A QUALITATIVE EXPLORATION OF EXPERIENCES FOLLOWING TRAUMATIC BRAIN INJURY

A thesis submitted to The University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Medical and Human Sciences

2013

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SCHOOL OF PSYCHOLOGICAL SCIENCES
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# Paper 1: Literature Review

## Experiences of Family Members Following Traumatic Brain Injury: A Metasynthesis of Qualitative Studies

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Abstract

A Qualitative Exploration of Experiences Following Traumatic Brain Injury

Melissa Robertshaw

Doctor of Clinical Psychology
University of Manchester
June 2013

Paper one is a systematic literature review utilising a metasynthesis approach to investigate experiences of family members of adults with a traumatic brain injury (TBI). A systematic literature search identified sixteen studies which met the inclusion criteria. These studies were then critically appraised and their findings synthesised. The synthesis demonstrated that family members of adults with a TBI faced significantly increased responsibilities towards the individual, at the expense of other commitments. As the individual’s process of recovery progressed, family members developed changed perspectives which served to reduce the impact of the injury on their lives. The development of these perspectives was mediated by the emotional consequences of the responsibilities undertaken and the family member’s unmet support needs.

The objective of paper two was to investigate the concept of acceptance in individuals with a TBI, and factors that facilitated or hindered this process. A qualitative methodology was employed and semi-structured interviews were conducted with eleven participants who had sustained a TBI. Interview transcripts were analysed using grounded theory methodology. A model detailing the process of acceptance in TBI was developed, encompassing five core categories: “understanding limitations”, “changed perspectives”, “confirmation of prognosis”, “adapt and overcome”, and “barriers to acceptance”. Participants’ narratives focused on their attempts to understand their changed selves, and the changed perceptions and support from others that facilitated them to move forward and adapt to achieve acceptance, in the context of barriers that prevented them from progressing.

The final paper is a critical appraisal of the research process focusing on my experiences of conducting qualitative research investigating acceptance in individuals with a TBI. This appraisal initially explains why a grounded theory methodology was selected. It then details my reflections on challenges encountered in recruitment, conducting the interviews, measurement and analysis. The knowledge and skills I gained through the process are identified, with reference to their importance for my learning and progression towards becoming a qualified clinical psychologist.
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I am particularly grateful to the individuals who generously gave their time to take part in the study and were willing to share their experiences.

Finally, I would like to thank my family and friends, for their patience, support and understanding over the last few years.
Literature Review

Experiences of Family Members Following Traumatic Brain Injury: A Metasynthesis of Qualitative Studies

Prepared in accordance with requirements for submission to Neuropsychological Rehabilitation: An International Journal (Appendix 1)

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Abstract

Aim: This study aimed to synthesise the experiences of family members of adults with a traumatic brain injury (TBI). Family members have become increasingly involved in the care and support of individuals with TBIs, a role that has been associated with negative consequences, including emotional distress and reduced quality of life.

Method: Six databases were searched for qualitative research, in addition to qualitative journals, between 1965 and February 2013, identifying sixteen studies that met the inclusion and quality criteria. The synthesis involved the identification of key themes and concepts from each study, and similarities and differences between them. Reciprocal and refutational translations were identified and then synthesised to create overarching themes to explain the impact of the injury on family members.

Results: Four over-arching, inter-related themes were identified capturing the experience of family members of adults with a TBI, comprising: 1. responsibility; 2. emotional consequences; 3. support needs; 4. changed perspectives.

Conclusion: The results demonstrated the significant impact that the TBI had on the lives of family members, and highlighted the pivotal role that family members played in supporting the individuals, in addition to the importance of considering their needs and offering appropriate support in order to facilitate this.

Key words: brain injury, metasynthesis, qualitative research, family, carers
Introduction

Traumatic brain injuries, defined as an external force to the head causing an alteration in brain function or other evidence of brain pathology (e.g. loss or decreased level of consciousness, confusion, disorientation or memory deficits; Menon, Schwab, Wright & Maas, 2010), are recognised as one of the leading causes of death and disability in Europe and the USA (Maegele et al, 2007; US Department of Health and Human services, 2010). UK estimates cite incidence of hospital admission due to head injury as between 229 and 453 per 100,000 (Tennant, 2005; Yates, Williams, Harris, Round & Jenkins; 2006), with variation in the data likely reflective of differences in classification systems used. Hyder, Wunderlich, Puvanachandra, Gururaj and Kobusingy (2007) note that studies reporting “head injuries” may also include injuries to the bones and soft tissue of the face, and that many TBIs may not be recorded if medical intervention is not received, thus true incidence is difficult to determine. However, the causes of TBIs are fairly consistently reported, with falls, violence and road traffic accidents amongst the most common (e.g. Kay & Teasdale, 2001, Kelly & Becker, 2001, Livingston et al. 2000).

The consequential negative impact of such injuries on resources, the individual and their families is widely acknowledged. In Europe TBIs are among the top three causes of injury related medical costs (e.g. Polinder et al. 2005; Polinder, Meerding, Mulder, Petridou & van Beeck, 2007), and have been associated with a detrimental impact on employment for the individual (e.g. Haboubi, Long, Koshy & Ward, 2001). This is particularly pertinent as TBIs most commonly occur in young adults (e.g. Yates et al., 2006; Thornhill et al., 2000), and the effects can be long term or life-long. Due to advances in healthcare resulting in life expectancies of individuals with TBI being similar to that of the general population (Strauss, Shavelle & Anderson, 1998), TBIs reflect a substantial impact on resources.

The direct effects of the injury on the individual can be varied, encompassing physical, cognitive, emotional and/or behavioural difficulties, all of which may interact and contribute to wider consequences such as reduced social participation and independence (Schretlen, 2000). Individuals with a TBI often report pain (Ivanhoe & Hartman, 2004) and fatigue (Ziino & Ponsford, 2006), both of which can occur on a long term basis (Olver, Ponsford & Curran 1996). High rates of anxiety and depression are also found in individuals post injury (e.g. Bryant et al., 2010; Koponen et al., 2002), in addition to the occurrence of challenging behaviour
It is therefore unsurprising that individuals report a reduced perceived quality of life post injury (e.g. Dijkers, 2004). Long term outcome is mixed, with a meta-analysis by Schretlen and Shapiro (2003) focusing solely on cognitive functioning finding that in mild TBI cognitive functioning returns, on average, to baseline within 1 to 3 months. However, in moderate to severe TBI despite improvement in the first 2 years marked impairments remained, even at more than 2 years post injury. Dikmen, Machamer, Powell and Temkin (2003) report a similar finding, noting that recovery to pre injury levels was limited in relation to functional status and neuropsychological functioning 3 to 5 years after moderate to severe TBI, although severity of injury was not predictive of outcome on emotional or quality of life measures. It is this context, of sudden unexpected change to the individual due to the injury, with an uncertain long term outcome, and potential significant burden of the individual to resources, that family members are faced with in the aftermath of TBI.

Many family members are placed into an informal care giving role for the individual with the TBI, becoming key participants in the care and support of the individual and their recovery, a role noted for its challenges (Sinnakaruppan & Williams, 2001). The pivotal role of family members of individuals with a TBI is evidenced by the association shown between family well being and outcomes for the individual. The well being and satisfaction of family members have been shown to have a reciprocal effect on the individual with a TBI, with greater levels in family members associated with greater levels in the individual (e.g. Johnson et al., 2010; Vangel, Rapport, & Hanks, 2011). The important role of family relationships in protecting individuals with a TBI from symptoms of depression has also been demonstrated. Family dysfunction or critical comments from family members have been associated with a higher incidence of depression (Schonberger, Ponsford, Olver & Ponsford, 2010; Weddell, 2010), and greater levels of anxiety and depression in relatives have been associated with greater levels of depression in individuals with a TBI (Norup, Siert & Lykke Mortensen, 2010). In addition, rehabilitation outcomes for individuals with a TBI have been shown to be closely associated with family outcomes (e.g. Sander et al., 2002).

However, the occurrence of a TBI has been associated with a range of negative outcomes for family members who provide care for the individual. Levels of distress and burden in family caregiver’s post TBI are reported to be high (e.g. Allen, Linn,
Clinically significant levels of anxiety and depression are commonly found amongst samples of family caregivers (Marsh, Kersel, Havill & Sleigh, 1998), and similarly, their quality of life has been shown to be negatively affected by the injury (Kolakowsky-Hayner, Miner & Kreutzer, 2001; Norup, Welling, Qvist, Larssiert & Mortensen, 2012). Such findings have been replicated at different time periods post injury, including up to 20 years after, indicating that difficulties may persist indefinitely (e.g. Hoofien, Gilboa, Vakil & Donovick, 2001; Kreutzer et al, 2009). Incidence of TBI has also been associated with changes in family functioning, with alterations in role, such as increases in family responsibilities, financial strain, and diminished social interaction and isolation experienced by family caregivers (e.g. Kolakosky-Hayner & Kishore, 1999; Kreutzer, Serio & Berquist, 1994; Leatham, Heath & Woolley, 1996).

The impact of the injury has predominantly been studied in relation to spouses and parents. The occurrence of a TBI is noted to place strain on marriage and intimate relationships (Wood, 2008). There is contradictory data on whether the type of relationship held predicts levels of caregiver stress, with some studies finding no difference (e.g. Ponsford, Olver, Ponsford & Nelms, 2003), whereas others report that the TBI has a more negative impact on spouses than on parents (e.g. Gervasio & Kreutzer, 1997). It has been suggested that this is due to spouses and parents experiencing different challenges due to the incidence of TBI (Brooks, Campsie, Symington, Beattie, & McKinlay; 1986), with spouses losing companionship and emotional support (Gervasio & Kreutzer, 1997; Willer, Allen, Liss, & Zicht, 1991), whereas parents return to a role which is more familiar to them (Hall et al., 1994). Although little attention has been paid to the experiences of other family members, the limited research available would suggest that the TBI affects the family as a whole, with clinically significant levels of distress and the occurrence of family dysfunction found in siblings (Gan, Campbell, Gemeinhardt & McFadden, 2006; Orsillo, McCaffrey & Fisher, 1993).

