten et al., 2012).

Finally, it is thought that the process at the core of mutual support is the sharing of personal knowledge of one's own experience (Elsdon et al., 2000). Mutual support has many potential benefits. These include encouraging a sense of community, providing and receiving emotional support and information, role modelling, learning ways of coping, helping others, developing social friendships and developing a sense of mastery and control (Corcoran, J., Mewse, A., & Babiker, G., 2007). However, there is very little empirical research investigating the benefit of mutual support groups and the factors that may be associated with outcomes. In addition, there has been a lack of research into the role that attending such groups may play in the individual's identity reformation following a TBI.

## **1.2. Rationale and Aims of Current Study**

Several qualitative studies have identified the function and benefits of support-groups in a range of contexts such as vulnerable families (Anderson et al., 2004), individuals who self-harm (Corcoran et al., 2007), mothers of children with disabilities (Soloman et al., 2001) and cult survivors (Durocher, 1999). Findings across these studies indicate that support groups may benefit those who attend in relation to control and agency, friendship, learning and interpersonal change. A limitation of the current brain injury literature is that most studies have focused

on the process of how self-identity is formed but little attention has been paid to how mutual support specifically impacts on the process of identity reformation. Current NICE (2007) guidelines state that practitioners should provide patients with details of support organisations but do not describe how this may assist recovery or what can be gained from attending such groups. Mutual support in other areas has found to be highly beneficial and therefore it seems appropriate to study the role of mutual support for people with a TBI. Derived from existing brain injury and mutual support literature, the research questions for the present study was:

What is the process of mutual support in TBI survivors' reformation of their identity?

A qualitative approach will allow for the exploration of what one brain injury survivor gains from being in the company of another brain injury survivor and will illustrate the diversity of narratives of those with TBIs. Further, to build an initial model of how mutual support impacts on identity formation, grounded in the narratives recounted by those with TBIs and the aim of gaining new insight, grounded theory (GT) methodology is most appropriate.

## **2.0. METHODOLOGY**

### **2.1. Design**

A qualitative design was adopted for the present study and individuals' narratives were captured using semi-structured interviews, which were analysed using GT. This methodology has been chosen as little is known about how mutual support impacts on an individual with a brain injury. In addition, little is known about whether mutual support contributes to their identity reformation. In addition, GT was considered an appropriate methodology in the present study as it has the potential to offer insight, enhance understanding of and provide meaning about those experiences and processes (Strauss & Corbin, 1998).

GT is a methodology that researchers use to develop theory inductively from data. In GT, the researcher does not begin with a theory and then attempt to "prove" or "disprove" it. Rather, the researcher starts with an area of interest and allows what is relevant within that area to emerge (Glaser, 1998). Modified forms of GT have been proposed which build on classic GT first described by Glaser & Strauss (1967). Charmaz (2000) proposes a modified form and promotes an overtly constructionist approach towards building a theory. 'Constructivist Grounded Theory' (CGT) emphasises the subjective nature of both data and theory and this approach was adopted for the current study (Charmaz, 2006).

## **2.2. Participants and Procedure**

### **2.2.1. Ethical Approval**

Ethical approval was gained by Coventry University Ethics Board (see Appendix F) and the study adhered to the British Psychological Society's Code of Conduct (2014).

### **2.2.2. Participant Recruitment**

Participants were recruited from a registered acquired brain injury charity that holds mutual support groups across the country. This charity offers a range of support groups to both individuals with brain injuries and their carers (see Appendix G for gatekeeper letter). Participants were all individuals who had experienced a TBI and were attending mutual support groups.

In order to meet the aims of the study the following inclusion/exclusion criteria were set:

Inclusion Criteria:

- Over the age of 18
- Suffered a TBI
- Accessing mutual support groups
- Proficient in spoken English
- Have capacity to consent to study

Exclusion Criteria:

- Significant cognitive impairments affecting memory as retrospective accounts will be necessary
- Significant verbal impairments as the study is based on interviews
- Unable to give consent

Purposive sampling methods were used to recruit participants who met the study's recruitment criteria. Information regarding the study was distributed to all members within the charity via email or via face-to-face contact with the researcher at designated meetings agreed with the charity secretary. Once the participants contacted the researcher expressing interest in taking part, a participant information sheet and consent form regarding the study was provided (see Appendix H & I). Individuals engaged in either a phone or email conversation with the researcher to discuss the study. Every effort was made to ensure that the participant did not feel pressurised to take part. Any questions

that were raised by potential participants were answered at this stage. If they agreed to participate, a mutually convenient time to meet was arranged to complete the interview.

### **2.2.3. Participant Details**

The sample consisted of eight participants with an age range of 30-56 years and mean age of 40. The length of time participants had attended the groups ranged from three months to eight years. Three of the participants were female and five were male. All participants identified themselves as White British (see Appendix J for demographic form).

### **2.2.4. Semi Structured Interviews**

Interviews utilised a semi-structured interview schedule and were recorded onto a digital recorder. A broad interview schedule was devised with the aim of eliciting data that would specifically address the research question of the present study (see Appendix K & L). Questions included in the interview schedule were informed by a review of relevant literature, conversations with the research supervision team, and recommendations made by the ethics committee. It comprised a series of open-ended questions, which initially focused on individuals' experience of their brain injury and then went on to address more specific research questions relating to their identity. The interview schedule was used flexibly to ensure that participants guided the course and flow of the

interview and to allow space for them to generate information that they considered significant to the study. In line with GT, as concepts emerged the interview schedule was amended to focus in on emerging areas of interest (see Appendix L). With the consent of the participant, each interview was recorded.

### 2.3.2. Collection of demographic data

Demographic details were collected from the participant at time of interview.

Table 1 provides demographic details of participants.

Table 1. Demographic details of participants

Pseudonym	Gender	Age	No. of years post injury	Nature of injury	Localisation & Lateralisation of TBI	No. of months/years attending group
John	Male	56	9	RTA	Right Frontal	8 years
Julia	Female	43	4	RTA	Right Frontal	3 months
Piers	Male	50	2	RTA	Right Frontal	18 months
Peter	Male	31	7	RTA	Left Frontal	6 years
Christina	Female	39	18	RTA	Left - Diffuse	8 years
Thomas	Male	40	18	RTA	Right - Diffuse	8 years
Fred	Male	30	22	Fall. Tumour <sup>6</sup> .	Brain stem	18 months
Louise	Female	31	14	RTA	Right & Left - Diffuse	8 years

\* Road Traffic Accident (RTA)

<sup>6</sup> Primary injury was TBI as a result of a fall, has subsequently had brain tumor resulting in further damage to the brain.

## 2.6. Data Analysis

The interviews were transcribed verbatim and transcripts were proof read and checked for accuracy against the digital recording. Interviews were analysed using the GT procedures provided by Charmaz (2006). The initial phase involved *line-by-line coding*; exploring each line of data and defining the actions or events happening within it (Charmaz, 2003).

Once this was complete, the second phase of coding, focused coding, was carried out (see Appendix M for sample transcript). This involves synthesizing, explaining and naming larger segments of data. This phase requires “*decisions about which initial codes make the most analytic sense to categorize data incisively and completely*” (Charmaz, 2006, p. 57). Focused codes were kept active to ensure that they accurately reflected what the participants were saying and what was happening in the data.

A large number of focused codes were identified, so a third phase of coding was carried out. Charmaz (2006) explains that if a large amount of focused codes are generated, it is beneficial to use Strauss and Corbin (1990, 1998; Strauss, 1987) method of *axial coding*. The objective of axial coding is to synthesize the data further. This phase involved re-evaluating and comparing data that had already been coded and endeavouring to identify the relationships between codes, a process known as *constant comparative method* (Glaser & Strauss, 1967, see Appendix N for example). This led to the final stage of analysis, the formation of

conceptual categories. In essence, conceptual categories help to tell a logical analytic story and demonstrate possible relationships between categories that have been developed in focused coding. The researcher aimed to achieve ‘*theoretical sufficiency*’ rather than theoretical saturation, which is in line with a constructionist viewpoint.

### **2.6.1. Validity, Reliability and Methods to Enhance Rigour**

Qualitative methods often come under scrutiny with regard to reliability and validity and the question of whether they accurately represent the phenomenon that is being researched: “*Validity is concerned with accurately identifying and understanding the experiences...reliability refers to the relative replicability of the interpretations made during analysis and theory building process*” (Crawford et al, 2009, p. 68). With this at the forefront, from the outset *memo writing* was used to capture thoughts, make comparisons and connections within the data, and to note questions and acknowledge potential directions. Memos facilitated the process of thinking about the data and discovering new ideas. Investigations of social meaning are liable to potential bias and therefore the researcher adopted a reflexive stance by considering and reflecting on their own interests in relation to the topic at hand (Charmaz, 2006).

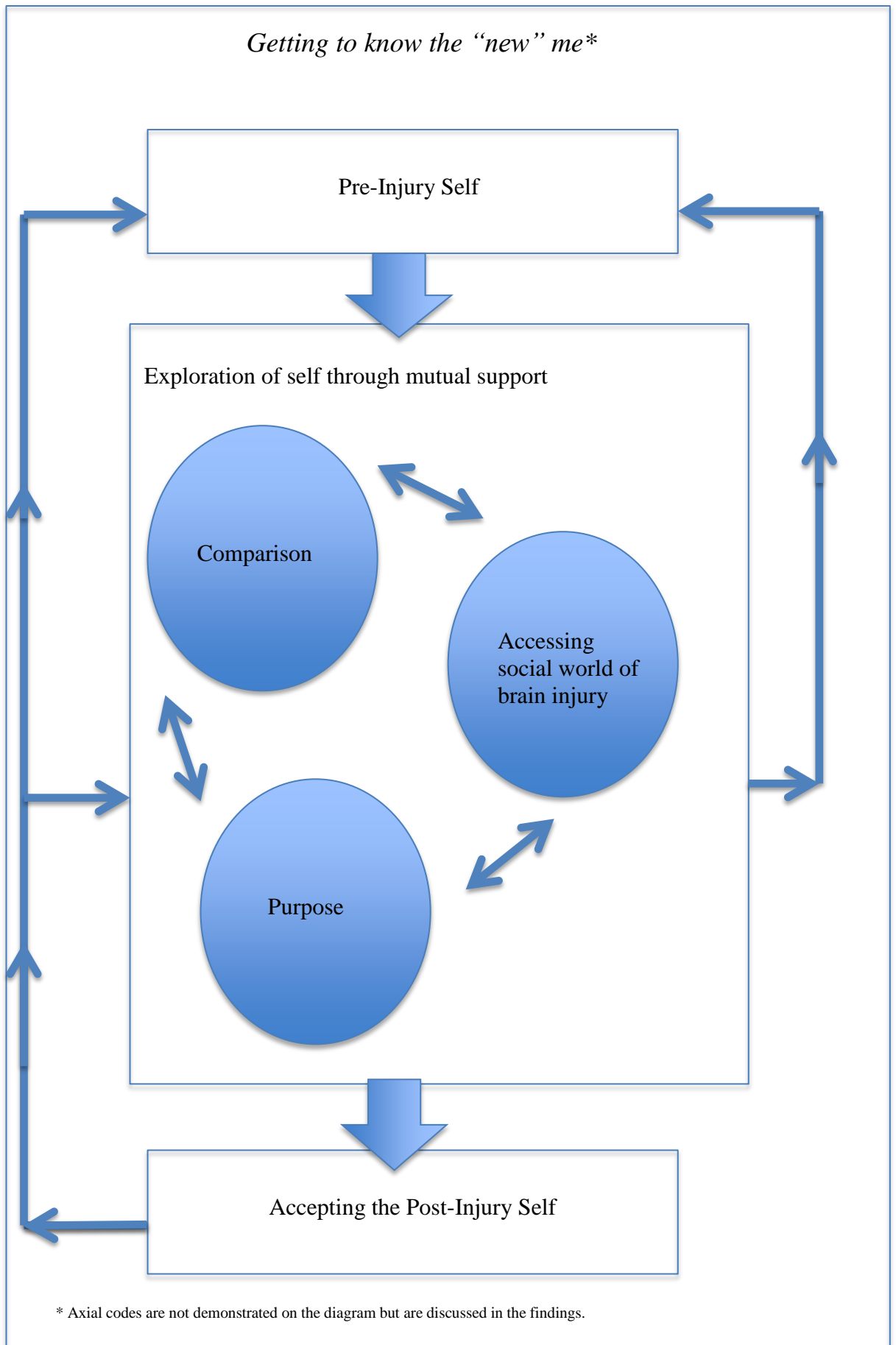
The nature of qualitative analysis means that it can be largely subjective due to the researcher being the tool for analysis (Starks & Trinidad, 2007). In an effort to limit this subjectivity and ensure trustworthiness of the data, cross validation

of the interpretation of the data was conducted. This process involved one other researcher who was familiar with GT completing the first phase of analysis on two separate transcripts. This approach enabled thoughtful reflections on the emerging findings.