However, not all family members report negative experiences after a relatives TBI. Wells, Dywan & Dumas (2005) found that family members reported higher levels of satisfaction than dissatisfaction with their care giving roles. Various studies have attempted to investigate factors that predict levels of distress in family members who provide care for the individual, focusing on factors relating to the individual with the TBI, and those relating to the family members themselves. A consistent finding is that the neurobehavioural sequelae of the injury, including greater behavioural or
cognitive difficulties, is predictive of greater family caregiver distress and family dysfunction, whereas the severity of the injury is not (e.g. Anderson, Parmenter & Mok, 2002; Knight, Devereux & Godfrey, 1998). With regard to family factors, social support has been identified as a principal element in moderating the effects of the TBI on family caregivers well being and satisfaction (e.g. Ergh, Hanks, Rapport & Coleman, 2003; Hanks, Rapport and Vangel, 2007). In addition the coping and problem solving style of the family caregiver has been implicated in moderating the impact of the injury, with use of ineffectual problem solving styles identified as a risk factor for depression in family caregivers (Rivera, Elliott, Berry, Grant & Oswald, 2007). Nabor, Seacat and Rosenthal (2002) also identified that caregiver needs were important, finding that a greater percentage of unmet needs predicted greater caregiver burden.

Despite the overwhelming evidence highlighting the distress and burden experienced by family members of individuals with a TBI, research evidence regarding interventions that specifically support the needs of such family members is limited. Interventions that have been considered range from support groups and provision of information, to formal therapies, such as family therapy (e.g. Hibbard et al., 2002, Kreutzer, Kolakowsky-Hayner, Demm, & Mead, 2002; Oddy & Herbert, 2003). Although evidence is limited, programmes including education about TBIs, incorporating outcomes, needs and care of the individual, have been found to be beneficial for family members placed in a caring role, with study findings reporting declines in distress and burden and improved quality of life and mood (Albert, Im, Brenner, Smith & Waxman, 2002; Hibbard et al., 2002; Smith & Godfrey, 1995).

Existing research has identified the detrimental impact of a TBI upon family members. However, the exact nature of interactions between variables that contribute to negative outcomes for family members are not fully understood and there is a lack of research investigating interventions to reduce such outcomes. The majority of research investigating family members of individuals with a TBI is quantitative, and there have been various reviews of quantitative research in this area (e.g. Blake, 2008; Oddy & Herbert, 2008; Perlesz, Kinsella & Crowe, 1999; Verhaeghe, DeFloor & Grydonck, 2005). Perlesz et al. (1999) commented on the need for research on the family as a whole and the effect of the injury on male relatives, who are poorly represented in the literature, as well as a more theoretically coherent framework of family adaptation post TBI, for which they state qualitative research would be an important contributor. Verhaeghe et al (2005),
Blake (2008) and Oddy and Herbert (2008) emphasised the need for information, support and care to alleviate distress in family members, while noting that the conceptualisation of such support, and at which point it is required is difficult to determine.

Qualitative research may provide further information regarding such factors, and there is a growing evidence base focusing on experiences of family members of individuals with a TBI. Such research can provide information about living through or with a particular experience, and thus may provide a greater understanding of the support needs of family members, and contribute to a richer knowledge regarding the process of adaptation over time. To date only one study has attempted to review this research. Martin (2012), focused on investigating and synthesising research on informal care giving in TBI. While this is a related area, family members are not the sole providers of care to individuals with a TBI, with others outside of the family system often involved, such as friends, in addition to paid care givers. Additionally, as discussed previously, the injury may impact on family members regardless of whether they are directly involved in the care of the individual. The inclusion of only five studies in Martin’s (2012) review, would appear to restrict its focus to a small proportion of the literature, significantly limiting the findings. It is perhaps due to this that the synthesis supports, but does not appear to further, the existing quantitative research in the area, highlighting carers concerns regarding future roles, a negative impact on carers occupation and the requirement of information and support to become expert in their roles.

The present study aimed to review and synthesise qualitative findings regarding the impact of a TBI on family members of adult individuals in whom the TBI occurred, encompassing all members of the family system. It was hypothesised that assimilating the views of different family members would provide an enriched understanding of family experiences and needs which could contribute to implications for clinical practice.
Method

Literature Search

Published articles investigating family experience after a relative’s TBI were identified via computerised searches of the following databases: AMED, CINAHL, EMBASE, MEDLINE, PsycINFO, and Web of Science. The search included studies that were published in English between 1965 and February 2013 when the review was conducted. The initial time point was defined as preliminary investigations found that there was little qualitative research published in this area prior to this date. Prominent qualitative journals were also manually checked (e.g. Qualitative Health Research, Qualitative Research, Qualitative Research in Psychology), along with the reference lists of the identified articles.

Difficulties in the identification of qualitative studies are well documented, (e.g. Evans, 2002; Barroso et al., 2003), due to limited database indexing and ambiguity in titles and abstracts of qualitative research. In an evaluation of search strategies for qualitative research, Flemming and Briggs (2007) state that where this is the case, broad based terms may be as effective in identifying qualitative research as more specific indexed terms. Therefore, in order to try and encapsulate an approach which would maximise sensitivity whilst also ensuring an appropriate degree of specificity, terms were initially divided into three distinct categories, in line with the approach used by the Evidence for Policy and Practice Centre (EPPI-Centre; 2008). These incorporated: 1. Terms relating to traumatic brain injury (e.g. TBI, head injury, brain damage); 2. Terms relating to family (e.g. parent, relative, carer); 3. Terms relating to study methodology (e.g. qualitative, interview, thematic).

Specific search terms used were selected based on previously published research, incorporating Cochrane reviews relating to the treatment of traumatic brain injury (e.g. Bennett, Trytko & Jonker, 2012; Ker & Blackhall, 2010; Saxena, Andrews & Cheng, 2008), Cochrane reviews relating to family (e.g. Candy, Jones, Drake, Leurent & King, 2011; Eccleston, Palermo, Fisher & Law, 2012), and review of qualitative methodological filters identified for specific databases (e.g. McKibbon, Wilczynski & Haynes, 2006; Walters, Wilczynski & Haynes, 2006; Wilczynski, Marks & Haynes, 2007; Wong, Wilczynski & Haynes, 2004; Shaw et al. 2002; a full list of search terms used is provided in Appendix 2)

Inclusion and Exclusion Criteria

To be included in the review, studies were required to meet the following criteria;
1. Report an original study employing qualitative methods (e.g. interviews, focus groups).
3. Investigate the experiences of adult family members of individuals who had experienced a TBI and were in adulthood at the time of the study. Studies which included individuals with a TBI in addition to family members were included as it was considered that they also contributed to family views and experience.

Studies were excluded if they:
1. Included families who had experienced other acquired brain injuries (ABIs) such as strokes, either singularly or in addition to those with a TBI, as it was considered that the traumatic nature of acquisition, and the greater prevalence in a younger age range of TBIs compared to other ABIs may result in different experiences for family members.
2. Included the views of other caregivers, such as professionals, as they were considered beyond the scope of the present review.
3. Predominantly focused on children, either as the individual with a TBI, or as the family members, as it was considered that this could be addressed in a separate review, and that experiences for this client group may be different due to the dependant nature of the relationship prior to the TBI.
4. Sought views on experiences of specific interventions following the TBI, as they were not felt to address the research question.

Critical Appraisal
There is no widely agreed criteria on which to assess the quality of qualitative papers (Walsh & Downe; 2006). Studies that met the inclusion criteria were therefore appraised for quality using a checklist developed from the Critical Appraisal Skills Programme quality appraisal checklist for qualitative research (CASP; 2010; Appendix 3), and criteria proposed by Walsh & Downe (2006; Appendix 4). The resulting checklist (Appendix 5) was used to appraise each study, with each question rated as either: 1 if the study fully met the criteria, 0.5 if it was demonstrated that the study partially met the criteria and 0 if the study did not meet the criteria. No studies were excluded on the basis of quality, to ensure that a wide range of family views were represented, and due to the lack of accepted methods for the exclusion of qualitative studies from synthesis on the basis of quality (Daly et al., 2007; Dixon-Woods et al., 2006). However, the quality ratings were intended to allow for consideration of the credibility and transferability of the results, and greater
weighting was intended to be given to studies with higher quality ratings in the synthesis. The studies were also rated by an independent researcher. Inter-rater discrepancies of between 0.5 and 1 occurred for 8 studies, which were addressed via discussion and review of each paper to reach a consensus.

**Synthesis of Findings**

The approach used for the synthesis was broadly based on Noblit and Hare’s (1988) meta-ethnography (steps provided in Appendix 6), which is the most commonly used and accepted method to synthesise the findings of qualitative research (Bondas & Hall, 2007), and has been used in several meta-syntheses (e.g. Downe, Finlayson, Walsh & Lavender, 2009). Contemporary use of the approach has moved away from some of Noblit and Hare’s (1988) original contentions, including that only papers using the same qualitative methodology could be synthesised. Noblit and Hare (1988) viewed that it would not be possible to translate studies of different methodologies onto each other while preserving the meaning of each study due to differing emphasis in types of data analysis, such as lived experience in phenomenology, and the role of the environment and context in ethnography. However, more recent papers have moved away from this notion (e.g. Campbell et al., 2003), and it is considered that inclusion of studies utilising differing methodologies can provide triangulation, and a more accurate depiction of the topic area. To this end, Walsh & Downe’s (2005) more recent guidelines for metasynthesis were also considered for the present review (Appendix 7), which develop on Noblit & Hare’s (1988) guidelines, while not based on the presupposition of only synthesising one qualitative methodology.

Initially, the studies were read several times and the key themes and concepts identified. These were then tabulated and considered using a compare and contrast approach to establish the relationship between them. This involved the identification of commonalities between metaphors and concepts, in addition to identifying those that contrasted, or overlapped without being directly comparable. This facilitated the translation of themes and concepts onto each other, with commonalities joined in a “relational translation” and explanations for contrasting “refutational translations” sought. Walsh and Downe (2005) note the importance of “refutational translations”, stating that they can contribute to a new theme that has not been identified in the initial studies.
The resultant themes were then progressively synthesised through grouping clusters of themes to create a final overarching group of themes and concepts, representing a new interpretation of the findings. This was represented in both written and diagrammatic form. In order to try and reduce synthesiser bias, following completion of the initial synthesis the findings were discussed with the research team and themes subject to further refinement to achieve a consensus.
Results

Characteristics of and Quality of Included Studies

The search initially elicited 1092 potentially relevant articles, of which 16 were considered appropriate to the review following a screening process for adherence to the inclusion criteria, as described in the Figure 1 below.

Figure 1: Flow Chart to Illustrate Results of Search Strategy

The sixteen studies collectively represented the perspectives of 508 family members of people who had experienced a TBI, who ranged in age from 14 to 82 years. The length of time since the injury ranged from 6 months to 26 years. The studies were from a range of countries, including Canada, USA, Sweden, Japan.
and Australia. A range of methods of data collection were used, with semi structured interviews conducted in person the most common. Other methods included one study using telephone interviews, two studies held focus groups and one study a written survey. A range of qualitative methodologies, including grounded theory, content analysis and phenomenological approaches were used. Table 1 detailing the study characteristics is provided below.

With regard to the quality of the studies, scores on the quality checklist ranged from 6.5 to 9, with none considered to be of poor quality with major flaws. It was considered that this would therefore not affect the credibility or transferability of the findings (Walsh & Downe, 2006). All of the studies demonstrated weaknesses in reporting of reflexivity, with no reference to this process in the majority of studies. One study did not explicitly define the type of qualitative methodology used, a major limitation, and seven studies did not adequately elaborate their methods of data analysis. However, all studies clearly described data collection and justification for this, and in general, reporting of findings was sufficiently detailed with adequate quotes to support the findings.
<table>
<thead>
<tr>
<th>Study</th>
<th>Authors &amp; Title</th>
<th>Focus of Study</th>
<th>Sample Characteristics</th>
<th>Data Collection</th>
<th>Analysis</th>
<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Carson (1993): Investing in the comeback: Parent’s experience following traumatic brain injury.</td>
<td>Experiences of parents following adult child’s TBI and return to the home.</td>
<td>Parents of children with a TBI from 20 families, 8-70 months post injury in the USA. Mean age: 47 (mothers), 48 (fathers)</td>
<td>1 or 2 interviews of 30 minutes to 3 hours duration</td>
<td>Grounded theory</td>
<td>6.5</td>
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<td>2</td>
<td>Gill and Wells (2000): Forever different: Experiences of living with a sibling who has a traumatic brain injury.</td>
<td>Experiences of living with siblings with a TBI.</td>
<td>3 sisters and 5 brothers, 3-14 years post injury in Ontario, Canada. Age range: 14-30</td>
<td>1 interview of 1 to 2 hours duration</td>
<td>Qualitative, descriptive</td>
<td>7</td>
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<td>3</td>
<td>Smith and Smith (2000): No map, no guide: Family caregiver’s perspectives on their journeys through the system.</td>
<td>Experiences of primary caregivers of TBI survivors in their attempts to obtain and co-ordinate services.</td>
<td>6 female and 2 male family primary caregivers 2-9 years post injury in Canada.</td>
<td>1 semi structured interview</td>
<td>Content analysis</td>
<td>7.5</td>
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<tr>
<td>4</td>
<td>Kao and Stuifbergen (2004): Love and load: The lived experience of the mother-child relationship among young adult traumatic brain injured survivors.</td>
<td>Experience and meaning of the relationship between young adult TBI survivors and their mothers.</td>
<td>12 individuals and 12 mothers, where the mother was the primary caregiver, 2-11 years post injury in Colorado, USA. Age range: 44-58</td>
<td>1 interview of 2-4 hours duration using specific concrete questions</td>
<td>Colaizzi’s (1978) Phenomenological Method</td>
<td>9</td>
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<tr>
<td>Study</td>
<td>Authors &amp; Title</td>
<td>Focus of Study</td>
<td>Sample Characteristics</td>
<td>Data Collection</td>
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<td>5</td>
<td>Leith, Phillips and Sample (2004): Exploring the service needs and experiences of persons with traumatic brain injury and their families: The South Carolina Experience.</td>
<td>Perception of service needs and gaps by people with a TBI and their families.</td>
<td>10 individuals and 10 family members 1-5 years post injury, in South Carolina, USA. Mean age: 58.9</td>
<td>1 Semi structured focus group interview</td>
<td>Content analysis</td>
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<td>6</td>
<td>Layman, Dijkers and Ashman (2005): Exploring the impact of TBI on the older couple: “Yes but how much of it is age, I can’t tell you…”.</td>
<td>Exploration of the meaning and impact of a TBI on older couples.</td>
<td>8 people with a TBI and 7 (2 female, 5 male) partners, 3-21 years post injury, plus a comparison group. Age range: 54-82</td>
<td>1 semi structured interview of 37-78 minutes duration.</td>
<td>Content analysis</td>
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<tr>
<td>7</td>
<td>Wongvatunyu and Porter (2005): Mothers experience of helping young adults with traumatic brain injury.</td>
<td>Experience of mothers helpingyoung adults with a TBI.</td>
<td>7 mothers of adult children who had experienced a TBI 8 months to 20 years previously, in Missouri, USA. Mean age: 53</td>
<td>3 interviews of approximately 1 hour over a period of 2 months, using an interview guide.</td>
<td>Descriptive analysis and inter-subjective dialogue (Porter, 1998)</td>
<td>7</td>
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<tr>
<td>8</td>
<td>Jumisko, Lexell and Söderberg (2007): Living with moderate or severe traumatic brain injury: The meaning of family member’s experience.</td>
<td>Experience of family members living with an individual with moderate to severe TBI.</td>
<td>8 close relatives of people with a TBI (incorporating 2 mothers, 1 father, 2 partners, 2 siblings &amp; 1 daughter), in northern Sweden. Age range: 28-56</td>
<td>1 interview lasting approximately 80 minutes, using an interview guide</td>
<td>Phenomenological Hermeneutic Interpretation (Ricoeur, 1976)</td>
<td>8</td>
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<tr>
<td>Study</td>
<td>Authors &amp; Title</td>
<td>Focus of Study</td>
<td>Sample Characteristics</td>
<td>Data Collection</td>
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<td>9</td>
<td>Rotondi, Sinkule, Balzer, Harris, and Moldovan (2007): A qualitative needs assessment of people who have experienced a traumatic brain injury and their primary family caregivers.</td>
<td>Determining the needs of individuals with a TBI and their family caregivers.</td>
<td>85 primary family care givers, and 80 individuals with a TBI, an average of 5.8 years post injury in Pittsburgh, USA. Age range: 18 to 69</td>
<td>1 semi structured telephone interview</td>
<td>Content Analysis based on Miles and Huberman (1994)</td>
<td>7.5</td>
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<tr>
<td>10</td>
<td>Fumiyo, Sumie, Akiko and Yasuko (2009): Psychosocial adjustment process of mothers caring for young men with traumatic brain injury: Focusing on the mother son relationship.</td>
<td>To elucidate the psychological process followed by mothers caring for sons with a TBI.</td>
<td>13 mothers of sons who had sustained a TBI 11 months to 3.5 years post injury, in the Kanto region of Japan. Age range: 30s to 50s</td>
<td>1 semi structured interview of 30 to 60 minutes</td>
<td>Modified grounded theory (Kinoshita, 2003)</td>
<td>8.5</td>
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<tr>
<td>11</td>
<td>Degeneffe and Olney (2010): “We are the forgotten victims”: Perspectives of adult siblings of persons with traumatic brain injury</td>
<td>Determining how the lives of adult siblings of individuals with a TBI changed after the injury.</td>
<td>272 adult siblings of individuals with a TBI, at least 6 months post injury, located across the USA. Mean age: 38</td>
<td>Response to 1 open ended question that formed part of a survey</td>
<td>Constant comparative method</td>
<td>8.5</td>
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<tr>
<td>12</td>
<td>Engström and Söderberg (2011): Transition as experienced by close relatives of people with traumatic brain injury.</td>
<td>Experience of transitions by close relatives of individuals with a TBI.</td>
<td>5 relatives of individuals with a TBI (1 sister, 1 wife, 3 mothers) 10-26 years post injury in the Northern part of Sweden. Age range: 36-76</td>
<td>1 interview of 40-100 minutes using open ended questions</td>
<td>Qualitative interpretive method (Thorne, Kirkham and MacDonald-Emes, 1997)</td>
<td>8</td>
</tr>
<tr>
<td>Study</td>
<td>Authors &amp; Title</td>
<td>Focus of Study</td>
<td>Sample Characteristics</td>
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<td>13</td>
<td>Ishikawa, Suzuki, Okumiya and Shimuzu (2011): Experiences of family members acting as primary caregivers for patients with traumatic brain injury.</td>
<td>Experiences of families caring for an individual with a TBI.</td>
<td>15 individuals providing primary care to individuals with a TBI (5 daughters, 5 husbands, 5 sons), 1-19 years post injury in the Chubu &amp; Kanto regions of Japan. Age range: 40s-60s</td>
<td>1 semi structured interview of 30-60 minutes</td>
<td>Content analysis (Berelson, 1952)</td>
<td>7.5</td>
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<tr>
<td>14</td>
<td>Gill, Sander, Robins, Mazzei and Struchen (2011): Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners.</td>
<td>Experience of intimacy from the viewpoint of individuals with a TBI and their partners.</td>
<td>18 couples where 1 person had a TBI, 6 months-25 years post injury, in Chicago &amp; Houston, USA. Age range: 21-61</td>
<td>1 semi structured interview of 60 to 90 minutes</td>
<td>Grounded theory (Jeon, 2004: Patton, 2001)</td>
<td>8.5</td>
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<tr>
<td>15</td>
<td>Hammond, Davis, Whiteside, Philbrick and Hirsch (2011): Marital Adjustment and stability following traumatic brain injury: A pilot qualitative analysis.</td>
<td>Experiences of spouses residing with individuals with a TBI.</td>
<td>Spouses living with individuals who had experienced a TBI, including 5 wives and 5 husbands, in Carolina, USA. Age range: 40-75</td>
<td>Gender specific focus groups with open ended questions</td>
<td>Constructivist approach to grounded theory (Charmaz, 2000)</td>
<td>8</td>
</tr>
<tr>
<td>16</td>
<td>Nalder, Fleming, Cornwell and Foster (2012): Linked lives: The experiences of family caregivers during the transition from hospital to home following TBI.</td>
<td>Experiences of family caregivers during the transition from hospital to home.</td>
<td>10 family caregivers (6 spouses, 3 parents, 1 ex-partner) in Australia. Age range: 18-55</td>
<td>1 semi structured interview of 30-145 minutes</td>
<td>Thematic using a framework approach (Ritchie and Lewis, 2003)</td>
<td>8</td>
</tr>
</tbody>
</table>
Synthesis

The synthesis of studies produced four over-arching themes regarding the impact of the injury and its sequelae on family members of individuals with a TBI that were reflected in the studies included. These incorporated: 1. Responsibility, 2. Emotional Consequences, 3. Support Needs, and 4. Changed Perspectives.