The researcher took a constructivist grounded theory approach which acknowledged the interaction between the research and participants, with the researcher's perspective being part of the process. The researcher had previous experience in community and post-acute brain injury services and it is from this experience that the researcher developed an interest in neurorehabilitation and social support. It is acknowledged that these experiences are likely to have influenced the research in relation to the assembly of the interviews and may potentially have introduced biases in the interpretation of the data. A bracketing interview was held prior to interviews taking place in an attempt to limit biases and identify what was already known about the research area; thus the data could be approached with this in mind (Ahern, 1999; Rolls & Relf, 2006; Finlay, 2008). It was pertinent to the methodology for the lead researcher to outline their position and how this may impact on the interpretation of data. The researcher was mindful to ensure the theory developed and analysis carried out was grounded in data from the interviews.

### 3.0. FINDINGS

GT analysis of the data facilitated the development of five conceptual categories that represent the TBI survivors' journey of reconstructing their identity. These categories represent the experiences of individuals reflecting on their *Pre-Injury Self* and the challenges they face prior to moving into a period of exploration within mutual support and finally accepting or feeling content with the changed individual and moving towards *Acceptance of the Post-Injury Self*. The diagram in Figure 1 demonstrates how individuals may move through a process of exploration following TBI and how several factors within mutual support assist or obstruct the formation of identity. These factors are *Pre-Injury Self*, *Comparison*, *Accessing social world of brain injury*, *Purpose* and *Accepting the Post-Injury Self* and are discussed in greater detail in the discussion. Figure 1 aims to demonstrate the process of how the different factors impact on one another. Descriptions of conceptual categories are outlined below with examples of how they interact but also stand alone as conceptual categories (see Appendix O for summary table of coding: focused coding to conceptual categories).



*Figure 1.* Model representing the outcome of the Grounded Theory analysis of understanding the process in which TBI survivors form identity through mutual support.

### **3.1. Conceptual Category 1: *Pre-Injury Self***

This conceptual category captures individuals' attachment to their pre-injury self and emerged as one of the primary categories. Within this category are three axial codes: Loss of Pre Injury Self; Holding On; and Maintained Identity.

#### **3.1.1. *Loss of Pre-Injury Self***

All participants shared a sense of loss in relation to physical, cognitive, behavioural and family factors. Social factors were also discussed and included loss of hobbies, relationships and occupation. Participants appeared to lack a strong internal sense of who they were as individuals after TBI. There was a sense of participants needing to redefine and re-evaluate previous constructs and wanting to resolve this disruption in their self-concept. Peter states:

*"I had a solid career. I was doing well for myself financially and my wages increasing by like ten thousand a year" (p. 7, L.216-218).*

Loss was heavily weighted within physical (e.g., not being able to walk), cognitive (e.g., memory) and familial factors (e.g., role changes). Six participants described loss of physical function. Louise describes losing the ability to walk, but finding strength in overcoming this loss:

*"...when I came out of the coma I was paralysed and when I was in hospital I couldn't bend my leg and I couldn't walk. Battling through the battle to walk again. Made me a stronger person" (p. 12, L.375-378).*

### 3.1.2. *Holding On*

Three participants had a strong sense of *holding on* and wanting to get back to their pre-injury self. Piers describes making good progress throughout recovery but wanting to get back to where he was:

*“...you see I’ve got to this stage now but I want, I want to go closer and closer to where I was” (p. 31, L.756-767).*

Four participants (Julia, Piers, Peter & Christina) reported being involved in lengthy medico-legal battles and having to hold on to their pre-injury self in order to gain some of *what should have been* through financial compensation and designation of blame. This appeared to draw out the recovery process, as participants were being reminded of how life *could* have been if the TBI had not occurred and holding on to this in their mind. Peter states:

*“...the whole point of my court case was, was from the car accident, was to help me regain the life I should have had” (p. 6, L.178-179).*

Julia highlights the process of holding on to the pre-injury self and having to let go of some of the things that she used to do:

*“...yeah took me a long time and just realising that I wasn’t going back to the life I had before the accident. And, and part of me thought maybe I would be doing a lot of other things that I used to do” (p. 14, L.338-340).*

### **3.1.3. Maintained Identity**

Several participants spoke about maintaining fundamental aspects of their ‘self’ despite significant damage to the brain and feeling as though the core of the ‘self’ was stable and unchangeable.

Louise, Julia and John all felt that fundamental characteristics of the ‘self’ had remained. Julia expresses this:

*“... essentially I am the same person as I was before my accident...which is, good cos I know with the head injury you can have the personality changes but yeh, essentially or fortunately I’m still me” (p. 10, L.242-245).*

### **3.2. Conceptual Category 2: Comparison**

This conceptual category demonstrates the participants exploring the self post-injury and specifically captures the individual’s comparison of him/herself with other members of the mutual support group. This involved factors within the group that assist and strengthen reformation of identity (e.g., feeling understood, being in similar situations, others facing the same difficulties, seeing others as more impaired) and those that obstruct or undermine the reformation of identity (e.g. anger at others, seeing self as worse off, others lacking empathy). Within this category are two axial codes: Comparison that assists the reformation of identity; Comparison that obstructs reformation of identity.

### **3.2.1. Comparison that assists the reformation of identity**

All participants thought about themselves in relation to other members of the group in a variety of ways that appeared to assist the reformation of identity.

Comparing physical disabilities was a common discussion among participants and such comparisons appeared to have a facilitative function in participants being able to gain perspective on their own difficulties. John states:

*“...it was pleasant to meet other people who have sadly had a brain injury like me and it was a good reminder that cos, umm, I’m less, yes, my feelings are I’m less impaired than other people, some people are horribly physically disabled as well. Whereas thankfully I’m not” (p. 1, L.26-29).*

Peter discusses feeling more confident by comparison, stating:

*“Some of these people that can’t even walk, they’re in a better, they can’t even talk, and stuff like that and how they got them doing all the activities, it’s amazing to watch that sort of thing. Erm, so yeah, that’s, I’m just trying to think how else it’s affected me. It’s given me confidence and reassurance in what I can do, basically” (p. 15, L.464-468).*

Fred discusses feeling less alone and finding comfort in being able to talk to others with TBI and states:

*“That I’m not on my own with head injury, there’s other people with more problems or less problems and er, yeah, I just er, it feels good to just, uh, be able to talk to people about that” (p. 3, L.71-73).*

Ben discussed how being with others who have experienced similar difficulties has impacted on the way he interacts with others. He describes that:

*“... a big part of it was being around other brain injured people. Seeing what other people go through, erm rehabilitation groups as well, seeing people try to recover from their head injury, it really changes you. Erm, So, yeah, I think it’s made me, me a lot more open minded, a lot more understanding and compassionate” (p. 2, L.47-53).*

Making comparisons and finding commonalities was expressed by five participants and appeared to put individuals at ease when engaging in the group and strengthened their internal sense of self.

### **3.2.2. Comparison that obstructs reformation of identity**

Peter, Ben, Louise, and Christina discussed and/or indicated that comparison in the group was in fact unhelpful.

Ben talks about comparing himself to others in the group and feeling that his brain injury can act as an excuse not to push himself:

*“...the negative side is that, you may start comparing yourself to somebody who is less fortunate in their outcome and then you sort of start thinking ah well, you know, I can just sit here and not speak and and, just cos of my brain injury so you can, a little bit, you have to watch yourself on that one there, you don’t want to start excusing yourself because you have a brain injury” (p. 3, L.185-189)*

Louise discusses the struggle of being with others with brain injury and how it can obstruct coping with her own difficulties:

*“And that’s sometimes when I don’t like [the group], cos you see it and you see it, and you see it and you see it, and you see it and you see and, go away! I’m dealing with my own, I’m trying to forget my own and then you bloody come and see it again. It gets rubbed in your face a bit” (p. 14, L.447-450).*

Christina spoke with anger when she compared herself to others in relation to using memory strategies and feeling as though she works harder than others the group:

*“Cos they’re not the kind of people I socialise with, the thing is, what actually really annoys me so much is that they don’t make an effort. They don’t, I mean, one of them gets her mobile phone out to remember what she has to say and I mean why the hell can’t she just think [sounds angry] of three things that remind her. I’ve worked, I still do little things, I mean, no one would know” (p. 4-5, L.128-132).*

Christina and Peter placed themselves outside of the group and very much saw themselves as leading the group rather than being a part of it. Neither of these participants valued friendships within the group and both placed themselves in a somewhat distant, seemingly aloof position. For example, the next quote demonstrates that Christina sees herself in a role of facilitating learning or possibly change in others:

*“I actually believe, this is probably me, but I believe that, the other people can get a bit of encouragement from me...Oh, but I think it’s good for them to see someone’s who’s suffered an injury. I still think I got such an incredible duff deal, physically, erm, but yeah” (p. 12, L.32-36).*

Comparison that obstructs the reformation of identity has the potential to prevent the individual reaching the acceptance of post-injury self and may see them refer back to their pre-injury self. In this sense the pre-injury self was seen as

comfortable, familiar and safe and it would seem only natural that individuals would seek this for themselves in times of internal conflict. However, the pre-injury self ceases to exist as it was due to the nature of TBI and it may be that individuals go through a process of having to redefine and re-evaluate their ‘self’ several times before they feel comfortable moving on and towards formation of a post-injury self.

### **3.3. Conceptual Category 3: *Accessing Social World of Brain Injury***

This conceptual category captures the individual’s ability to explore and *access the social world of brain injury*. Within this category are four axial codes: Authentic Friendships; Banter and Laughter; Being Understood; and Hijacked Identity.

*“The group is, errr, a point of contact for, erm, for me and the world of brain injury...Erm, and its, fun, social time as well” (Int 7, p. 2, L.54-56).*

#### **3.3.1. *Authentic Friendship***

Participants described the development of supportive friendships within the group as being different from those outside of the group. There appeared to be genuine empathy and understanding through shared experiences and recognition that the presence of such friends is a support in itself, often extending beyond the group and existing as part of the post-injury self.

Louise discusses forming friendships through shared experiences and states:

*“Everyone lives on their own, everyone has no friends, everyone finds it hard to make friends so with the group it’s a bit easier cos you’re all in the same boat” (p. 3, L.96-98).*

And continues to explain how the friendships exist outside of the group by attending a members wedding:

*“I was getting desperate cos I was thinking, there are no, what, no other people that live with a brain injury and get on with everything. But this has proved to me that they do. And they’re all cool people and you make friends with them and all cool. And one of them I went to her wedding and it was all cool” (p. 3, L.87-91).*

However, not all participants found friendship within the group. Ben and Peter described different reasons for avoiding forming closer attachments with others in the group.

*“Other friends and things like that, I mean, I can enjoy the moment but I can’t see, I find it very hard to get close to people cos there’s no, I can’t relate to them” (p. 11, L.345-347).*

Peter discusses having to be wary of friendships due to compensation he received as part of his medico-legal case:

*“...but also back to the friendship side of things, you’ve always got to have your barriers up to know exactly what they want [friendship or money]” (p. 28, L.902-904).*

Louise also speaks of not being able to form friendships within or outside the group:

*“I don’t have other friends, no, I have acquaintances that I know, people I know” (p. 13, L.394-395).*

Similarly, Fred speaks of being unable to make friends easily but suggests that he has always found this difficult, even prior to his injury:

*“Er, my friends, er, I had er, er a difficult time with a lot of my friends before my head injury” (p. 7, L.199-200).*

### **3.3.2. Banter and Laughter**

*Banter and Laughter* emerged as a common experience, which manifested as looking forward to attending the group, lifting mood and allowing the individual to access maintained parts of their pre-injury self.

Piers discusses having banter within the group and enjoying this as it reminded him of being at work:

*“...we just had a bit of a banter which is one thing I miss cos going to work there was always banter” (p. 2, L.42-43).*

Peter also discusses the enjoyment he feels by attending the group:

*“and just have some banter with them and get that, kick, to see them smile. It’s very, it’s so warming to see them smile, enjoying themselves.” (p. 14, L. 452-544)*

### 3.3.3. *Being Understood*

*Being understood* emerged primarily as a sense of being accepted within the group, including understanding or accepting differences, which led participants to feel at ease with each other and express themselves authentically, and thus contributing to the development of the post-injury self.

Julia discusses feeling understood within the group in relation to her difficulties, and how this leads her to feeling less isolated:

*“Yeah and just getting to know other people with head injuries and yeah not to feel isolated and to feel oh, there’s people there who are having some of the same problems I’m having or finding that tough like me and yeah” (p. 9, L.209-212).*

Fred suggests that communication difficulties have contributed to him not being understood by others:

*“Er, for a long time after my head injury, I really found it exhausting, listening and talking. The ebb and flow of conversation, it’s erm, it was just like, I could even talk, if I could monologue, like I am a bit now, erm, if I could monologue then I would set into speak mode and I would just speak. People generally, like, like there’s a lot wrong with that guy” (p. 6, L.190-194).*

Louise found similar communication difficulties with regard to her speech:

*“...people, lots of people used to look at me very vaguely and go, what? That really annoyed me. So I worked so hard...” (p. 3, L.90-91)*

Piers, Ben and Julia felt able to challenge views of others outside of the group where they lacked understanding, which led to increased confidence and a sense of empowerment in some instances. Julia spoke about her role in educating others about people with TBI, stating:

*“I do talks about my accident to help other head injured people and that’s what I feel I want to do, yeah.” (p. 15, L.348-350)*

#### **3.3.4. Hijacked Identity**

This axial code demonstrates how some participants felt their identity was “hijacked” as a consequence of having a TBI and how this was reinforced within the group. Ben describes this:

*“I don’t wanna have my, erm, identity hijacked by the brain injury” (p. 16, L.513-514).*

*“...groups tend to love slapping a t-shirt on you, stamping your forehead and erm, making you hold this flag. Saying ‘I’m brain injured’” (p. 15, L.481- 487).*

Ben also describes feeling as though the mutual support group loses sight of the individual person and how this prevents him engaging in the group, stating:

*“And I’ve found that that has actually prevented me from participating in a lot of things, cos I don’t want to be labelled as, erm, er, I’m Ben. And Ben has a brain injury, not I’m a brain injury, oh by the way I’m Ben as*

*well. This brain injury has a name, it's not that way round" (p. 16, L.507-510)*

John, Peter, Louise and Ben felt being labelled "brain injured" lost sight of the individual and promoted stigmatisation.