Following the injury family members undertook the responsibility of providing direct care to the individual, altering their priorities such that the individual was prioritised, and resulting in changes in the nature of their relationships. Over the process of recovery these responsibilities led to them gaining a changed perspective on life, as they learnt to find a balance in the provision of appropriate care for the individual. Family members also planned for the future, gained a deeper understanding of life, and subsequently hoped for greater societal understanding about TBI. These perspectives were mediated by the emotional consequences of the responsibilities undertaken and the family member’s unmet support needs. Emotional consequences included responses to the individual as a changed person following the TBI, in addition to those associated with the strain of providing care. These factors also impacted on the support needs of the family members, as they sought to support the individual through searching for information and advocacy, but faced barriers in their attempts to do so. Changed perspectives had a reciprocal effect on the responsibilities of the family member, with the process and time point of the individual’s recovery altering responsibilities and perspectives. A diagrammatic illustration of the relationship between overarching themes is shown below (Figure 2), in addition to a table of the individual study concepts that comprise each theme (Table 2)
Figure 2: Diagrammatic Illustration of Themes

- RESPONSIBILITY
- EMOTIONAL CONSEQUENCES
- SUPPORT NEEDS
- CHANGED PERSPECTIVES

Process of recovery
Table 2: Individual Study Concepts as Related to Themes Identified

<table>
<thead>
<tr>
<th>Study</th>
<th>Responsibility</th>
<th>Emotional Consequences</th>
<th>Support Needs</th>
<th>Changed Perspectives</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caring &amp; Practicalities</td>
<td>Reconciling the changed person</td>
<td>Advocacy</td>
<td>Search for Information</td>
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<tr>
<td>1</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
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<td>2</td>
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Over-arching Theme 1: Responsibility

The theme of responsibility was evident across all studies and incorporated three sub-themes reflecting the different responsibilities with which family members were faced, in a sudden and unexpected manner, including caring and practicalities and altered priorities, which led to changed relationships.

Responsibility Sub-theme 1: Caring and Practicalities
Family members described the different caring roles in which they were placed following the injury, including provision of direct physical care to the individual with the TBI, such as aiding in personal care and activities of daily living, and monitoring the individual to ensure their well-being.

Participation in direct caring responsibilities largely occurred during the early stages following transfer from hospital to home, with levels of support reducing as the individual progressed in their recovery. Support encompassed activities such as aiding with bathing, toileting, mobility and feeding. In addition, family members took responsibility for supporting access to rehabilitation, through provision of transport and organisation of appointments. Family members in two studies took the responsibility for not only carrying out these tasks, but also supporting the injured individual to gain new skills, as this mother stated;

“She had to do everything over, so it was like having a newborn baby again in a bigger person’s body, and you just have to teach her everything over”. (Mother, Study 7; Wongvatunyu & Porter, 2005).

There was a sense reported in four studies of a need to look out for and monitor the individual. This included directly monitoring them to ensure their safety, and changing the environment to reduce risk of accident given the individuals changed physical and cognitive abilities. This appeared to be motivated by concern regarding the possibility of further injury, and a lack of trust in the persons abilities following the injury, resulting in family members need to protect them.

“We worry about him. We’re afraid he might be taken advantage of because he’s so naive, so trusting. If he tells us he’s made a new friend we’ll always make a point to try and meet them in person, just to see what they are like, just to make sure that the person has good intentions toward him”. (Sibling, Study 2; Gill & Wells, 2000).
Responsibility Sub-theme 2: Altered Priorities
Due to the caring roles that they undertook, family members described how the individual became central to their lives, and how they were prioritised at the expense of other relatives, employment, and other interests and commitments. As this parent in Study 1 (Carson, 1993) states;

“You kind of give up your life, you know, what you’re used to doing, a lot of your outside activities and my work to accommodate and care for her. You’ve got to make that adjustment, which is a big one”.

Changes to employment were frequently reported, including ceasing work, or reducing or changing working hours in order to accommodate the needs of the injured individual, motivated by a sense of responsibility to care for them. This often had financial implications, providing an additional strain on the family.

Lives were described as a “juggling act” (partner, Study 14; Gill et al., 2011), with a need to be available to the injured individual, and a balance required between the demands of work, home and needs of all family members, a source of considerable stress. A sense of guilt was also reported by parents in feeling that they were overlooking the needs of their other children.

Responsibility Sub-theme 3: Changed Relationships
This sub-theme relates to changes in the relationships between family members following the altered role they held in lives of the individual. This included changes in the type of relationship shared, and in the quality of relationships.

Changes in relationships were frequently reported, with family members feeling that they were undertaking a role akin to parenting a young child.

“I felt I was taking care of him more like a mother rather than a partner. You know, it was like dealing with a child now”. (Wife, Study 6; Layman et al., 2005)

There were notable gender differences in reporting of changed relationships, as in four studies female partners and siblings referred to undertaking a mothering relationship with the individual. In contrast male partners stated that their relationship had become more like a friendship, with male siblings viewing
themselves as undertaking the role of the “older sibling”, regardless of the direction of the age difference between them.

The impact of these changes related to alterations in the quality of the relationships held. Interestingly parents rarely referred to alterations in relationship quality with the injured individual, commenting instead on the reduction in time they had with their other children, and relationships outside of the family. This was perhaps due to their perception that they were returning to a familiar role with the injured individual.

Siblings referred to a change in closeness, with three studies reporting that the injury had brought siblings closer together, with closeness associated with spending time together. However, in one study half of the siblings felt less close to the individual, spending less time with them due to their challenging behaviour. Such behaviour, in addition to the individual having communication difficulties, was cited as a barrier to intimate relationships in partners, which were considered to be changed negatively.

“I think an intimate moment is when you pour your heart out. And we can’t do that anymore”. (Partner, Study 14; Gill et al., 2011).

However, partners in two studies reported a deepened relationship despite the barriers the injury caused, due to the dependent nature of the relationship and having a committed bond prior to the injury.

Changes in relationships were not specific to the individuals relationships with different family members as difficulties between other family members were reported. Marital problems were cited in two studies due to altered priorities impacting on relationships. Additionally, siblings who cared for the family member reported that their own families could feel overlooked in comparison.

**Over-arching Theme 2: Emotional Consequences**

This theme encapsulates the emotional consequences of the injury in the family members, including the impact of changes in the individual following the TBI, and the emotional consequences of the caring role that they undertook.
**Emotional Consequences Sub-theme 1: Reconciling the Changed Person**

Participants recognised that the TBI had changed the individual, and in three studies participants reported that this led them to feel as though they were faced with getting to know a new person. A range of emotions were identified by families in response to the changes, ranging from shock and panic when they first heard about the injury, to sadness, grief and a sense of loss for the person they once knew and the relationships they formerly held.

A sense that the injury was not fair was reported, with siblings in two studies reporting feelings of guilt that they could engage in aspects of life whereas their relative could not. This was perhaps particularly pertinent to siblings due to similarities in age, but marked differences in ability.

“Sometimes I feel loss of the brother I don’t have. I sometimes feel sad for his life when I see others having fun and seeing how he is with no self confidence and inept in social situations”. (Sister, Study 11; Degeneffe & Olney, 2010)

Emotional responses varied when different time points were considered. In one study family members reported looking to the future and feeling disappointment that future plans and dreams involving the person were ruined. Two studies referenced relatives referring to the past and recalling how the person used to be, causing feelings of despair and frustration. However, family members who focused on the present reported positive appraisals, indicating a level of optimism about the situation. For example,

“Many things in her daily life are difficult but she will not be defeated; these qualities make me very proud of her”. (Sister, Study 11; Degeneffe & Olney, 2010)

**Emotional Consequences Sub-theme 2: Caregiver Strain**

This sub theme relates to the strain of undertaking the responsibility of directly caring for an individual with a TBI, along with the altered priorities and changed relationships that this entailed.

Initially family members expressed feeling anxious and unprepared. However those with more ingrained caring roles emphasised the negative impact of the injury on their lives, reporting fatigue, frustration and stress.
“Everything is just harder. Things get missed. Things don’t get done anymore. It’s tiring: I’m tired......I’m always sad; I am always on the verge of tears”. (Family care giver, Study 16; Nalder et al., 2012)

In two studies resentment was reported due to the change in circumstances the families had undergone, along with a sense of hopelessness that the situation would not change as they could not see an end point to their circumstances, viewing their lives as irrevocably changed with a lack of support exacerbating their negative emotion.

“I had to pretty much take over everything and there’s some resentment coming in. So now there is some deterioration, and I can see it spiralling, and I’ve even gotten angry at the situation...and I’ve actually gotten angry at him too”. (Partner, Study 14; Gill et al., 2011).

Feelings of isolation were also reported by family members, particularly as the time since the injury increased and they started to lose contact with friends, a factor that was attributed to a lack of understanding about the injury, in addition to altered priorities.

**Over-arching Theme 3: Support Needs**

Due to the responsibilities that the family members took on, and the subsequent emotional consequences, family members reported various support needs. This included the need to become informed about the TBI, their subsequent advocacy for the individual, and the barriers that hindered their progress.

**Support Needs Sub-theme 1: Search for Information**

Family members reported the need for honest information following the initial occurrence of the injury, with regard to information about TBIs, care plans and prognosis. However, it was noted in three studies that too much information could be unhelpful, as an over focus on negative aspects was distressing.

“Something the doctors don’t need to do in the beginning is be so disheartening”. (Family member, Study 5; Leith et al., 2004)
It appeared important for information to be communicated in a sensitive manner at this time, taking into account the shock the family members experienced at the occurrence of the injury, with repetition of information helpful to aid understanding. Medical terminology also required explanation, as a lack of understanding led to frustration and fear regarding the impact of the injury on the individual.

Once the individual returned to the community, family members sought information regarding caring for the individual and facilitating their recovery, a source of considerable anxiety. This was hindered by delays in community service provision.

**Support Needs Sub-theme 2: Advocacy**

In the context of the struggle for information, family members took on the responsibility of advocating for the individual, a role for which they identified a need for greater support. This was predominantly related to interaction with support services, a process described as a “struggle”, a “fight” and a “battle”, in the pursuit of better care, and for which resourcefulness and assertion were required in seeking out appropriate services and support for the individual. In two studies family members reported concern as to the level of care provided by services, appearing to lack trust in them, increasing their need to monitor the individual.

“They had a regimen, and I went up one day and they were trying to get him to go to some class, and he could hardly stand he was so tired...I found it quite astonishing that a family member had to step in to make that kind of judgement that was so obvious”. (Family care giver, Study 3; Smith & Smith, 2000).

Advocacy also involved making decisions on behalf of the individual, which was more difficult in the absence of adequate information provision by services, as reported in two studies, or as was identified in Study 3 (Smith & Smith, 2000), if this involved going against the wishes of the individual.

The beneficial impact of attending a support group was noted, with networking and information sharing a vital source of support. Family members in two studies spoke positively of meeting others who had been through the same experience. However, there was disappointment that professionals did not direct them to such services.
Support Needs Sub-theme 3: Barriers

Barriers that family members experienced included obstacles to accessing services, difficulties in obtaining information, and experiencing isolation. Difficulties accessing services were particularly encountered at the transition to rehabilitation or community services. Family members reported not being included in decisions made by healthcare professionals, particularly those which related to future care, and not being aware of services available, leading to anger and frustration.

There was a sense that family members did not feel listened to by professionals, and they described feeling that insufficient information was provided regarding available support. Lack of time and lack of knowledge of support options for individuals with a TBI amongst medical professionals and support agencies were cited as reasons for this, adding to the difficulties experienced in provision of appropriate care.

“They don’t listen to us who are close to her and know what she needs...they must investigate here and there to see if she needs that help which she is entitled to...you must push and shove in order to get this help...”. (Family member, Study 8; Jumisko et al., 2007).

Difficulties in accessing services contributed to family members feeling unsupported and isolated in their roles as caregivers. Those in primary caregiver roles hoped that other relatives would become more involved in the provision of care, with support or contact with friends and other family members decreasing as the length of time since injury increased. Inaccurate perceptions regarding the individual following the injury were cited as reasons for this. Feelings of frustration and hopelessness were reported in response.

“The longer we went the more isolated we felt and the more hopeless we felt when someone did try to reach us” (Family member, Study 5; Leith et al., 2004).

Over-arching Theme 4: Changed Perspectives

The experiences of the family members in gaining unexpected responsibilities, and the subsequent emotional consequences and support needs associated with this experience led to changed perspectives over time.
**Changed Perspectives Sub-theme 1: Balancing**

Following the progression of time and recovery, family members became focussed on balancing the individual’s independence and dependence. The type of support they offered changed to address the independence of the individual, and the possibilities of whether skills could be regained were considered. This process was characterised by uncertainty, which appeared to be attributable to the family member’s lack of trust in the individual’s abilities, and a lack of information provided by services. In three studies parents reported reservations around the promotion of independence. This was not reported by other family members and was perhaps reflective of the nature of the parental relationship and a need to protect the individual and prevent them from harm.

“The last year I’ve really had to come to grips with the fact that being protective of him because of his accident is not doing him any favours. It’s really important to me to care about him and love him and be interested in what he’s doing, but I need to let him make his own decisions”. (Parent, Study 1; Carson, 1993)

Difficulties in “letting go” often led to strained relationships between the individual and their parent, and both the individual and the family member found it difficult as they endeavoured to return to “normality” as this highlighted deficits and that aspects of recovery could not be controlled. However, it appeared that improvements and a decrease in dependence were beneficial in reducing caregiver strain.

**Changed Perspectives Sub-theme 2: Future Concerns**

Family members identified the need to think ahead to the future, which began from when the individual was in hospital, and remained pertinent through all stages of recovery. This was motivated by a recognition that the individual’s own planning skills were diminished, with the family members taking responsibility for planning instead. This ranged from short term factors, such as consideration of safety at places they visited in the community and organising appointments, to more long term goals such as planning vocational activities they could partake in.

Family members also acknowledged the long term nature of the support they would need to provide, with their lives dependant on the recovery of the individual, which could lead to negative emotions. They also voiced concern regarding what would happen if they were no longer able to provide support for the person, with siblings
who were not currently in a direct primary care giving role recognising that they would be undertaking this role in the future and making adjustments to their lives accordingly.

“One day I will be the main caregiver for all my family members. I’ve had to readjust my ‘life goals’ to accommodate him”. (Sibling, Study 11; Degeneffe and Olney, 2010)

**Changed Perspectives Sub-theme 3: Personal Growth**

Family members reported that the experience of having a relative with a TBI led them to gain an altered perspective on life. They gained a deeper understanding of the meaning of their lives, and a shift in their values and priorities that would not have happened without the injury, having re-evaluated what they considered to be important in life.

For siblings personal growth was reflected in a change in life choices, as they shifted away from focusing on themselves to prioritising actions that would help others. For some this involved changing their future career plans to wanting to work in helping professions due to gaining greater understanding of others following the injury. For others this meant putting their family first, with less emphasis on pursing their own interests.

“I changed careers from business to counselling – I don’t believe I would have entered human service without my brother’s and my experience. I am more sensitive to non-visual handicaps-disabilities”. (Sister, Study 11; Degeneffe & Olney, 2010)

A sense of the fragility of life was also gained in family members following the injury, particularly in partners, with recognition of what might have happened if they had lost their relative. This highlighted the importance of, and strengthened, their relationships due to a sense of gratefulness for their partner’s survival.

“It brought us closer together...knowing that he could have been taken away from me within an instant”. (Partner, Study 14; Gill et al., 2011)
**Changed Perspectives Sub-theme 4: Societal Understanding**

Family members reported that due to the difficulties gaining information and accessing support, and feelings of isolation following the injury, there was a need for greater awareness and understanding of TBIs in wider society. It was hoped that individuals would be able to become an active member of society. Family members considered that greater understanding would improve acceptance of the individual and their difficulties by society, reducing the isolation that both they and individual experienced, thus decreasing their sense of responsibility.

“Since the number of people with disabilities who are forced to lag behind for their entire lives will probably increase in future, I hope that society would be able to support them”. (Mother, Study 10; Fumiyo et al., 2009)

In one study mothers themselves shared their experiences with other family members, friends and colleagues to inform them about TBIs and to highlight issues around safety with a view to preventing occurrence of the injury.
Discussion

The purpose of this review was to synthesize qualitative findings to gain insight into the experiences of family members of adults who have a TBI. The synthesis of 16 studies led to the identification of four over-arching themes and a model to show the experience of family members following the TBI. There were similarities between concepts across studies indicating the likelihood that the studies captured common experiences for family members. The results showed that family members were faced with significantly increased responsibilities towards the individual, at the expense of other commitments, leading to a range of emotional consequences and the need for support, which was not always available or accessible. Through these experiences they gained a changed perspective on their own lives, and that of the individual and society, which served to reduce the impact of the injury on their lives.

This synthesis supported, and considerably enhanced the findings reported by Martin (2012) in her meta-synthesis of caregiver experiences, providing a more detailed and comprehensive perspective on the experiences of family members and the relationships between themes. Commonalities in themes were also evident with a recent meta-synthesis focusing on experiences of individuals with a TBI (Levak, Kayes & Fadyl, 2010), with their theme of emotional sequelae mirroring the emotional consequences identified in the present study. Levak et al. (2010) also included themes relating to support which overlapped with the support needs identified by the family members in the present study, although interestingly the struggles family members reported with services were not evident in individual's descriptions in Levak et al’s (2010) study, which is perhaps reflective of family members protecting them from this.

It was evident from the studies reviewed that the responsibilities that family members faced represented the principal impact of the injury on their lives. The concept of responsibility was reported by all family members, including siblings who were not always the primary caregiver. This theme is frequently described in qualitative studies relating to family caregivers, including those dealing with other areas of illness, such as cancer, palliative care and mental health (e.g. Linderholm & Friedrichsten, 2010; Wennman-Larsen & Tishelman, 2002).

In the quantitative literature responsibility, along with the associated emotional consequences, is reflected through research in the area of caregiver burden. Although definitions of burden vary in the literature, Buhse (2008) characterises the
concept as a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the care giving experience. This description appears to encapsulate the recognised components. Caregiver burden has been commonly linked to models of stress and coping, the majority of which are based on Lazarus and Folkman’s (1984) transactional stress theory (e.g. Pearlin & Scaff, 1995; Zarit, 2002). The principle of Lazarus and Folkman’s (1984) model is consistent with the present review as they propose that appraisal of a stressor is determined by assessment of coping resources and options, with an imbalance between demands and resources resulting in stress. In the review, family members competing demands and struggle to gain resources, in addition to a lack of support resulted in caregiver strain.