Louise states her dislike for the brain injury label:

*"Yeah everyone goes to silver strikes [bowling group] then all the other brain injured people, I don't like saying that but they can sort of meet up... I hate it when other people do it. But I know, I know I am a brain-injured person but you don't. When you see an old person you don't say, oh well, this group of old people" (p. 6-7, L.185-199)*

Peter ponders whether his ideas within the mutual support group have been rejected due to his brain injury:

*"The question is are they, are they then not taking me up on my offers because of my head injury?" (p. 13, L.405-407)*

The conceptual category of accessing the social world of brain injury appeared to primarily provide the individual with a social space in which they could be understood and as a way of forming authentic friendships. However, some individuals struggled when the focus was entirely on TBI rather than the individual and felt this prevented them from forming bonds and enjoying being part of the group.

### **3.4. Conceptual Category 4: *Purpose***

This conceptual category refers to the participants within the group gaining *purpose and self-efficacy*. It would appear that through attending the group participants were able to test out their abilities which would in turn foster their identity and progression toward acceptance of the post-injury self. One axial code formed this category: Purpose and self-efficacy.

#### **3.4.1. *Purpose and Self-efficacy***

*Purpose* emerged as an important function of the mutual support group for participants and appeared to give individuals a productive place in the world, and an opportunity to discuss personal goals and ambitions: Illustrating this, Louise states:

*“It gives you purpose to life, like after work I’m not just going home thinking what the hell will I do this afternoon...So it’s quite nice, it gives you purpose and you can meet other people” (p. 13, L.422-427).*

Julia speaks of the group supporting her and generating hope that she can achieve personal goals or ambitions that may have not seemed possible initially. The group appears to be a strong source of motivation in this regard:

*“To plan things, to organise things and I think it is a very erm, very good as well cos also it says then that things are possible, we can help you get there if, you know, you want to do something like erm, if you want to climb mount Kilimanjaro, we will help you plan that, you tell us what it is you’d like to do and then we’ll, yeah, we’ll help you with that challenge and I think it’s a very refreshing and different sort of approach isn’t it...” (p. 6-7, L.141-146).*

Louise acknowledges her pre-injury desires to travel and feeling that her brain injury prevented her from travelling as she once wished. She explains that through the group her wishes and pre-injury desires were possible:

*“I thought my travelling experiences were over... going away, sleeping in a tent, did I ever think I’d sleep in a tent in Namibia, ever? Even before my accident but after my accident? No way” (p. 14, L.426-437).*

John discusses being part of an international charity mission and benefiting from helping others:

*“Going to a place I’ve never been to before, helping out kids in Namibia at the school there because they are under privileged people” (p. 4, L.116-117).*

Piers discusses his pre and post injury self experiences and feels these can be used to help others:

*“...there’s so much in my life that has been a good experience that I want to try and do that again but I also wanna say because I’ve done it, you know I can help, a – others but b – be part of it so I can take others with us, you know, bring them back up to the things, to the level that I got to and, uh, yeah” (p. 32, L.772-775).*

### **3.5. Conceptual Category 5: Accepting the Post-Injury Self**

*Accepting the Post-Injury Self* refers primarily to accepting the changed individual. Several participants demonstrated adjustment and acceptance whereas others found this more difficult and thus remained stuck or moved in and out of

the different facets of the model. One axial code formed this category; Acceptance.

There was a sense among several participants that recovery was an evolving and fluid process. Julia states:

*“And yeah, just on, the rehab road, the long road, yeah, it’s a long road, erm in the head injured field... I’m very very fortunate that actually that I have been able to overcome it and just feel I’m improving all the time” (p. 4, L.93-99).*

Piers also demonstrates a level of acceptance:

*“...this is my life now, which is ok, erm, this is where I’m aiming for” (p. 30, L.742-743).*

### **3.6. Core Category: *Getting to know the “new” me***

*Getting to know the “new” me* appeared to reflect in part the process of what it is like to be part of a mutual support group and its impact on identity. Getting to know the “new” me both influenced and was influenced by the conceptual categories (Pre-Injury Self; Comparison; Accessing the Social World of Brain Injury; Purpose; Accepting the Post Injury Self). These conceptual categories reflect the experience of being in a group with others who had been through similar experiences and how these concepts were influenced by each other in potentially recursive and collaborating cycles.

For example, if an individual compares themselves favourably to others in the group it may make them feel more comfortable and confident in their abilities. This increase in confidence may encourage the individual to be more emotionally available and thus more able to form authentic friendships within the group. Authentic friendships can be a source of support and security, which is facilitative in that it can give the individual the confidence to engage in activities that they would not ordinarily have engaged in. This engagement or re-engagement with activities may imply a process of testing out abilities and possibilities for the post-injury self and through this process, forming or reforming a post-injury identity.

However, if any one of the conceptual categories comes under threat this could impact on the individual's internal sense of identity and discourage them from accepting the post-injury self. Put simply, should an individual offer an idea to the group (e.g., let's start a coffee morning) that gets dismissed, it may leave the individual feeling rejected or misunderstood. This in turn may influence their perception of the group and potentially their involvement in the group, with consequences for whether they engage in this social world of brain injury. This then may trigger a yearning for their pre-injury self. This demonstrates that the process is not static but dynamic and it is possible that individuals move between all of the conceptual categories.

## **4.0. DISCUSSION**

### **4.1. Summary of the findings**

The aim of the present study was to understand the process of how mutual support impacts on a TBI survivor's identity. The findings of this study produced a model of TBI survivors' experience of mutual support when reforming their identity. The model attempts to demonstrate an individual's journey towards developing or reforming post-injury self-identity through various aspects of mutual support and the way in which those aspects influence one another.

The journey of getting to know the "new" me began with individuals reflecting on the pre-injury self. Embedded within this were several factors (e.g., loss, holding on and maintained identity) that ultimately assisted or obstructed the individual in moving forward and exploring the post-injury self through mutual support. Having a sense of where an individual started or had travelled from (pre-injury self) appeared to be an important part of being understood by themselves and others.

Closely linked to the pre-injury self was the exploration of the individual within mutual support. The exploration of the self encompassed three conceptual categories, namely Comparison, Accessing the Social World of Brain Injury and Purpose, all of which were provided through mutual support. These factors played an important role in the reformation of identity and moving towards a

post-injury self. However, identity reformation was threatened when individuals compared themselves as less fortunate, were unable to engage with others or felt they lacked purpose within the group. Should any of these conceptual categories be threatened, the individual might refer back to the pre-injury self.

Referring back to the pre-injury self reminded the individual of uncertainty and loss but also allowed them to regain a sense of worth and validity (e.g., look at who I was and what I did), strengthening confidence and self-esteem. This conflict demonstrated that participants' connection to their pre-injury self is an important part of building a new identity.

Accepting the post-injury self emerged primarily as accepting what had been lost and being content with the new self and is influenced by all that is encompassed within getting to know the "new" me. It is important to note that accepting the post-injury self is accessed through reinforcement and exploration of the conceptual categories. That is, if an individual begins to feel disempowered, it could impact on their friendships and ability to relate to others, moving them back towards the pre-injury self and to a position of having to begin the journey again. In essence, the formation of identity following brain injury is complex and appears to be facilitated by a journey of exploration of the old and new self through mutual support.

#### **4. 2. Relevance of findings**

Similar to the findings in the Muenchberger et al. (2008) research, individuals in the current study found themselves in an on-going process of re-defining ‘who they are’ and re-constructing their sense of self. Participants did not simply reach acceptance through mutual support and then remain acceptant and content with their sense of self; redefining and reconstruction was reinforced through the process of getting to know the “new” me.

As previously described, social isolation, loss of roles and disrupted familial relationships are all typically associated with TBI and were found within the conceptual category ‘pre-injury self’ (Kendall & Terry, 1996; Levin, 1995; Prigtano, 1992). Individuals in the study talked about the important connection with their pre-injury self and sense of loss. Loss of self-identity following TBI is well documented and many researchers suggest that the pre-injury self of the TBI survivor is lost indefinitely or negatively altered following injury (Crisp, 1992; Klinger, 2005). However, the majority of participants in the current study contradict this finding and strongly felt that the core of the individual remained unaltered. This may have become a protective factor in their recovery, providing hope that they were fundamentally the same individual.

Medved & Brockmeier (2008) have challenged the ‘lost self’ discourse, stating that brain injury survivors maintain their sense of self and experience high self-continuity across their brain injuries. However, a number of additional factors

may account for this (e.g. age, support system, gender, personality characteristics prior to injury) which were not directly considered in the current study due to its qualitative nature.

Through exploration of the self, participants tended to compare themselves to others in the group. This comparison is consistent with literature around social comparison in identity theory. Festinger (1954) noted that individuals would compare 'upwards' if they wish to improve themselves, considering that others are better off than they are. The downward comparison process is thought to facilitate positive self-image, that is, individuals compare themselves to those who are worse-off (Wills, 1981). Participants Peter and Piers demonstrated this process. However, Christina and Louise both found that the upward comparison process is not always helpful or empowering, and the downward comparison did not always make them feel better.

Accessing the social world of brain injury incorporated several factors that reflect Thomas et al. (2007) 'sociocentric self' which includes friends (*authentic friendships/ banter and laughter*), group membership (*being understood*), and stigma/labels (*hijacked identity*). However, Thomas et al. (2007) does not discuss this in relation to being with others with similar difficulties. The current study suggests that there remains a struggle with the reformation of the sociocentric self, even when individuals are around those that they perceive to understand their difficulties. In addition, stigma and labels (*hijacked identity*) occur within the 'in-group' despite mutual understanding and sharing of experiences. Nochi

(1998) uses the term *labelled self* in relation to the sense of change derived from stereotyping and how these labels contribute to a sense of abnormality and powerlessness. Several participants discussed only being seen as a brain injury rather than an individual and this notion is reflected in the literature. Conneeley (2002) states that the TBI label has the potential to reach 'master status'; meaning that all other individual characteristics are forgotten and individuals are reduced to a 'person with a TBI' rather than a unique, individual human being (Chamberlain, 2006).

Having a sense of purpose is documented as a key factor in identity formation following TBI. Nochi (1998) identified meaningful occupation (*purpose*) and acceptance (*being understood*) as a necessity in successful identity reformation. Kurtz (1997) reported that in support-group contexts this sense of purpose and increased self-efficacy occurs when "...one becomes able to take action for oneself and on behalf of others" (p. 26), which manifests as self-confidence arising from resolution of group members' common issues and resulting in acceptance of the post-injury self.

Acceptance of the post-injury self was identified through acceptance of change in the self and considered an important part of reforming identity post TBI. Gracey et al. (2008) found that following brain injury, people make sense of themselves in terms of the meaning and felt experiences of social and practical activity which is in line with the current findings and consistent with social identity theory. Soloman et al. (2001) reported 'identity change' as a group membership

outcome that involved assertiveness, focus, internal strength, acceptance of self and improved relationships. It may be that being within a social context allows the individual to make sense of their impairments and abilities with others rather than alone which strengthens their self-identity and place within the social world

#### **4.3. Study Strengths**

The aim of the current study was to explore the process in which TBI survivors reform their identity through mutual support. This study focused on mutual support in TBI due to the paucity of literature in this area and therefore provides novel findings regarding the role it may play within the participants drawn from this population. In addition, support group literature tends to focus on positive benefits and outcome of attending such groups. The current study identified areas where mutual support can be stifling and obstructive to the reformation of self-identity. The inclusion criteria aimed to provide a basis for homogeneity, as all participants had suffered a TBI and were involved in mutual support groups. The methodology adopted allowed for the voice of brain-injured individuals to inform the development of an explanatory model grounded firmly in the experience of such individuals.

#### **4.4. Limitations**

All qualitative studies run the risk of researcher bias impacting on their findings. However, in GT, the perspective of the researcher is accepted and reflected upon

by taking it in to consideration as part of the research process through use of bracketing interviews, memos, and reflective journals.

Given limitations of time, saturation did not occur in all conceptual categories and given that the researcher took a constructivist GT approach, the resulting model represents one of many possible perspectives on the data (Henwood & Pidgeon, 1995). In contrast to quantitative research, it is not the intention of the qualitative researcher to produce findings that are generalisable to the wider population (Giles, 2002). Nonetheless, the model that has been developed does reflect the participants' journey towards identity reformation and tentative inferences could be made regarding TBI survivors who are engaging in mutual support, which may be subject to larger-scale quantitative investigation at a future point.

With regard to the participant sample, it is acknowledged that there may be a potential recruitment bias as the current study did not include individuals that were not involved in mutual support groups and it may be that those individuals have a different experience or journey in terms of post-injury identity formation. Further research could replicate the present study using an even more heterogeneous sample, i.e. individuals that don't attend mutual support groups or individuals that don't have strong support networks, which could be helpful in testing the categories identified here and refining them where indicated. In addition, the sample consisted of individuals who were all part of the same mutual support group and it could be that there was a group script around the

impact of mutual support. In addition, the model was not triangulated with participants. Hence, the results should be interpreted with caution in the absence of a replication study.

#### **4.5. Clinical Implications and Future Research**

The UK Government and official guidelines have stipulated the importance of increased access and referral to support groups. It is therefore important for the clinical practitioner in the acute, post-acute and community stages of TBI recovery to educate individuals and families on the nature of mutual support groups and how they can be accessed (DOH, 1994; NICE, 2004). Incorporating mutual support groups into brain injury services throughout the recovery process may very well result in a reduction in depression and social isolation both of which are common outcomes within TBI and could potentially reduce pressure on NHS finance, time and resources (Ylvisaker et al., 2008).

The model developed in the present study suggests a complex and varied process with regards to identity formation following TBI. As suggested by Wilson & Gracey (2009), a pertinent goal of rehabilitation is to facilitate recovery and encourage individuals' adjustment post-injury, which in turn may impact on re-creating a sense of self-identity (Ownsworth, 2011). Thus, it is important that more consideration is given within services to identity changes following TBI. Furthermore, given that social support is a well-documented protective factor for

individuals, it is important that this be made available within inpatient rehabilitation and community services (Barrera & Ainley, 1983).

#### **4.6. Conclusion**

Grounded in participants' narratives, the present study demonstrates a conceptual model of the potential role of mutual support in reformation of identity following TBI. The model offers tentative explanations as to how individuals reform their sense of identity through acknowledgment of their pre-injury self, exploring the new self through mutual support and accepting or becoming content with the changed self. It would appear that mutual support plays a potentially valuable role for TBI survivors in the reformation of identity post-injury. Attending mutual support groups may raise difficulties (e.g., comparing the self unfavourably to others) that obstruct the reformation of identity and make the group feel less enjoyable. However, it is felt that the benefits of attending these groups (e.g., banter and laughter, feeling understood) outweigh the disadvantages and encourage individuals to continue to attend. It is vital that information regarding mutual support groups is disseminated to brain injury survivors and their families at discharge and follow-up outpatient appointments and/or easily accessed via leaflets and websites. These findings point to a role of mutual support in the 'rehabilitation' of identity post-injury, which will be of interest to practitioners and support services working in the area of Neuro Rehabilitation.

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## **Chapter III: Reflective Review**

### **Getting to Know the “Scientist-Practitioner”**

Chapter word count: 3,442 (excluding references).

## **1.0. INTRODUCTION**

This paper encompasses my reflections on *Getting to know the Scientist-Practitioner* whilst completing my training in clinical psychology, as related to the research process and my background prior to training. My thoughts and views in relation to clinical psychology and the wider system that surrounds it have changed greatly since commencing the Clinical Doctorate. In this review I shall explore these changes in relation to my own identity and how this has been reformed through training. A process of reformation of identity has been generated in my empirical paper (Chapter 2), and I shall use the model proposed and apply my own learning experiences throughout. It is hoped that this approach will evidence my experience and exploration of *Getting to know the Scientist-Practitioner*.

## **2.0. Pre-Training Self**

My experience in neuropsychology prior to training meant that I understood the role and importance of the scientist-practitioner on a clinical level. I had become immersed in conducting evidenced based neuropsychological assessments, interpreting results, writing reports and feeding back findings to clinicians, clients and families. Working with an expert in rehabilitation medicine allowed me to explore and observe innovative research on a daily basis. I was encouraged to lead experimental drug trials with patients in vegetative and minimally conscious states and looking back, I was given a great amount of responsibility

for someone who was relatively early on in their career. However, it taught me a lot about remaining hopeful and exhausting every possibility to provide someone with the best quality of life despite the odds being against them. In addition, this experience also strengthened my clinical observational skills, analytical skills in terms of analysing results and in encouraging people with very different abilities to engage in formal assessments.

I felt privileged to be working in such an empowering and evolving environment and felt I was gaining the best of both worlds through research and clinical time with patients. On reflection however, there was little space to consider the emotional impact of the role. I do not remember being asked by my then supervisor how I felt being with people who had suffered such catastrophic trauma and whether it impacted on me personally or professionally. This surprises me, as I have come to value the reflective element of supervision and have found it pivotal in my learning and engagement with clients. I was however, very eager to please at that time and may have dismissed any opportunity to discuss my personal reflections in any depth for fear of being seen as weak or incompetent. This makes me wonder about the challenges scientist-practitioners face emotionally? Particularly when in an environment where the medical model supersedes the biopsychosocial model. Indeed, over training I have come to learn that it is part of the clinical psychologist's role to introduce and drip feed the importance of psychological and social factors, and the potential impact that clients can have on the professional.

Interestingly, I did very little therapeutic work prior to training and felt overwhelmed and out of my depth when my then supervisor asked me about talking therapies or mention Cognitive Behavioural Therapy (CBT). I found comfort when informing my practice with evidence and applying medical and scientific principles to my practice and contributing to the evidence base through the research I was undertaking (Marzillier & Hall, 1999). I was content and safe behind structured neuropsychological assessments, and looking back I feel this shielded me from understanding the patient on an emotional level, and possibly reducing individuals to just that, a 'patient' with a reduced IQ, rather than an individual.

My time outside of work was spent volunteering for a new and inspiring brain injury charity that offered mutual support to brain injury survivors and their families. Spending time with individuals who had suffered brain injuries in a social capacity invited me to see that there was more to be done than neuropsychological assessments. In addition, I had been greatly influenced by attachment theory whilst on my Child and Adolescent Mental Health (CAMHS) placement and wondered about how individuals' pre-morbid personalities, characteristics and relationships with others would influence their identity reformation following a TBI. Relationships with others begin the moment we are born and they often provide individuals with love, support, stability and a sense of knowing where we fit in the world (Bowlby, 1969). My sense was that this awareness of knowing one's place in the world was lost or had been destabilised in many of the individuals that I met who had suffered brain injuries.

However, subjectively I could see progression, encouragement, and genuine friendships being born through the support of others in similar circumstances, which led me to wanting to explore this in more depth.

## **2.1. Exploring the Scientist-Practitioner**

*Exploring the Scientist-Practitioner* discusses my journey through training, encompassing several aspects, namely comparison with others, accessing the social world of clinical psychology and purpose.

### **2.1.2. Comparison**

*“The best is the enemy of the good enough”* (Russian Proverb).

Social comparison theory proposes that we establish our own social and personal worth based on how we rank ourselves against others (Festinger, 1954). As a consequence, we are persistently making self and other appraisals in relation to intelligence, success, achievement etc. I am aware of my tendency to compare myself to others and will often distance myself to avoid doing this. When I began the course I felt worthy of my place even though by comparison I lacked therapeutic skills; I came to realise I had other qualities to offer.

For much of the course, I have managed to keep self-comparisons at bay, enjoying the company of my peers and feeling content in my abilities as a

Trainee Clinical Psychologist, both academically and clinically. I moved through each placement with little difficulty, being particularly drawn to working within older adult settings. The familiarity and safeness of neuropsychological assessments resurfaced and I became more comfortable ‘sitting’ in the room with clients and their families without the protection of a manual. During my final year training I had an uncomfortable battle with myself when comparisons with my peers resurfaced with regards to the research process.

I battled with the choice of methodology for my research for some time. My head was telling me that I was a quantitative researcher. However, my heart was telling me that I would not be able to grasp the rich experience of mutual support and the brain injury survivor through the use of quantitative methods. It felt as though I could again strip the individuality of the participant by quantifying their experience to a number. I was also aware that the majority of my peers had chosen qualitative methods and felt I would be able to seek support from them as I moved through a relatively unknown domain. This transition from quantitative to qualitative methods demonstrated a significant change in my development as a clinical psychologist. I was moving out of my comfort zone and seeing the benefits of pushing myself beyond what I know.

*“Grounded theory coding generates the bones of your analysis. Theoretical integration will assemble these bones into a working skeleton. Thus, coding is more than a beginning; it shapes an analytic framework from which you build your analysis.”* (Charmaz, 2006, pg. 45)

The choice of using GT was not a difficult one, the experiences of brain injury survivors and their identity has been researched heavily and I had no intention of going over old ground (Thomas, 2007; Tajfel & Turner, 1979). My eyes had seen something new and I was determined to capture that. Generating a model and demonstrating a process of identity reformation felt closer to my personal preferences than did exploring lived experiences via Interpretative Phenomenological Approaches (IPA). However, the majority of my peers had chosen IPA as their methodology, leaving myself and one other to grapple with GT. At times GT felt overwhelming and lonely and the subjective nature of qualitative methods had me second-guessing my abilities as a qualitative researcher.

### **2.1.3. Accessing the social world of the scientist-practitioner**

*“At every point in our research in our observing, our interpreting, our reporting and everything else we do as researchers-we inject a host of assumptions. These are assumptions about human knowledge and assumptions about realities encountered in our human world. Such assumptions shape for us the meaning of research questions, the purposiveness of research methodologies, and the interpretability of research findings” (Crotty, 1998, p.17).*

Rolls and Relf (2006) state that one of the biggest challenges qualitative researchers face is the exploration of how their assumptions and experiences may influence the construction of knowledge. Although I understood the rationale behind bracketing interviews, I lacked appreciation of how my assumptions could impact on the research I was conducting. The bracketing interview surprised me and I was shocked at how emotional I became throughout. By putting myself in the position of the participant and answering the questions as if I were the one who had suffered a brain injury, filled me with anxiety and a sense that my identity was under threat. This allowed me to appreciate how my participants may feel throughout the interview. In addition, I held assumptions that the participants would be clinically depressed, lacking quality of life and experiencing relationship difficulties. I was able to see that these assumptions were based upon my working in in-patient post-acute neuro-rehabilitation services and may have been reflective of some individuals' stage of recovery.

I enjoyed the interview process, however being in the room with a client as a clinician felt starkly different from being in the room with a client as a researcher. As a clinician, I have not felt bound to ask clients specific questions and therapy is often led by what the client brings in to the room. As a researcher I felt stifled by a piece of paper and worried about diverting from the questions for fear of confounding the results. Discussions with supervisors and peers around these issues allowed me to feel more comfortable in the process. In addition, the first couple of questions on the interview schedule were based around building rapport with the participant that made it feel less research

focused. In addition, the nature of GT allows the researcher to explore participants' responses in more depth should the discussion shed light on emerging categories (Charmaz, 2006).

The bracketing interview shed light on the difficulties I may face emotionally hearing the narratives of TBI survivors and the process of how they reformed their identity. Knowing this in advance meant that I could plan my time effectively, for example not doing one interview after the other and organising regular debriefs with supervisors. However, this was based on my assumptions and for all but two of the interviews, I found the experience inspiring and uplifting. I wondered how much of this was entrenched or borne through the ethos of the mutual support group rather than the individual.

Two interviews in particular stand out in my mind. The first involved a young girl of similar age to myself and her background resembled that of many young twenty year olds. It made me acutely aware of the fragility of life and the importance of a strong support system. However, it was her sadness and silent longing to regain her pre-injury self that remained with me for some time. I realised that even though she presented as one of the more empowered and confident members of the group, she held deep sadness about her post-injury self.

The second involved a young, assertive and strong-minded gentleman who appeared to want to interview me and assess my future goals rather than talk of

his experience of mutual support. This interview tested and frustrated me considerably, the clinician in me wanted to explore the avoidance, but the researcher in me wanted to stick to the interview schedule. Interestingly, when listening to this interview back, it became one of my favourite interviews, I felt there was a real battle in this gentleman accepting his brain injury and he appeared to be fighting hard in all areas of his life to establish some kind of belonging.

#### **2.1.4. Hijacked Identity**

Like in the model presented in the empirical paper (Figure 1; Chapter 2), I often felt as though my identity had been hijacked by clinical psychology. This journey began over nine years ago and in this time I have very rarely taken my eyes off the ball or thought about much else. My identity has very much been enmeshed within psychology and all that the course entails. However, this very identity was threatened by personal circumstances at the beginning of third year and making me wonder if I would in fact complete the course to the standard I would have hoped. On reflection I had very much lost my way with the research process at this time, which prevented me from being present in supervision meetings and lacking attachment to my data. I was temporarily at a loss as to who I was and what I wanted from the course. I had realised that for a long while I had defined myself within clinical psychology and so much of my identity was caught up in this. I no longer wanted clinical psychology to be the whole of me, but part of me, in a similar way to my participants not wanting to be solely defined by their

head injury. This obstacle I faced came at a difficult time in the research process and threatened the quality of my work, however I learned very quickly the importance of self-care and the need to utilise support systems when necessary.