The findings also highlight that a TBI impacts on all family members. Those who were not primary caregivers to the individual, such as siblings, reported a level of responsibility, emotional consequences and changed perspectives. Research focusing on the experiences of family members who are not the primary care giver is limited. However, in a study focusing on primary, secondary and tertiary family caregivers of individuals with a TBI, Perlesz, Kinsella & Crowe (2000) found that primary caregivers were at greater risk of anxiety and depression, however other family caregivers did report psychological distress. Similar findings are reported by Ponsford, Olver, Ponsford and Nelms (2003), focusing on family members 2-5 years post injury, in which anxiety and depression were more prevalent in family members responsible for care. This would be consistent with the present review, as the theme of “caregiver strain” related to those who provided direct care, an additional emotional consequence that other family members did not report. However, as the review highlights, while caregivers experience greater emotional consequences, other family members should not be overlooked, especially those who may gain a greater caring role over time.

The need for accessible services to provide support for both the individual and the family member was evident in the review. UK guidelines on head injury and rehabilitation for acquired brain injury (National Institute for Clinical Excellence; NICE, 2007: Royal College of Physicians & British Society of Rehabilitation Medicine; BRSM, 2003) acknowledge this perspective, with NICE (2007) highlighting that early support and acknowledgement of family members can better prepare them and reduce psychological sequelae, leading to improved outcomes for both the family member and the individual. The Royal College of Physicians and
BRSM (2003) also propose that early referral to self help groups may be beneficial for family members to gain practical information beyond that which the service may be able to provide, which is consistent with the need for information and advocacy services included in the studies reviewed.

Limitations
The validity of the use of a meta-synthesis approach is subject to much debate. Critics argue that findings in qualitative research studies are far removed from the individual’s experience, and subject to various levels of participant and researcher interpretations (Richards, 1998; Smith, 2004). Additionally, Sandelowski, Docherty & Emden (1997) contend that summarising qualitative studies destroys the original findings. There is also dispute regarding the inclusion of studies utilising different interpretive methods, due to the difference in focus and theoretical structures (e.g. Jensen & Allen, 1996). However, the input of other researchers in the development of themes and the model in the current synthesis was intended to reduce the level of researcher bias. The inclusion of studies using different methodologies can also be viewed as a method of triangulation, which enhances credibility (e.g. Finfgeld, 2003). It is also considered that this review aims to sit alongside the primary research studies, rather than supersede them.

Quality ratings of qualitative studies are another contentious issue, with debate about appropriate criteria on which to rate studies spanning many years (e.g. Holloway & Wheeler, 1996; Perakyla, 1997). Although quality ratings were completed in the present study, no studies were excluded on the basis of quality and it was not felt to be an accurate tool for which to determine transferability of results. There was a small range in the scores attained by studies (6.5 to 9) and it was considered that the criteria used were too broad to accurately distinguish the nuances of quality between the studies. For example, it was notable that Carson’s (1993) grounded theory study attained the lowest score, as this utilised a defined qualitative methodology which could be considered of greater methodological rigour than for example, a content analysis. However, despite adequate explanation of the themes, methods of data collection and analysis were not well defined in this study, reflecting the lower score. This is perhaps reflective of the age of the paper, as it was published prior to the development of recent quality ratings and differing expectations of reporting may have been used at the time. Although it had been intended to give greater emphasis to higher quality papers in the review, in practice studies with well defined and elaborated themes had greater influence.
This review only included research that was published in peer reviewed journals in English. This discounted unpublished dissertations/PhD theses, book chapters and other unpublished literature sources, in addition to studies published in different languages that may have provided further insights.

With regard to limitations of the review itself, although a model is proposed, this is not without limitations as the concepts defined in the studies fell short of describing the exact mechanisms involved to progress to having a “changed perspective”. Reference was made in the studies to adjustment and acceptance, however these themes were inadequately elaborated and it was unclear as to the processes that hindered and facilitated these concepts or the meaning of them to the family members. As the qualitative literature in the area of TBI has only developed relatively recently, studies appear to have focused quite broadly on experiences of family members, however it is considered that there is now a need for future studies to explore more specific areas, and the mechanisms involved in adjusting to or accepting what has occurred.

Additionally, the review included studies that were conducted in five countries and despite the commonalities between concepts reported in studies, it is possible that there were differences in experiences of family members due to differing family roles, expectations and values across cultures which were not considered. It is recognised, both in studies focusing generally on family care giving, and those specifically investigating the area in TBI, that different family members assume caring roles, and differing levels of negative effects are seen when caring is compared across ethnicities (e.g. Dilworth-Anderson, Williams & Gibson, 2002; Hart, O'Neil-Pirozzi, Williams, Rapport, & Hammond, 2007). In a related vein, support services can be variable both nationally and internationally, with some countries providing free healthcare and others requiring payment, which may contribute to altered expectations of support. It was explicitly stated in one study conducted in Japan (Fumiyo et al., 2009), that families had to have a greater degree of involvement due to a lack of rehabilitation services. The role of family member’s expectations of care provision and the degree to which they were met may have implications for the level of responsibility they feel and the consequent emotional sequelae. Therefore while the inclusion of studies from a diverse range of countries was beneficial with regard to the ability to generalise findings, the influence of cultural factors should not be discounted.
Implications for the future

The review highlights the integral role of family members in supporting an individual with a TBI, and contributing to their recovery and outcome. Many family members provide unpaid support for the individuals, at considerable cost to their own lives and well being, however their needs appear overlooked. It appears particularly important for more research to consider the impact of the TBI on family members, and the underlying processes that contribute to better outcomes for both the individual and the family members. It is clear from the quantitative literature, and the similarity of findings in the present study to the meta-synthesis of individual’s experiences completed by Levak et al. (2010), that family and individual experiences are intertwined, thus to disregard families would be at the expense of the individual.

Additionally, interventions to support family members of individuals with a TBI require further development and evaluation. The review clearly showed that family members sought information and support but found that their needs were not met. They described difficulties in accessing appropriate services, both for the individual and for themselves. It is important for services to include the family, provide them with appropriate information in a sensitive manner and support them in their role as caregivers.

Conclusions

This review and synthesis of qualitative papers relating to the impact of the TBI on family members identified important issues with regard to the experiences of family members including the responsibility they gained, and the subsequent emotional consequences and support needs associated with this, which could impede their ability to move forward and gain a changed perspective on life. The findings highlight the pivotal role that family members play in supporting the individuals, and the need to consider their needs and offer appropriate support in order to facilitate this.
References


Main Paper

An Exploration of Individual’s Experience of Moving Towards Acceptance Following a TBI: A Grounded Theory Study

Prepared in accordance with requirements for submission to Neuropsychological Rehabilitation: An International Journal (Appendix 1)

Word Count: 8857
Abstract

Aim: This study aimed to investigate the concept of acceptance in individuals with a traumatic brain injury (TBI). The concept of acceptance has been largely overlooked in the TBI literature, and definitions vary. This study employed a qualitative methodology to investigate acceptance in individuals with a TBI, and factors that facilitated or hindered this process.

Design: Semi-structured interviews were conducted with eleven participants who had sustained a TBI between 5 months and 12.5 years previously.

Method: Interview transcripts were analysed using grounded theory methodology.

Results: A model detailing the process of acceptance in TBI was developed, encompassing five core categories: “understanding limitations”, “changed perspectives”, “confirmation of prognosis”, “adapt and overcome”, and “barriers to acceptance”. Participants’ narratives focused on their attempts to understand their changed selves, and the changed perceptions and support from others that facilitated them to move forward and adapt to achieve acceptance, in the context of barriers that prevented them from progressing.

Conclusion: The results provide a qualitative understanding of acceptance for individuals with a TBI, and emphasise the importance of individuals acknowledging and adapting to their changed selves in maintaining psychological well being, highlighting implications for rehabilitation services.

Key words: Brain injury, acceptance, adjustment, qualitative research, grounded theory
Introduction

Traumatic brain injuries (TBIs) are defined as an external force to the head causing an alteration in brain function or other evidence of brain pathology (Menon, Schwab, Wright & Maas, 2010). The long term outcome following a TBI can be varied, with long term impairment in cognitive functioning and functional status reported, independent of severity of injury (e.g. Dikmen, Machamer, Powell & Temkin, 2003; Schretlen & Shapiro, 2003). Gaining a greater understanding of processes that underlie individual’s recovery would be beneficial for improving rehabilitation services. There is a body of literature concerning recovery in TBI, including coping and adjustment. Acceptance has been identified as a predictor of adjustment in the area of chronic illness (e.g. McCracken, 1998; Pakenham & Fleming, 2011). However, the concept has been largely overlooked, particularly in the area of TBI. This is perhaps due to a lack of clarity over definitions as Yates (2003) states that the terms adjustment, coping and acceptance have been used interchangeably in the literature.

Historically the concept of acceptance has been included in various stage of change models relating to disability and loss (e.g. Kubler-Ross, 1967; Hollingsworth, Didelot & Levington, 2002, Livneh, 1986, Livneh & Antonak, 2005). However, definitions of acceptance within the models vary. For example, Hollingsworth et al. (2002) refer to acceptance as “assimilating the disability”, while Livneh and Antonak (2005) discuss an affective acceptance of oneself as a person with a disability including a restored self concept and renewed life values. The role of personal values in acceptance is also emphasised in acceptance of loss theory (Dembo, Leviton & Wright, 1975; Wright, 1983) which proposes that acceptance of disability requires adjustment to an individual’s value system.

A more recent definition can be found in an alternative domain, acceptance and commitment therapy (ACT; Hayes, Strosahl & Wilson, 1999). In ACT, acceptance is defined as “the active and aware embracing of private events . . . without unnecessary attempts to change their frequency or form’ (Hayes, Luoma, Bond, Masuda, & Lilli, 2006, p. 7). It is evident therefore, that while conceptualisations of acceptance appear related, no widely recognised definition exists.
Research relating to acceptance in individuals with a TBI is limited, however the concept has been studied more widely in relation to adjustment in physical health and disability. With regard to the literature focusing on acceptance as defined by ACT, Pakenham and Fleming (2011) reported improved adjustment was associated with greater acceptance in individuals with multiple sclerosis (MS), including lower distress, and greater positive affect and life satisfaction. Studies focusing on intervention with ACT have demonstrated similar effects. For example in a study with individuals with diabetes, improvement in physical health was mediated by acceptance and self management behaviour (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007). These studies serve to illustrate the important role of acceptance in adjustment to physical health conditions.