## **2.2. Purpose**

At the beginning of the research process I wanted to produce research that would make a difference to rehabilitation at a national level. This was naïve and no doubt a consequence of working with a professor of rehabilitation who had in fact guided rehabilitation for a number of decades. I could however, produce research that would be beneficial to clinicians working within this field and would strengthen my own understanding of the difficulties those individuals with brain injuries face. At the forefront of my mind throughout this process was the way I felt being in a room with TBI survivors, I was inspired and amazed at how these individuals and families coped in the face of utter catastrophe. It was these individuals that empowered me to become a clinical psychologist and provided me with a sense of purpose on a daily basis.

Participants appeared to thrive when they immersed themselves in purposeful activity and a sense of engaging in worthwhile activities, and in much the same way I found this in my own practice. However, reflecting on the model I often felt disempowered and demotivated, particularly in relation to the literature review. Initially, I was excited by the prospect of conducting a systematic review in an area of interest and felt it would be an area that I would excel. However, I

battled with finalising an idea and realised the world of brain injury had changed and evolved in the time I had spent on training. Consequently I fell behind and became overwhelmed in literature that didn't appear to make any sense to me. It was a matter of going back to the beginning, remembering why I had chosen brain injury as a topic of interest and a turning point came when my supervisor asked, "What makes you get up in the morning?" It was a simple question but powerful enough to focus me throughout this journey by keeping in mind why I started.

### **2.3. Accepting the Post-Training Self**

*"Shoulda, woulda, coulda"* (Unknown).

Once I had moved through the disappointment of falling behind with the research process, given up on timetables that were unrealistic and accepted that I would not be in a similar position to my peers, I was able to move forward. I allowed myself time to become immersed in my data and found I enjoyed the lengthy process of GT. My subjectivity concerns were put to rest by the constant comparative method and discussions with fellow GT researchers (Charmaz, 2006). Having taken a constructivist grounded theory (CGT) approach I was able to acknowledge and take comfort in considering the interaction between the research and participants, with the researchers' perspective and views being part of the process. I punished myself considerably throughout the process for not having enough time to analyse data or not having more frequent in depth

discussions about initial focused codes and conceptual categories with my peers or supervisors. However, the time I had was enough to produce a coherent model that is grounded in the data and therefore I have achieved what I set out to do. In an ideal world I would have enjoyed spending more time applying theoretical sampling and achieving theoretical saturation. Although disappointing, it is a good foundation upon which to build future research. In addition, once the literature review came together, I began to enjoy the critical appraisal and truly believed that a review of literature was important to services and national guidelines. I also believe that when I return to brain injury rehabilitation or any other service where children are a part of the wider system, I will be well equipped in demonstrating why it is important that we, as professionals, consider their needs.

#### **2.4. Getting to know the Scientist-Practitioner**

When interviewed for the Clinical Doctorate three years ago, one of the questions I was asked at interview was “Can you be a good clinical psychologist, as well as a researcher?” My answer at the time was yes, but looking back I lacked the experience or knowledge to provide such a definitive answer. I have indeed got to know the Scientist-Practitioner and I think a number of factors impact on this role being done effectively. Firstly, time. Finding time to incorporate both clinical work and research has been tremendously difficult for me and likely due to my inexperience with qualitative measures and personal difficulties. However, I can only wonder if this would become more difficult

once qualified with clinical and family commitments taking priority. Secondly, ethical approval is time consuming and can often take months. In considering the current economic state of the NHS and clinical psychology jobs being under threat, I wonder if busy practitioners will engage in such lengthy procedures when their position is relatively unknown. Finally, a supportive and understanding team is crucial. I was lucky in that whilst I was completing my thesis, I was on placement within physical health and brain injury was an area of interest for my supervisor. Thus, I was able to spend some free time on placement focusing on my work. However, it was difficult to juggle the two together and I often found I was not fully attached or attuned to either placement or thesis work as I was spreading myself too far. In light of this, a busy practitioner would need the support of their supervisor and the team around them.

In summary, I do still believe that it is feasible to become an active researcher alongside being a clinician with the appropriate support in place. This process has opened my eyes to the demands of this role but I feel I have gained invaluable skills that will encourage me to carry out research in the future. In addition, I feel our training prepares us to face challenges of this nature and the robustness of the course facilitates this role.

### **3.0. Conclusions and Future Directions**

The journey of *Getting to Know the Scientist-Practitioner* has been reflective of running a marathon. There have been parts that I have enjoyed and excelled in and parts where I have dreaded continuing for fear I would fail. In addition, there were moments where I was relatively content and happy with my progress. I have considered the role of the pre-training self and the process of being a trainee clinical psychologist from the stance of a researcher. I have also demonstrated changes in perspectives as I have evolved through training and how this may impact on my clinical work and particularly in relation to the participants that formed the sample for my empirical paper. Aside from the invaluable practicalities learnt through conducting research, this process and training as a whole has taught me a lot about myself and the kind of clinical psychologist I would like to be and this most certainly involves a research component. Like running a marathon, it was emotional for the last few miles but completing it proved I did have the skills and ability to see it through until the end.

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## APPENDIX A

### Author Guidelines

# NeuroRehabilitation

## An Interdisciplinary Journal

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Manuscripts should be organized in the following order:

- Title page
- Body of text (divided by subheadings)
- Declaration of Interest
- Acknowledgements
- References
- Tables
- Figure captions
- Figures

Headings and subheadings should be numbered and typed on a separate line, without indentation.

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### **Title page**

The title page should provide the following information:

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- Name(s) of author(s); please indicate who is the corresponding author
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- Present address of author(s), if different from affiliation
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- Abstract
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The abstract should be clear, descriptive, self-explanatory and not longer than 200 words, it should also be suitable for publication in abstracting services.

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**OBJECTIVE:**

**METHODS:**

## RESULTS:

## CONCLUSIONS:

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Each table should be provided on a separate page of the manuscript. Tables should not be included with the text content.

Each table should have a brief and self-explanatory title.

Column headings should be brief, but sufficiently explanatory. Standard abbreviations of units of measurement should be added between parentheses.

Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.

Any explanations essential to the understanding of the table should be given in footnotes at the bottom of the table.

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SEPTEMBER, 2010

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Author names	<p>List the name (not just initials) of each author, <i>without</i> credentials, in order, horizontally across the page.</p> <p>If there are two authors, list them as follows: Janice M. Morse and Author Two</p> <p>If there are three or more authors, list them as follows: Janice M. Morse, Author N. Two, Writer Three, and Fourth Author (and so forth)</p> <p>After each name (or <i>after</i> the comma following a name, if applicable), use a superscript number to link that particular author with his or her <i>primary</i> affiliation (see the section on author affiliations, below).</p>
Author affiliations	<p>Using the same superscript numbers as used with the authors' names (see above), list <i>only the primary affiliation</i> of each author (see the sample manuscripts).</p> <p>Spell out all city, state, and country names (exception: use USA instead of United States). Spell out any organization or institution names (for example, <i>University of Utah</i> instead of <i>U of UT</i>, or <i>World Health Organization</i> instead of <i>WHO</i>).</p>
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Author's / Authors' Note	<p><i>This is optional.</i> This is the place to mention, perhaps, that portions of the article were presented at a professional meeting, or other information of that sort.</p>
Acknowledgments	<p><i>This is optional.</i> The section is limited to two (2) or three (3) <i>brief</i> sentences. Overlong acknowledgments will be reduced at the copyeditor's discretion. Do not include long descriptions of persons being acknowledged, and do not include roles, titles, or credentials.</p>

	Avoid phrases such as <i>We wish to thank</i> , <i>We would like to thank</i> , and <i>We want to thank</i> , and just use a simple, <i>We thank</i> , or <i>We acknowledge</i> .
Declaration of conflicting interests	<p>You must use one of the following statements, in the <i>exact</i> words shown below.</p> <p><i>If you have no conflicts of interest (or potential conflicts of interest):</i> The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.</p> <p><i>If you have conflicts of interest:</i> The author(s) declared a potential conflict of interest as follows: [Then, <i>in sentence form</i>, list all specific author relationships with organizations and/or products that were declared].</p>
Funding	<p>You must use one of the following statements, in the <i>exact</i> words shown below.</p> <p><i>If you did not have financial support:</i> The author(s) received no financial support for the research and/or authorship of this article.</p> <p><i>If you did have financial support:</i> The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: [Then list, <i>in sentence form</i>, all entities/organizations that funded the research and/or authorship].</p>
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The abstract should be placed on page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and briefly describe your article. Place your keywords below the abstract, on the same page (see "Keywords," above).

Double space the entire abstract page (including the keywords). Briefly state the purpose of your research, the main findings, and your primary conclusions. Make sure the abstract is written in the first-person, active voice.

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Note that the sample manuscripts beginning on page 33 are abbreviated for illustration purposes, and might not contain all optional elements that could be included in an actual manuscript. The sample articles contain all four heading levels.

The main text of the manuscript begins on page 2 of the document, immediately after the abstract page. *Write your article in the first-person, active voice.*

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There are very specific requirements for the preparation of in-text citations; refer to the *APA Publication Manual*, 6th edition, for details. Every in-text citation should have a corresponding reference in the reference list—*no exceptions*.

During the review process, author citations should include only the word *Author* and the year: (*Author, 2008*). If and when the manuscript is accepted for publication, the missing information can be restored.

Double space the entire manuscript document, *except for text contained in figures*. Use only U.S.-English spelling (except in the references, as appropriate, and for direct quotations from published written sources). Use U.S.-English translations of non-English quotations or excerpts. Use a minimum of two (2) heading levels.

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*Elements such as listing order, spelling, punctuation, spacing, capitalization, and the use of italics or Roman (regular) font are as important as the content of the reference.* Note that if an author has two or more initials, there should be spaces between the initials; incorrect = X.Y.Z.; correct = X. Y. Z.

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Use *only* the 6th edition of the *Publication Manual of the American Psychological Association (APA)* as your source of instruction for references (this is critically important). Translate non-English titles into English (see *APA* for instruction on how to do this). Reference and cite all other studies mentioned in the article. Test all Internet URLs (Web addresses) immediately before submission to ensure that they are accurate, and that the sites are still accessible; do this prior to submission of all revisions and accepted manuscripts, as well.

## APPENDICES

Appendices are not encouraged, and are published only at the editor's discretion. If included, appendices should be placed in the main manuscript document following the reference list, and before the bios or any tables. *Appendices must be referred to in the text.*

## APPENDIX B

### Data Extraction Form

#### Study Details

Sample	N	Age Range	Population(s)	Other relevant demographics

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#### Area of Interest

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#### Context

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Key operational definitions

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Study Aim/Objective

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Hypothesis

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#### Study Design

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Statistical tests used

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Outcome

---

Key limitations

---

Additional relevant details

**APPENDIX C**  
**Quality Appraisal Example (Caldwell et al., 2005)**

<b>Quality Framework</b>	
1. Does the title reflect the content?	
2. Are the authors credible?	
3. Does the abstract summarise the key components?	
4. Is the rationale for undertaking the research clearly outlined?	
5. Is the literature review comprehensive and up to date?	
6. Is the aim of the research clearly stated?	
7. Are all ethical issues identified and addressed?	
8. Is the Methodology identified and justified?	
<b>Quantitative</b>	<b>Qualitative</b>
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?
11. Is the population identified?	11. Is the context of the study outlined?
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?
15. Are the results presented in a way that is appropriate and clear?	
16. Is the discussion comprehensive?	
17. Are the results generalizable?	17. Are the results transferable?
18. Is the conclusion comprehensive?	