Similar findings are reported in areas pertinent to individuals with a TBI, pain and fatigue, as high levels of both are reported following the injury (e.g. Ivanhoe & Hartman, 2004; Ziino & Ponsford, 2006). In another study using the ACT definition of acceptance, McCracken (1998) found that higher levels of acceptance were associated with lower pain related anxiety and avoidance, less depression, and lower physical and psychosocial disability ratings. With regard to fatigue, acceptance has been linked with more emotional stability and less psychological distress, independent of fatigue severity in individuals with chronic fatigue syndrome (Van Damme, Crombez, Van Houdenhove, Mariman & Michielsen, 2006). This study used an alternative conceptualisation of acceptance, utilising the Illness Cognitions Questionnaire (Evers et al., 2001), which when investigated in the domain of chronic pain by Viane et al. (2003) has been shown to measure a different aspect of acceptance to the that of the ACT related Chronic Pain Acceptance Questionnaire (CPAQ; McCracken, 1999), with higher scores on both measures predictive of greater mental well being. This highlights that acceptance is multifaceted, in addition to the importance of acceptance in adjustment.

With regard to acceptance in the area of TBI, and more widely, acquired brain injury (ABI) research is limited. However, Snead and Davies (2002) found that individuals with ABIs who had greater levels of acceptance of personal disability had higher scores on measures of quality of life and greater community integration. Acceptance has also been considered in the area of ABI by Klonoff (2010) who proposed a patient model of experiential recovery for clients engaging in therapeutic input which incorporates a phase of acceptance,
referred in this instance to an ability and willingness to cope with a new reality and identity

There has been greater focus on acceptance in individuals with ABIs in qualitative research, where it is often identified as a theme in participant’s narratives. For example, Fraas and Calvert (2009) discuss acceptance of the injury in their study regarding characteristics leading to productive life post ABI, stating that emotional and psychological changes were necessary to accept, with time also cited as an important factor, a finding also reported by Howes, Benton and Edwards (2005) in their study solely focusing on experiences of women post ABI. In addition, Gill, Wall and Simpson (2012) identified acceptance as a theme in the context of perspectives of rehabilitation, with acceptance reflecting individuals coming to terms with their acquired brain injury and its subsequent impact on their lives. In a study specifically focusing on TBI, O’Callaghan, Powell, and Oyebode (2006), found that “accepting my changes” was important for individuals gaining awareness of their post injury deficits. These findings highlight the importance of acceptance to individuals with ABIs in relation to various aspects of recovery.

It is apparent that acceptance is a pertinent issue in relation to physical health and disability. The inclusion of the concept in stage of change models relating to disability and loss, in addition to the focus in ACT on developing acceptance, and the narratives that individuals with ABIs discuss with regard to acceptance as a stage of recovery, highlight the importance of moving towards acceptance. However, research investigating acceptance in TBI is limited, and acceptance has not been comprehensively defined in the literature. In addition, no study to date has focused solely on the experience of acceptance in individuals with a TBI. The present study therefore aimed to explore how individuals with a TBI move towards acceptance, and factors that may have facilitated or inhibited acceptance of their post injury selves. This would identify psychological factors that relate to recovery, and contribute to informing development of psychological interventions for this client group.
Method
This research focused on exploring individual’s experience of moving towards acceptance following a TBI. A constructivist approach to grounded theory was used to address the aims, in line with that proposed by Charmaz (2006). The analysis involved the creation of theoretical categories from the data, and consideration of the relationships between these categories to generate a theory. This incorporated the use of a constant comparative method whereby data is continually compared with data, and categories with categories, allowing the researcher to analyse areas of similarity and difference within the data. This process occurs simultaneously alongside data collection, allowing affirmation and refinement of developing ideas with analysis of initial data shaping future data collection.

Reflexivity
The active role of the researcher is emphasised within the framework of grounded theory, as the interaction between the researcher and the data are viewed as pivotal in determining the results (e.g. Charmaz, 2006). In order to be reflexive, Elliott, Fischer and Rennie (1999) highlight the need to “own ones perspective” through recognition of values, previous knowledge and presuppositions, and the researcher’s role in the research process.

The researcher was a 28 year old White British married woman who gained an interest in the research topic from working therapeutically with clients with cognitive impairments, including ABIs, on a neurological rehabilitation ward. The sudden and unexpected nature of the client’s acquisition of their injuries and the considerable impact that they had on their lives led the researcher to reflect on the psychological aspects of recovery. Due to seeing clients at a particular stage in their recovery, and planning for leaving hospital to environments that could be considerably different to those in which they resided prior to the injury, the researcher considered how individuals came to accept what had happened to them, and how this may be beneficial to their long term outcomes, as this had been a pertinent issue affecting psychological well being in the researcher’s clinical work with different client groups. The study was also influenced by the researcher’s supervisors, comprising of a clinical neuropsychologist and two clinical psychologists, with whom the interviews and emerging themes were discussed in regular supervision meetings.
Recruitment

Approval for the study was gained from a local National Research and Ethics Service committee (NRES, Appendix 8-9), and the relevant NHS Trust’s Research and Development departments (R&D; Appendix 10-12).

An opportunity sampling approach was used, with 11 participants recruited, seven via two outpatient NHS neuropsychology services, in addition to four from regional branches of two charitable organisations. The researcher met with clinicians at the outpatient neuropsychology services and one of the charities to provide them with details about the study such that they could identify potential participants who met the inclusion criteria. For the other charity, the researcher presented directly to potential participants at regional group meetings. It was anticipated that between 10 to 15 participants would be required to reach theoretical sufficiency (Dey, 1999).

Participants were provided with information packs regarding the study (Appendix 13 & 14), and those who returned a consent to contact form (Appendix 15) to the researcher were contacted to clarify that they met inclusion criteria, and a time arranged for the interview if they wished to participate. Interviews were held at a convenient location for the participant, including in their homes or local NHS or charity bases that were familiar to them. Prior to the interviews commencing each participant was required to read and sign a consent form detailing the nature of the study, confidentiality, and anonymity procedures (Appendix 16). Participants were informed of their right to withdraw from the study at any point. Identifiable information was removed from transcripts, with all participants assigned a number. All data were stored in locked filing cabinets with access limited to the research team.

Inclusion Criteria

The inclusion criteria comprised: (1) adults, aged 18 to 65 who had experienced a TBI in the previous 0 to 15 years, (2) capacity to consent to take part in the research, (3) ability to understand the written and verbally presented information, (4) ability to participate in an interview about their experiences that involved a degree of flexible thinking/reflection and not have any physical or sensory impairment that may impinge on their ability to do this. Individuals were excluded if they had pre-morbid psychological or substance misuse difficulties.
Prior to the interview commencing, demographic and injury related information was collected (Appendix 17). In addition, the Wechsler Memory Scales 4th Edition Brief Cognitive Status Exam (WMS-IV BCSE; Wechsler, 2009) was administered, as a measure of current cognitive abilities of participants. The WMS-IV BCSE is designed to evaluate global cognitive functioning, incorporating the areas of orientation, memory, and executive functioning, and provides a classification of functioning ranging from average to very low. Classification is focused on impaired performance, with the average classification representing 25-100% of the normative sample, and the very low classification comprising less than 2%.

Development of the Interview
In adherence to grounded theory methodology, semi-structured interviews were carried out and audio recorded using a digital voice recorder. The interview schedule comprised of eight open ended questions with corresponding prompts, focusing on changes in individuals lives following the injury, their understanding of having the injury and their perceptions of acceptance regarding the injury (Appendix 18). The schedule was developed through supervision and review of relevant literature. It was based on the aims of the research and intended only as a prompt to facilitate discussion. Questions were designed to be direct and clear in nature to account for potential cognitive difficulties of participants. If participants became distracted or were unable to recall what they had been discussing during the interview, questions were either repeated or a short prompt given detailing the topic area, in order to try and prevent the researcher’s interpretation influencing their response (DiCiccio-Bloom & Crabtree, 2006). In adherence to the principles of grounded theory, the interview schedule was revised following five interviews to include prompts relating to emerging themes regarding acceptance. These included prompts relating to comparison to others, trust, and the impact of the injury on the time point in their life.

Data collection occurred over a five month period, with interviews lasting between 54 and 127 minutes each, with a mean of 77 minutes. Immediately after each interview brief memos and reflections were noted in the researcher’s reflective journal, including thoughts, feelings and ideas, to capture early insights into the data collected.
Data Analysis

Interviews were transcribed verbatim by the researcher, and then analysed in accordance with Charmaz’s (2006) grounded theory methodology. Initially, the transcripts were coded line by line, to encapsulate the meaning of the participant’s words (extract of coded transcript provided in Appendix 19). During this stage the researcher’s reflections about the codes, similarities and differences between data and possible links to existing theory were recorded, in the form of “memos”. This occurred in parallel with further interviews being conducted, allowing initial codes to be explored in greater detail and refinement of the interview process. Once line by line coding was complete, codes were compared, grouped and placed into categories, with consideration of the process through which the categories occurred and the consequences of them. Memo's were used to facilitate this task, with additional memo's written throughout the process to support and organise ideas generated. Core categories were then developed into conceptual models through linkage to each other and existing literature (Charmaz, 2006).

The original proponents of grounded theory (Glaser & Strauss, 1967) proposed that data collection should continue until saturation is achieved, whereby further data does not provide additional aspects to categories or new theoretical insights. However, Dey (1999) contends with this view, suggesting that it is rare, if not impossible to research theoretical saturation. Instead, Dey (1999) proposes that “theoretical sufficiency” would be more appropriate, in which researchers should focus on the ability of data to create a sufficient theoretical account. This study adhered to this approach, with the concept of theoretical sufficiency used to guide recruitment and analysis. This meant that analysis aimed to develop categories suggested by the data, however there was possible scope for further analysis.