## APPENDIX D

### Quality Appraisal

Met criterion = 2, partially met criterion =1, not met criterion =0

Quality Framework		Butera-Prinzi et al. (2004)	Charles et al. (2007)	Ducharme et al. (2002)	Kieffer-Kristensen et al. (2011)	Kieffer-Kristensen et al. (2013a)	Kieffer-Kristensen et al. (2013b)	Moreno-Lopez et al (2011)	Pessar et al. (1993)	Stanescu et al. (2011)	Stanescu et al. (2013)	Uysal et al. (1998)
1. Does the title reflect the content?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Are the authors credible?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Does the abstract summarise the key components?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes
4. Is the rationale for undertaking the research clearly outlined?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes
5. Is the literature review comprehensive and up to date?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes
6. Is the aim of the research clearly stated?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
7. Are all ethical issues identified and addressed?		Partially	Yes	No	Yes	No	Partially	Yes	No	Partially	No	No
8. Is the Methodology identified and justified?		Yes		Yes	Yes	Yes	Partially	Partially	Partially	Yes	Partially	Partially
<b>Quantitative</b>	<b>Qualitative</b>	Qual	Both	Quan	Quan	Qual	Quan	Qual	Quan	Quan	Qual	Quan
9. Is the study	9. Are the	Yes	Yes/Yes	Yes	Partially	Yes	Partially	Partially	No	Partially	Yes	Partially

design clearly identified, and is the rationale for choice of design evident?	philosophical background and study design identified and the rationale for choice of design evident?											y
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	Yes	Yes/Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Partially	Yes
11. Is the population identified?	11. Is the context of the study outlined?	Yes	Yes/Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method	Yes	Yes/Yes	Yes Partially	Yes	Yes	Yes	Yes	Partially	Yes	Partially	Yes

	identified?											
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	Yes	Yes/Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Yes
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	Yes	Yes/Yes	Yes	Yes	Yes	Partially	Yes	Partially	Yes	No	Yes
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes/Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes
16. Is the discussion comprehensive?		Yes	Yes/Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
17. Are the results generalizable?	17. Are the results transferable?	No	No /No	No?	Partially / No	No	Partially?	No	No	No	No	No
18. Is the conclusion comprehensive?		Partially	Yes/Yes	Yes	Yes	Partially	Partially	Partially	No	Partially	No	Partially
<b>Score</b>		<b>32/36 89%</b>	<b>32/36 32/36 89% / 89%</b>	<b>31/36 86%</b>	<b>33/36 92%</b>	<b>31/36 86%</b>	<b>30/36 83%</b>	<b>28/36 78%</b>	<b>23/36 64%</b>	<b>31/36 86%</b>	<b>19/36 53%</b>	<b>29/36 81%</b>

## APPENDIX E

### Summary of study Characteristics

Author(s) and Year of Publication and Quality Rating	Aims/Objectives	Sample	Design & Measures Used	Key Findings	Strengths	Weaknesses
<p>Butera-Prinzi et al. (2004)</p> <p>89%</p>	To explore the child's experience of having a father with ABI	<p>N = 4</p> <p>Age range 7-12 years</p>	<p>Qualitative:</p> <p>Phenomenological Approach</p>	<p>Children were negatively impacted and at risk of emotional and behavioural difficulties</p> <p>Children reported profound grief, social isolation, fear of family disintegration, violence</p> <p>Children demonstrated resilience and reported positive outcomes, such as having greater independence due to parents having other responsibilities.</p>	<p>Childs experience</p> <p>Evidences "rich and complex picture"</p> <p>Little/few studies of this nature</p>	<p>Can't generalise</p> <p>Small sample size</p> <p>Children who were receiving counselling</p> <p>Fathers with ABI – not mothers. We know from other studies there are gender differences</p> <p>No TBI – all ABI (although gives definition of TBI – not ABI)</p> <p>Minimising of difficulties / worried out may impact on MFGP</p> <p>2-4 years since onset, different in acute stages</p> <p>Only used eldest children</p> <p>Two parents families</p> <p>No control group</p>
<p>Charles et al. (2007)</p> <p>89%</p>	To explore multi family group work (MFG) intervention with families with a parent with an ABI and impact on the child.	<p>N = 9</p> <p>Age range 7-13 years</p>	<p>Mixed Methods</p> <p>Qualitative: Thematic Analysis of MFG sessions</p> <p>Quantitative: Within Subjects</p> <p>A comprehensive range of validated assessments were used (See appendix X for further details on measures used)</p>	<p>Parents reported generally reduced levels of personal distress at follow up (not clear why) but continuing high levels of mental and family dysfunction.</p> <p>Children were generally reported to be well functioning based on the BASC.</p> <p>Children showed reduced</p>	<p>Defines ABI and what that excludes</p> <p>Good description/validity/reliability of measures used</p> <p>Child self-report measures</p> <p>Information about family, details of accident/nature of ABI (including TBI, stroke, tumour)</p> <p>Clearly states aims</p>	<p>Small sample size</p> <p>No evidence of comparison group</p> <p>Based on family relationships, not on individual loss, grief, changes in personality, identity and family roles</p> <p>Families 'in crisis' at time of group</p> <p>Intervention</p> <p>No control group</p>

				feelings of shame and isolation. Reported benefit of provision of mutual support, increased understanding, sharing diff experiences, moving from blame to compassion	Differentiates each family member experience  Not all 2 parent families. That is where parents are cohabitating, married or in a stable partnership.  Details of families ABI pre and post relationship - different from other studies	
Ducharme et al., (2002)  86%	To assess intervention of errorless compliance training for parents with an ABI for improving child compliance.	N = 8  Age range 2-7 years	Quantitative: Multiple base line across subjects design  Measure of self esteem and child compliance also completed.	Generalised and durable increases were observed in child compliance after treatment.  Increased parent self esteem.	Series design To aid parents with ABI's Intervention helping children with difficulties	Small sample size Parents required intensive prompting
Kieffer-Kristensen et al.(2011)  92%	To relate illness and family factors to emotional and behavioural problems in school age children (7-14yrs) of parents with ABI and their spouses.	N=35  Age range 7-14 years	Quantitative: Cross Sectional Between Subjects	46% of children in ABI group met the clinical diagnostic criteria for PTSD total score to 10% in the diabetes group. Parent's ratings on the child behaviour checklist showed significant elevations on the externalising, internalising ^ total scores when compared to the normative sample.	Control group Separated TBI Child self-report measures Demographic characteristics ABI clearly defined Parent/family/teacher – several perspectives	Small sample size – limited statistical power Two parents families – can't generalise this to norm population 4 years, mean time since injury, scores may have been different in acute stages Self-report – potential of minimising difficulties, not wanting to concern parents.

<p>Kieffer-Kristensen et al. (2013a)</p> <p>86%</p>	<p>To listen and learn from children showing high levels of post traumatic stress symptoms after parental ABI</p>	<p>N=35</p> <p>Age range 7-14 years</p>	<p>Quantitative: Within Subjects</p> <p>A comprehensive range of validated assessments were used (See appendix X for further details on measures used)</p>	<p>ABI families – the children’s emotional functioning depends upon family factors and primarily on the level of parental stress in the healthy parent</p> <p>The family stress variables in the healthy parent was significantly related to post traumatic stress symptoms and emotional and behavioural problems in the children.</p>	<p>Number of variables</p> <p>Children self-report their experience</p>	<p>Small sample size</p> <p>Use of volunteer, non-referred sample – limits the generalisation</p> <p>Two parent families</p> <p>Age/gender – difficult to distinguish correlation due to sample size</p> <p>No control group</p> <p>Small proportion of sample is TBI</p> <p>Severity of TBI?</p> <p>Severity of any TBI not stated</p> <p>Lack of understanding around treatment program they are providing.</p>
<p>Kieffer-Kristensen et al. (2013b)</p> <p>83%</p>	<p>To examine post-traumatic stress symptoms (PSS) and psychosocial functioning in children with a parent with an ABI</p>	<p>N=14</p> <p>Age range 7-14 years</p>	<p>Qualitative:</p> <p>Phenomenological Approach</p>	<p>Themes identified</p> <ul style="list-style-type: none"> <li>-Fear of losing the parent</li> <li>-Distress and estrangement</li> <li>-Chores and responsibilities</li> <li>-Hidden loss</li> <li>-Coping and support</li> </ul> <p>Children experienced several losses during different stages in their parent’s illness and that these losses were often suppressed or neglected both by the children and the parents so as to protect the ill parent.</p>	<p>Qualitative – few studies looking at the experience of the child</p> <p>Rich data</p> <p>TBI 4/14 – differentiates Information on BI characteristics</p> <p>Similar findings in other studies – cancer</p> <p>Highlights needs to work directly with children</p>	<p>All children had elevated post traumatic symptoms – no comparison group</p> <p>All were part of treatment program – lack of understanding about this program. Fear of not being involved in the programme if not part of interviews? Or exaggerating symptoms?</p> <p>Variance in length of interviews</p> <p>Younger children had difficulty expressing feelings</p> <p>Data has been used for other studies – over represented?</p>
<p>Moreno-Lopez et al (2011)</p> <p>78%</p>	<p>To explore the experiences of adolescent offspring following parental moderate – severe ABI</p>	<p>N=9</p> <p>Age range 13-20 years</p> <p>Siblings were included</p>	<p>Qualitative: Grounded Theory</p>	<p>Adolescents appeared to go through a process of re-evaluation of life priorities, sense of fragility, and increase in appreciation of family needs. Have a protective role within the family, assisting family with long-term challenges.</p>	<p>Reports by children</p> <p>Adolescents – interesting developmental age, complex transition.</p> <p>Explores supportive relationships</p> <p>Participants demographics/characteristics</p> <p>Develops model/theory</p> <p>Triangulation</p>	<p>Sample 6 girls/3 boys</p> <p>Reports theoretical sampling but unable to recruit based on ideas.</p> <p>Nvivo – use of software – emerging self in data?</p> <p>Skewed by gender/siblings</p> <p>Small sample and homogeneous in terms of demographic characteristics</p>

				Alternative parental figures and peer friendships appeared to play a central role for participants.	Reflexivity Credibility checks Rich data Coherent / clear model – shows interrelation – it's justified in verbatim text. Variability of the sample with regards to wide age range of adolescents is considered a strength States weaknesses and ways to strengthen further research Implications for clinical practice	Results should be viewed with caution due to limited small main sample, recruiting difficulties Recruitment bias – families coping better felt more willing to take part and expose their lives
Pessar et al. (1992)  64%	Effect of parental brain injury and subsequent disabilities on the children.	N= 24 (Made up of family units)  Age range 2-23 years	Quantitative: Cross Sectional Within subjects  A comprehensive range of validated assessments were used (See appendix X for further details on measures used)	22/24 families reported negative changes in children's behaviour since the injury  In 10 of the families, significant and problematic changes occurred  Types of problems involved poor relationship with injured parent, acting out behaviour and emotional problems  Correlates of poor outcomes for the children were Injured parents gender  Compromised parenting performance of the injured parent  Compromised parenting performance of the uninjured parent and depressed in the uninjured parent.	Dynamic nature of family interactions and relationships Taken in to account age, gender, years married and education Impact upon all family members.	Small sample – larger sample of families and children would lead to greater confidence in findings Larger sample of mothers – for understanding gender differences 'units' of families – no regard for the individual child Use of the uninjured parent as principle source of information may confound the findings If parent is depressed may bias responses No behaviour observation of the children No comparison group Definition / severity of TBI – defined by level of PTA
Stanescu et al. (2011)	Examining the interrelation between family functioning and	N=46 (Made up of family units)  Age range 11-18 years	Quantitative: Between Subjects	Family dysfunction as a whole positively correlates with psychological symptoms	Clear definition of TBI – severity 58 families – larger than other studies but still small	Needs more in-depth interpretation F-COPES data were not available from adolescents

86%	<p>children's mental health in families with a brain injured parent.</p> <p>Investigate predictive power of family functioning for children's psychological well-being.</p>		A comprehensive range of validated assessments were used (See appendix X for further details on measures used)	of adolescents; four sub dimensions of family functioning predicted children problems, namely affective responsiveness, affective involvement and roles and communication.	<p>Informs focused intervention concepts – family therapy</p> <p>Support/predictive element</p> <p>Results supported by previous studies of parental illness</p>	<p>perspective</p> <p>Small sample size</p> <p>Inclusion criteria – excluded families with problems prior to current illness, or single parent families, divorced, not legally constituted, could exclude exactly the kind of family which perhaps are in more need of support</p> <p>No comparison group.</p>
<p>Stanescu et al. (2013)</p> <p>53%</p>	To identify main coping strategies used by adolescents with TBI parent.	<p>N = 5</p> <p>Age range 14 and 17 years</p> <p>2 girls, 3 boys.</p>	<p>Qualitative:</p> <p>Interpretative phenomenological approach</p>	<p>Emotional regulation and social support are associated particularly to girls.</p> <p>Boys tend to not seek help in solving problems or share their feelings.</p> <p>Coping styles used cover closeness (e.g., emotional balancing, search for social support, taking over responsibilities) and avoidance strategies; distraction, trivialising events, internalisation.</p> <p>Externalise of grievances occurs in this age group, ranging up to conflicted outbreaks towards parents.</p> <p>Identification with the parent perceived as stronger and as closer to the child is a powerful coping mechanism.</p>	<p>Clear aims / objectives</p> <p>Addresses gender differences</p> <p>In-depth view of adolescents experience</p>	<p>Doesn't define TBI</p> <p>Doesn't define nature of parents difficulties – could be ABI?</p> <p>What does counselling involve?</p> <p>Not described.</p> <p>Little known about family set up</p> <p>Could be other factors involved aside from TBI.</p> <p>Time of counselling – shock, adaptation and acceptance unlikely to have started</p>
Uysal et al. (1998)	The effects of parental TBI on children and the	N = 32 (Made up of family units)	Quantitative: Between subjects	Parents with TBI reported less goal setting, less	<p>Childs perspective</p> <p>Control group</p> <p>Perspectives of</p>	<p>On average 9 years since onset – would expect there to be level of acceptance</p>

81%	effects of parental TBI on levels of depression for all family members.		A comprehensive range of validated assessments were used (See appendix X for further details on measures used)	<p>encouragement of skill development, less emphasis on obedience to rules and orderliness, less promotion of work values, less nurturing and lower levels of active involvement to their children.</p> <p>Spouses of individuals with TBI reported less feelings of warmth, love and acceptance towards their children</p> <p>Children of TBI parent perceived both parents as less actively involved in parenting roles</p> <p>No differences in the frequency of behaviour problems were found between parents with TBI and children of parents without TBI.</p> <p>Parents with TBI and their children experienced more symptoms of depression relative to respective comparison groups.</p>	<p>spouse/parent/child</p> <p>Variety of measures</p> <p>Break down of brain injury characteristics</p>	<p>Children may minimise / or resilience – of disability or parenting skills</p> <p>Small sample size</p> <p>Parents with TBI may be overly critical of their own parenting behaviour</p> <p>Children of parents with TBI may rate their parent using the “halo effect” (i.e. Their parents are doing very well despite the TBI)</p> <p>Sample over represents those families with positive outcomes by virtue of selection bias (i.e., either individuals experiencing parenting (or family) difficulties may have been less willing to participate in this study, or divorced or separated individuals who were not currently living with their children were eliminated from this study)</p>
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Step	Status	Actioned by	Actioned on
Project	Submitted	<a href="#">Rebecca Casey</a>	Mon, 25 Nov 2013 02:54 PM
Supervisor	Approved	<a href="#">Eve Knight</a>	Tue, 10 Dec 2013 08:08 PM
Referrer	Referred to Reviewer	<a href="#">Joanna Hemming</a>	Thu, 06 Feb 2014 11:22 AM
Reviewer	Approved	<a href="#">Reviewer</a>	Mon, 10 Feb 2014 12:17 PM
Finalizer	Approved	<a href="#">Elaine Cartmill</a>	Mon, 10 Feb 2014 07:06 PM

5 Steps

**Projects**

- > My Projects
- > Create Project (New)

**Support**

- > Read this first!
- > User Guide
- > Contact People
- > Documentation
- > Health & Safety
- > CU Disclosure Protocol



The following **ethics** request has been approved by Elaine Cartmill. All the relevant documentation will be available for you to download within the next 24 hours. Please log back into **Ethics** and select the request from your listing. Select the Downloads tab to retrieve the documentation.

Please proceed with good **ethics**.

Ref:	P19002
Project Title:	The Role of Mutual Support on Identity in those with Acquired Brain Injuries.
Applicant:	Rebecca Casey
Supervisor:	Eve Knight
Module Code:	D38PY
Module Leader:	

Go to [ethics.coventry.ac.uk](https://ethics.coventry.ac.uk) to view this request in more detail.

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## MODERN UNIVERSITY OF THE YEAR 2014

Source: The Times and The Sunday Times Good University Guide 2014

## APPENDIX G

### Gate Keeper Letter



The Silver Lining  
Grapes House  
79a High Street  
Esher  
Surrey  
KT10 9QA  
Charity No: 1132902  
[www.thesilverlining.org.uk](http://www.thesilverlining.org.uk)

10 Ambassador Court  
Kenilworth Road  
Leamington Spa  
CV32 6JF

2 April 2014

Dear Sir /Madam

**RE: Rebecca Casey, Ref Module: D38PY, Student Number: 4652683**

Please accept this letter as confirmation that our Charity, The Silverlining has agreed for Rebecca to conduct a Research Study for her thesis proposal into the effects of brain injury and we give her full permission to contact our clients as part of her research to assist her to critically explore how one's identity develop through mutual support following an acquired brain injury.

Rebecca will be conducting interviews with our Silverlining clients across all our Regions. We have therefore given Rebecca permission to contact them directly.

Please contact me if you require further confirmation of this study.

With Best Wishes,

Dr. Sherrie Baehr  
Charity Founder and Trustee

## APPENDIX H

### Consent Form

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7685 8328  
Fax 024 7685 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF  
WARWICK

Coventry  
University

### CONSENT FORM

**The Role of Mutual Support on Identity in those with Acquired Brain Injuries.**  
**Researcher: Rebecca Casey, Trainee Clinical Psychologist**

I .....(insert name)

give my full consent to take part in the following research investigation with the full understanding that I may withdraw my data for up to two weeks after the interview without giving any reason.

If I withdraw from the study, the data that I have submitted will also be withdrawn. I have received an information sheet explaining what the study is about and what will be expected from me.

I understand that the information that I will submit will be confidential, and used only for this study and all identifiable data relating to me will be removed.

*Please initial the boxes*

I have had the opportunity to meet with researcher Rebecca Casey	<input type="checkbox"/>
I have read and understood the participant information sheet	<input type="checkbox"/>
I have had the opportunity to ask any questions	<input type="checkbox"/>
I understand that the interview will be audio-recorded	<input type="checkbox"/>
I understand that all my information and data will be kept confidential	<input type="checkbox"/>
I understand that I can withdraw without this affecting any care received	<input type="checkbox"/>
I understand that I may withdraw my data with no reason for up to two weeks after interview	<input type="checkbox"/>

Participant Name..... Date..... Signed.....

**Dean of Faculty of Health and Life Sciences**  
Dr Linda Meriman: Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**  
Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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## APPENDIX I

### Participant Information Sheet

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7688 8328  
Fax 024 7688 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D., CPsychol

THE UNIVERSITY OF  
WARWICK

Coventry  
University

**INFORMATION SHEET:**  
**The Role of Mutual Support on Identity in those with Acquired Brain Injuries.**

*The researcher would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part.*

**What is the purpose of the study?**  
*This study aims to assess the impact of mutual support following an Acquired Brain Injury (ABI). The researcher hopes to make a case that mutual support plays a role in the rehabilitation process following an ABI.*

**Why have I been chosen to take part?**  
*You have been chosen to take part in this study as you have suffered an acquired brain injury.*

**Do I have to take part?**  
*This study is optional; you do not have to take part in this study.*

**What will happen to me if I take part?**  
*If you agree to take part you will engage in an interview discussing Acquired Brain Injury. The interview will take place in your home or at a quiet prearranged location.*

*The meeting will begin with a short introduction from the researcher telling you about themselves and the research. Together, you will complete a demographic form detailing basic information (e.g. date of birth, ethnicity etc.) and details of your acquired brain injury (e.g., onset, type etc.). The researcher will ensure that you have understood what is expected of you and give you the opportunity to ask any questions.*

*The interview will then take place and will be recorded using a Dictaphone. You will be asked some questions surrounding the research topic. Once the interview is complete you will have the opportunity to ask any questions and you will be debriefed by the researcher.*

Dean of Faculty of Health and Life Sciences  
Dr Linda Merriam Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology  
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

1

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**What is the duration of the study?**

*It is expected that the interview will take approximately 1.5 hours.*

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

*There are no direct benefits. However your results will help towards the understanding of how mutual support psychologically impacts upon an individual.*

**Will I be contacted again?**

*You may be contacted again should we wish to continue your interview or clarify the content. If you wish to receive feedback regarding the outcome of the research please state on your demographic form.*

**Will my taking part be kept confidential?**

*All information that is collected about you during the course of research will be kept strictly confidential, and any information about you that leaves the location of interview/university will have your name and address removed so that you cannot be recognised.*

*Your data will be numbered and you will be given this number on a card to keep. If you wish to withdraw during or after the study this number will be used to identify your data. Your data will be available to those who read the study, but your name will not be identified.*

*Any data you do provide today will remain both confidential and anonymous and will be used only for the purposes outlined here.*

*You may use the contact number below should any queries or concerns arise in the future.*

**What if there is a problem?**

*If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.*

*If you remain unhappy and wish to complain formally you can do this through the Coventry University by contacting Helen Liebling on 0247 688 7806.*

*If this is not satisfactory please contact the Patient Advisory Liaison Service (PALS) on 0247 636 2100.*

**Harm**

It is not predicted that you will come to any harm as a result of taking part in this research. However, if you are harmed because of the research due to negligence, you may be able to take legal action against Coventry University, but you may have to pay for legal costs.

**Family Doctor/General Practitioner**

Your family doctor/general practitioner will not be informed of your involvement of this research.

**The Results**

It is anticipated that the results of this study will be published. You will not be identifiable in any publications.

**Who is organising and funding the research?**

The research is organised by Rebecca Casey, who is currently undertaking a Doctorate in Clinical Psychology at Coventry and Warwick Universities. The project is not externally funded.

**Who has reviewed the study?**

This study has been through the University Peer Review process and been approved.

**Thank you for taking time to read this sheet – if you have any further questions please contact a member of the research team.**

**Please keep this copy. If you misplace it please contact the research team who can give you another copy.**

**Please note that any information you may supply today will only be used for the purposes outlined and your participation in the study is voluntary, with the right to withdraw at any point.**

Thank you.

Researcher:  
Rebecca Casey ([Caseyr4@uni.coventry.ac.uk](mailto:Caseyr4@uni.coventry.ac.uk))  
Trainee Clinical Psychologist  
Coventry and Warwick Clinical  
Psychology Doctorate

Academic Supervisor:  
Dr Eve Knight  
([e.knight@coventry.ac.uk](mailto:e.knight@coventry.ac.uk))  
Programme Director  
Coventry & Warwick Clinical Psychology

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7688 8328  
Fax 024 7688 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D., CPsychol

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### **The Role of Mutual Support on Identity in those with Acquired Brain Injuries.**

#### Invitation Letter

Dear Participant

You are invited to take part in research. The research is looking at the role of mutual support on identity in adults with acquired brain injury. Mutual support is a process of giving and receiving help based on key principles of respect, shared responsibility, and mutual consensus of what is helpful. It is about understanding another person's situation empathically through a shared experience.

This research will involve taking part in an interview discussing your experience of your brain injury and what you gain from attending mutual support groups. It will take approximately one and a half hours of your time. Please read the information sheet for more information.

If you would like to take part please let Rebecca Casey know. You can contact them directly (contact details on information sheet).

Thank you.

Yours sincerely,

Rebecca Casey  
Trainee Clinical Psychologist

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Trevelian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

## APPENDIX J

### Participant Demographic Form

Coventry University  
Priory Street, Coventry CV1 5FB  
Telephone 024 7688 8328  
Fax 024 7688 8702

Programme Director  
Doctorate Course in Clinical Psychology  
Dr Eve Knight  
BSc Clin.Psy.D. CPsychol

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#### DEMOGRAPHIC Information

#### The Role of Mutual Support on Identity in those with Acquired Brain Injuries.

Name	Surname	
Gender	Male	Female
Ethnicity (please state)		
AGE	DOB	

Onset of Injury (please state approx. date)			
<b>Type of ABI</b>			
Stroke: Infarct	Stroke: Other	Anoxia	Other (Please State)
Stroke: Haemorrhagic	Trauma	Toxic	
Stroke: Subarachnoid	Inflammatory	Tumor	
<b>Localisation of Injury</b>			
Right Hemisphere	Frontal	Brain Stem	Global/Diffuse
Left Hemisphere	Cerebellar	Bilateral	Unknown

Upon discharge from acute or post acute care were you informed of any  
mutual support groups? (Please circle) Yes No

Are you currently involved in any mutual support groups / charities (e.g. The  
Silverlining or Headway)? (Please circle) Yes No

If yes, could you please state length of involvement.....

Would you like to be notified of the results of this  
study? (Please circle) Yes No

Thank you

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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## **APPENDIX K**

### **Interview Schedule Version 1**

# **Universities of Coventry & Warwick Doctorate in Clinical Psychology**

## **The Role of Mutual Support on Identity in those with Acquired Brain Injuries.**

### **Interview Schedule**

#### **Confidentiality**

The information you give me in this interview will be confidential and the report will be written in a way that what you say will be anonymous. However, if you tell me something that suggests you may be at risk of harm or another person may be at risk of harm, I have a duty to inform a health care professional. Is there anything you would like to ask me about this?

#### **Introduction**

My name is Rebecca and I am researching what impact the groups that you attend (name of group) have had on you. I am interested in your experience within these groups since you suffered your brain injury.

The interview is really a conversation that will allow you to share your experience with me. I am particularly interested in your experiences within the groups that you attend.

Do you have any questions for me?

#### **Introduction questions**

- Could you briefly tell me about the events that led up to you attending this group?

- How would you describe the person you were before you had your head injury?
- Tell me about how you became involved in the group?

### **Intermediate questions**

- What does the group mean to you?
- What changes have occurred in your life since attending this group?

Prompts:     Positive/Negative changes?  
                      Can you give an example?  
                      Can you tell me a bit more about that?

### **Identity**

- Tell me how you would describe the person you are now?  
                      Prompts:     What do you think has contributed to this?  
                                      Can you tell me a bit more about that?
- How do you see yourself in relation to your family/friends/colleagues?

Prompts:     Has this changed since your injury?  
                      (If yes) In what way has it changed?  
                      Who do you relate to best? Why is that?

- How do you think these people see you as a person?  
                      Prompts:     Has this changed since your injury? How?

### **Ending Questions**

- Is there anything else you would like to tell me about in relation to attending these groups?
- Is there anything you would like to ask me?

## **APPENDIX L**

### **Interview Schedule Version 2**

# **Universities of Coventry & Warwick Doctorate in Clinical Psychology**

## **The Role of Mutual Support on Identity in those with Acquired Brain Injuries.**

### **Interview Schedule**

#### **Confidentiality**

The information you give me in this interview will be confidential and the report will be written in a way that what you say will be anonymous. However, if you tell me something that suggests you may be at risk of harm or another person may be at risk of harm, I have a duty to inform a health care professional. Is there anything you would like to ask me about this?

#### **Introduction**

My name is Rebecca and I am researching what impact the groups that you attend (name of group) have had on you. I am interested in your experience within these groups since you suffered your brain injury.

The interview is really a conversation that will allow you to share your experience with me. I am particularly interested in your experiences within the groups that you attend.

Do you have any questions for me?

#### **Introduction questions**

- Could you briefly tell me about the events that led up to you attending this group?

- How would you describe the person you were before you had your head injury?

### **Intermediate questions**

- What does the group mean to you?
- What changes have occurred in your life since attending this group?

Prompts: Positive/Negative changes?  
Can you give an example?  
Can you tell me a bit more about that?

### **Identity**

- Tell me how you would describe the person you are now?  
Prompts: What do you think has contributed to this?  
Can you tell me a bit more about that?
- How do you see yourself in relation to your family/friends/colleagues/community groups?

Prompts: Has this changed since your injury?  
(If yes) In what way has it changed?  
Who do you relate to best? Why is that?

- How do you think these people see you as a person?  
Prompts: Has this changed since your injury? How?

### **Ending Questions**

- Is there anything else you would like to tell me about in relation to attending these groups?
- Is there anything you would like to ask me?

## APPENDIX M

### Sample Transcript and Example of Coding

Line by line code is demonstrated on the left hand side. Focussed Coding is demonstrated on the right.

Peter 004

65 (P) Erm, so it was a hell of a lot, erm, you know, so two month of post traumatic,  
 66 oh sorry, seven weeks of post-traumatic amnesia (cognitive consequences)  
 67 (I) Mmm hhhmm *no assumption about my knowledge*  
 68 (P) Where as you probably know, I had to relearn, pretty much everyone's  
 69 names, how to eat, sleep, walk, talk, who they are (relearn skills)  
 70 (I) Mmm *Relearning of skills - physically & cognitively*  
 71 (P) And everything really. Erm, and my poor mother I mean, she'd lost my Dad a (family)  
 72 year and five months before that as well and we were a very close family. So my (guilt)  
 73 mum had been through absolute hell. (sadness)  
 74 (I) yeah *other experiencing difficult times - mum*  
 75 (P) And then at the, so it started off with, in the (name of hospital) hospital, *Transitions*  
 76 whilst I was in intensive care, err two weeks later they transferred me to the *whilst in hospital*  
 77 neuro ward at the erm, (name of hospital)  
 78 (I) Oh right, ok  
 79 (P) And I was there for a month and a half, two months? Err, and then I was at a *(time to recover)*  
 80 rehabilitation hospital at, err, with Dr (name), at, at, erm in (name of place), the *rehabilitat*  
 81 rehab hospital there. Erm, yeah, and there were certain things that were pointed *rehabilitat*  
 82 in my mums direction, my issue is that, well firstly, in PTA and er just coming out (cognitive)  
 83 of it. I wasn't really, kind of, at the time, there are things that I remember physical  
 84 remembering For some unknown reason I remember having, getting the consequence  
 85 blood clot in my right leg. *Recalls getting a blood clot*  
 86 (I) Mmm (memory / professionals recalling)  
 87 (P) I remember the pain that I went through and I remember the nurse that was, *pain*  
 88 I was, cos everyday they used to wheel me down to the shop to get a newspaper,  
 89 not that I'd even read it, it's just a routine to try and teach me to get back in to *(routine)*  
 90 learn things on a daily basis (re-learn)  
 91 (I) Yeah  
 92 (P) Just exercising the brain. (cognitive)  
 93 (I) Yeah *routine altered brain to adjust*  
 94 (P) But I remember her taking me down there in the wheelchair cos I couldn't,  
 95 obviously I couldn't walk cos I had no skin on my left foot *(recollections)*  
 96 (I) Gosh *recalls being in wheelchair - unable to walk on damaged foot*

Peter 004  
 - post acute.  
 - LT - life.  
 - labels.

32 (P) Errr, and he errr, so yeah I was a passenger in his car, erm, they lived in  
 33 (name of place) in the middle of nowhere, erm so it was like single track roads, (narrative of  
 Explains location of accident - country roads  
 34 country roads, this, that and the other. He just came round a corner, erm, under accident)  
 35 the speed limit er, but he, er it was deep and there was water and he, er, should  
 36 have been going slower round the corner really, and it was dark and wet and (blame)  
 Blaming - driver could have been going slower  
 37 heavy rain and he aquaplaned the car, lost control of the car, the car then went  
 Heavy rain contributed to accident  
 38 sideways and hit the curb into a fence, the fence came through the window and  
 The car hit a fence, fence came through the window - causing brain damage  
 39 hit me in the face, erm, and I had. From what I remember, 4 brain haemorrhages. (physical  
 40 I had a Glasgow coma scale of 3, coma, erm, for a bit that lasted a month. I had outcome)  
 Consciousness was low for a month post accident  
 41 75% brain swelling against the skull. I had 11 teeth smashed out, some that (consequence)  
 Considerable damage to face  
 42 rammed back into place, they're dead now. I had them out, lots of these are fake  
 Lost many teeth  
 43 down here (points to bottom row of teeth). Erm, smashed all my jaw, my jaw has  
 44 now got the longest metal plate on the outside and on the inside and screwed in  
 Considerable damage to jaw  
 45 the jaw up here (points to upper jaw).  
 46 (I) mmm

47 (P) Both broke my wrists, burst my lung, normal stuff. I had a blood clot on my physical  
 Explaining injuries  
 48 right leg, cos I was in hospital for so long, wasn't moving round enough and that's outcome  
 Secondary consequences from being in hospital for so long  
 49 why now I'm registered disabled cos I can't walk too much on my leg and the consequence  
 Registered disabled - not able to walk distances  
 50 more I walk on my leg, I have to wear compression stockings, everyday, for the m - label  
 51 rest of my life because the majority of the valves that circulate the blood in my registered  
 Physical impact on the rest of life  
 52 deep vein are gone and broken, they won't recover.  
 Expresses that part of him will never recover.  
 53 (I) Mmm } disabled  
 54 (P) So my erm, my leg now swells and over the years it will ulcer and I'll be in a long term  
 Explains further complications that may happen in future outcome  
 55 wheelchair. So the point being, the less I use my leg now the better.  
 56 (I) Right, ok.

57 (P) That's why I've got a blue badge. (justifying 'disabled' label)  
 Justifies blue badge - disability label  
 58 (I) Yeah

59 (P) Errmm, so they forgot to extend the bed out when I was in a coma and as I (blame,  
 Blaming of services for bedsores  
 60 was coming out of it I was rubbing my foot on the end of the bed and I got a negligent  
 61 blister from my toes to my heel, so they had to take the skin off the whole foot to consequence  
 Lost skin on foot due to hospital negligence.  
 62 (I) Gosh  
 63 (P) the whole top 3 or 4 layers, something like that, to get rid of the blistering. Physical  
 a sense that it could have been prevented.  
 64 (I) Yeah consequence

John 001

- 66 here's the card and here's the other side of it, not much to see on the other side.  
67 And he says well I've written out the ticket already so you'll have to, um, you'll  
68 have to um ask (XXXX), and well that's ridiculous, umm, umm, he say's no, I've  
69 written out the ticket already you'll have to um um put in a claim against you. I  
70 said well look, can't you take that away and he said no, I can't do that. So he stuck  
71 the sticker with the sticky seam on the back of it on my windscreen. So I took it  
72 off and said look, you know, that's ridiculous, have a, and what I did, all I did, I I I  
73 pushed, I slapped it back on his chest, nothing too offensive. So it stuck on his  
74 chest.  
75 (I) Mmm, yeah.  
76 (P) Er, and then he took it off his chest and he then took it off his chest, threw it  
77 on the ground a disappeared off. So I thought, well, what's happened, you know,  
78 I'll have to put a claim in against it. And then the next day the police came round  
79 to my house here and,  
80 (I) Gosh.  
81 (P) saying I'd struck this chap umm and so I said, I said and what, what, if I  
82 struck him what, what, did I break anything, was there any blood? Had I really  
83 smashed him (smashed fist against palm), I would've done. No there isn't but you  
84 shouldn't go round hitting people, I didn't hit him. I explained the story umm and  
85 I had to put a claim in, a counter claim to say that the parking ticket was invalid.  
86 Erm and he said well yes, we agree with you that, that, that fine against you will  
87 be taken off but I'm on police records now as somebody who hits people.  
88 (I) Oh gosh.  
89 (P) So, I've hit you. (Laughs)  
90 (I) (Laughs) Oh dear.  
91 (P) So that's my (xxxx) streak, yes, yes, all I did was slap my finger on it. But me  
92 slapping something on it, not like that, it's it's more forceful so.  
93 (I) So kind of, maybe more, erm,  
94 (P) Yeah, well.  
95 (I) more instances of maybe, aggression?  
96 (P) Yes, yes aggression.  
97 (I) than before?

Managing  
emotional  
change  
&  
consequences

Experiencing  
conflict

Consequences  
of  
behavioural  
change

Managing  
aggression

## APPENDIX N

### Example of Constant Comparative Method

Below is an example of how I carried out the constant comparative method as proposed by Glaser and Strauss (1967) and later informed by Charmaz (2006). The two extracts below show the similarities from two separate interviews that led to the generation of a focused code in the analytic process.

#### Reflective Journal Extract - Participant 5

Christina intrigued me. She is the first participant that has talked about *not finding the group helpful* and wondering why she actually attends. She seemed angry by other members in the group. Christina discussed that she is *worse off than others in the group* and that she also *works harder*. By *comparison* she feels annoyed by the group and sees *herself as 'better' than others* but feels she has *more severe disabilities* than the rest of the group. I really wondered why she continued to attend the group if it frustrated her so much.

#### Reflective Journal Extract - Participant 4

Peter's interview was lengthy and I often felt as though I was being interviewed. Peter described a catastrophic accident and listed each and every injury. He described his *injuries in comparison to others* in the group and noted that *his were far more severe*. Yet, he had also had the best recovery. He saw himself as 'special' and that *he had a recovery like no one else in the group*. He spoke of *not needing the group* and referred to members as 'them'.

## APPENDIX O

### Summary Table of Coding

Table demonstrating the development of focused coding, axial coding and to the final conceptual categories.

Conceptual Categories	Axial Codes	Focused Coding examples
Pre-Injury Self	Loss	<ul style="list-style-type: none"> <li>- Used to have friends through work</li> <li>- Moving house/city</li> <li>- Unable to walk</li> <li>- <i>'I had a solid career'</i></li> </ul>
	Holding On	<ul style="list-style-type: none"> <li>- Wanting to be as close as possible to person I was before injury</li> <li>- Legal case lasting eight years</li> <li>- A sense of regaining the life that should have been through compensation</li> </ul>
	Maintained Identity	<ul style="list-style-type: none"> <li>- Feeling that fundamental parts of self are the same</li> <li>- <i>'Essentially the same person'</i></li> <li>- Feeling that fundamental parts of personality have remained since the accident</li> </ul>
Comparison	Comparison that assists the reformation of identity	<ul style="list-style-type: none"> <li>- Being the same as others</li> <li>- Learning of others journeys</li> <li>- Things could have been much worse</li> <li>- Feeling less impaired</li> </ul>
	Comparison that obstructs the reformation of identity	<ul style="list-style-type: none"> <li>- Seeing self as worse off than others</li> <li>- Feeling hopeless in relation to others level of progression</li> <li>- <i>'I got such an incredible duff deal, physically'</i></li> <li>- Feeling frustrated at being more 'brain injured' than others</li> </ul>
Accessing the Social World of Brain Injury	Authentic Friendship	<ul style="list-style-type: none"> <li>- Feeling that members in BI group are authentic 'refreshing'</li> <li>- Going to a group members wedding</li> <li>- Enjoying being with friends in the moment</li> <li>- Despite others going through similar experiences – lack of connection remains</li> <li>- Not having friends since injury</li> </ul>
	Banter and Laughter	<ul style="list-style-type: none"> <li>- Enjoying company of others</li> </ul>

		<ul style="list-style-type: none"> <li>-Feeling uplifted seeing others enjoy themselves</li> <li>- Missing companionship</li> </ul>
	Being Understood	<ul style="list-style-type: none"> <li>- Having TBI in common</li> <li>- Feeling less alone</li> <li>- Others experiencing same difficulties</li> <li>- Speech making it difficult for others to understand</li> <li>- Processing information is harder</li> </ul>
	Hijacked Identity	<ul style="list-style-type: none"> <li>- <i>'hijacked identity'</i></li> <li>- Being labelled brain injured</li> <li>- Loss of idiosyncrasies</li> <li>- Impact on maintaining job</li> </ul>
Purpose	Purpose and Self-efficacy	<ul style="list-style-type: none"> <li>- <i>'It gives you purpose to life'</i></li> <li>- Organising social activities</li> <li>- Triggering past experiences of responsibility</li> <li>- To plan things for others</li> </ul>
Accepting the Post-Injury Self	Acceptance	<ul style="list-style-type: none"> <li>- <i>'this is my life now'</i></li> <li>- Accepting of support</li> <li>- Engaging &amp; taking on new roles</li> <li>- Content with group membership</li> </ul>
Core Category: Getting to know the "New" me		