Reliability and Validity

Guidelines for qualitative research were referred to in order to ensure adherence to rigorous methodological processes and for quality control purposes (e.g. Elliot et al., 1999). This highlighted the importance of recognising reflexivity, situating the context of the sample, and presenting the results in a coherent model, with themes illustrated through the use of direct quotes. This was facilitated through the use of a reflective journal that documented the process of theory
development and allowed consideration of the researcher’s influence on the analysis. In addition the developing model was shared and discussed in regular supervision meetings, all of which served to enhance the transparency of the research. To ensure reliability, a researcher who was independent of the interview procedures checked the credibility of the coding. This aimed to verify the researcher’s interpretation of the data, rather than gain an objective analysis. There was a total of 98% agreement, thus providing external validity to the researcher’s interpretation. Discussion regarding discrepancies did not result in alteration to the analysis or impact on the subsequent theory developed.
Results

Participant characteristics are depicted in Table 3 below. The sample of 11 participants comprised 4 females and 8 males, with an age range of 19 to 60 years. All participants were of White British ethnicity and resided in the North of England. Nine of the participant’s injuries were sustained through road traffic accidents, including as pedestrians, on bicycles or travelling in cars, with the remaining two sustained through falls. Time since injury ranged from 5 months to 12 years 6 months (mean: 4 years 8 months). Six participants had skull fractures from the injury, while five had intracerebral bleeding. Classifications on the WMS IV BCSE ranged from low to average, indicating that some participants were experiencing cognitive difficulties at the time of the interview. Severity of injury ranged from moderate to very severe, as measured by length of post traumatic amnesia following the injury (Russell & Smith, 1961).
**Table 3: Demographic and Injury Information**

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Age</th>
<th>Gender</th>
<th>Time since Injury</th>
<th>Severity of Injury</th>
<th>Cause of Injury</th>
<th>Nature of Injury</th>
<th>WMS IV Brief Cognitive Status Exam</th>
<th>Percentile</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>49</td>
<td>Male</td>
<td>2 years 8 months</td>
<td>Very severe</td>
<td>Fall</td>
<td>Intracerebral Bleeding</td>
<td>5-9%</td>
<td>Borderline</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>22</td>
<td>Male</td>
<td>2 years 11 months</td>
<td>Very severe</td>
<td>RTA</td>
<td>Skull Fracture</td>
<td>10-24%</td>
<td>Low average</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>29</td>
<td>Female</td>
<td>4 years 10 months</td>
<td>Very severe</td>
<td>RTA</td>
<td>Intracerebral Bleeding</td>
<td>25-100%</td>
<td>Average</td>
<td></td>
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<td>4</td>
<td>51</td>
<td>Female</td>
<td>4 years 8 months</td>
<td>Moderate</td>
<td>RTA</td>
<td>Intracerebral Bleeding</td>
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<tr>
<td>5</td>
<td>48</td>
<td>Female</td>
<td>4 years 8 months</td>
<td>Severe</td>
<td>RTA</td>
<td>Skull Fracture</td>
<td>5-9%</td>
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<td>6</td>
<td>59</td>
<td>Male</td>
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<td>Very severe</td>
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<td>58</td>
<td>Male</td>
<td>7 years 7 months</td>
<td>Very Severe</td>
<td>RTA</td>
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<td>Low average</td>
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<td>Male</td>
<td>1 year 5 months</td>
<td>Very severe</td>
<td>RTA</td>
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<td>RTA</td>
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<td>Female</td>
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<td>25-100%</td>
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Using grounded theory, a model to explain the process of moving towards acceptance in individuals with a TBI was developed. Four overarching categories, incorporating; “understanding limitations”, “changed perceptions”, “confirmation of prognosis”, and “barriers to acceptance” were developed, in addition to a meta theme of “acceptance (adapt and overcome)”. A visual representation of the theory and the relationship between categories is depicted in Figure 3 below.

Participant’s narratives illustrated that they went through a process of progression from lack of awareness in the initial stages following the injury, to gaining an understanding of limitations over time, through the support of other’s and comparison. This understanding was vital for acceptance, and led to changed perceptions of themselves, their view on life, and a greater appreciation of others. Understanding was also necessary to seek information regarding prognosis, with confirmation of the finality of their recovery important in removing uncertainty, contributing to changed perceptions, and the creation of realistic aims and goals. It was important for individuals to use practical adaptations in their lives, and give back to help others in demonstrating their acceptance as they were able to “adapt and overcome”. However, this was not a fluid process, with various underlying barriers that could act as a hindrance, particularly if they set aims and goals they could not achieve, or if comparison and confirmation of prognosis led to experience of negative emotions, such as frustration and sadness. Feeling judged by others, and a lack of trust in their abilities were also barriers to acceptance, which often led to withdrawal from social activities. In order to step over the threshold of acceptance individuals were reliant on others support to encourage them to engage in activities and gain a greater understanding of their difficulties.
Figure 3: Model of Categories and their Relationships

- Reliant on others
- Understanding of Limitations
- Acceptance Threshold
- Barriers to Acceptance
  - Negative Emotions
  - Lack of Trust
  - Others Judgements
- Acceptance (Adapt and Overcome)
  - Adaptations
  - Giving Back
  - Aims/Goals
- Withdrawal
- Changed Perspective
- Confirmation of Prognosis
- Reliant on others
- Understanding of Limitations
- Acceptance Threshold
Meta Theme: Acceptance (Adapt and Overcome)

Through moving through a process of developing an understanding of their limitations and gaining changed perspectives, participants were able to “adapt and overcome” to achieve acceptance. This referred to the use of practical adaptations to aid functioning, giving back, and having realistic aims and goals to work towards, which participants described as examples of how they had achieved acceptance, in the context of barriers that hindered their progress.

a) Adaptations

All participants commented on the adaptations they had made to their lives following the TBI and felt that this demonstrated their acceptance. This ranged from making adjustments to activities or roles they had formerly undertaken, to use of environmental aids, such as memory prompts or mobility aids, and allowed them to engage in activities of daily living or roles that they had previously undertaken.

“..because I’ve got these limitations I can’t do the things as instantly as I would have done but I just kind of leave them and put them to one side and then do them a bit slower, and then, it’s kind of.....if you think there was a circle and you’ve gone round it with a square”. (Participant 2)

Many participants engaged in hobbies that were seen as therapeutic or helping in recovery, such as memory or word puzzles, and they commented on their perceived importance in keeping their “mind active”. It was hypothesised that it was important for participants to demonstrate a skill, or engage in activities that that they were good at and some participants had acquired new hobbies to achieve this following the injury, which prevented negative emotions.

“.. I’ll sit downstairs and watch, listening to music or watch telly making my cards and it fulfils my day then, instead of sitting down feeling miserable”. (Participant 3)

b) Giving Back

This sub-category refers to participants commenting on the importance of helping others in order to accept the injury. For some this related to wanting to protect others from injury, as following their accident awareness had been raised of safety issues and adaptations made to improve safety for others.
“There’s a lot of people round here who go out wearing hats now, because of what happened to me. So at least it’s done one good thing. Made all them wear protection hats now, you know”. (Participant 8)

Others spoke of wanting to volunteer to help others with a brain injury, through either raising money or sharing their knowledge and experiences. They acknowledged that they had benefited from the help and expertise of others and wished to contribute to themselves, often commenting on the advances in technology that had made their recovery possible.

“...computing, technology, understanding, better ways of doing it, feedback from people like me who’ve had an accident, what can people do better. That’s all helped, the greater level of care”. (Participant 1)

c) Aim/Goal/Target

This sub-category related to participants having a clear goal or target that they wished to achieve. Participants saw themselves as responsible for their recovery and spoke of their resilience and perseverance in trying to achieve their goals, demonstrating their acceptance. Self belief was important when working towards goals and achievements were seen as motivating.

“When they was teaching me how to walk again and that, I knew then I’d do it. I knew. Come on (name)”. (Participant 5)

Participants referred to “trying” to achieve things, appearing to acknowledge that they did not achieve everything they set out to do, and were not always successful in their endeavours.

“..so I just do it, so your brain injury’s not even an excuse, you try to improve the person that you are and it’s just accepting it that way”. (Participant 3)

However, some participant’s goals related to returning to their former selves, such as “being what I was before my accident”, and “being back to where I was before the accident”. It was hypothesised that this prognosis was not always realistic and that when individuals failed to reach such goals, this could lead to negative emotions and prevent them from accepting the injury.
Core Category 1: Understanding Limitations

In order to move towards acceptance participants described a process of understanding the effects of the injury on their lives. They started from a position of lack of awareness of the nature of the injury, and of their changed physical and cognitive abilities. It was hypothesised that through the support and understanding of others, upon whom they became reliant, and through comparison between their current and former selves and others, they were able to reach a level of understanding regarding their difficulties and their changed lives, without which they could not accept what had occurred.

a) Reliance on others

Support from others was an integral part of an individual’s recovery, and participants felt that they could not do it on their own. Following the injury, they were reliant on others, including family members, friends and professionals to provide information regarding the injury, give practical support and highlight their changed abilities.

In the initial stages following the injury, participants were reliant on others to explain what had happened, as many participants had no memory of the accident.

“... Doctor came and started explaining everything to me. This is how I know what happened to me”. (Participant 5)

Participants spoke of questioning others to seek such information and to gain advice. Others also provided suggestions for ways to cope, such as strategies to aid with cognitive deficits, or ways for individuals to occupy their time.

The practical support participants received related to requiring support to leave the house, for transportation and to complete activities of daily living.

“.. I don’t go anywhere really without someone taking me somewhere, so you feel kind of fairly dependent on other people”. (Participant 9)

Participants also became heavily reliant on others to highlight deficits following the injury. This was initially difficult for participants to acknowledge, and they reported
finding it frustrating and a barrier to their acceptance. However repeated experiences of others highlighting their difficulties led to increased understanding.

“She (wife) has to do it. And at the time you think, “don’t start, don’t start treating me like that”, you know, but it happens and it has to be done, yes, it has to be done”. (Participant 5)

Some participants appeared to rely on others to prompt their memory, or to act as an external locus of control, as they were unable to inhibit their own behaviour and therefore relied on others to do it for them.

“... my daughter started to apologise for me first, and she said “oh, that’s one of the things that my mum does now”. (Participant 4)

b) Comparison

This category relates to participants comparing their current situation to their former selves and to others in order to try and understand their limitations. This could have either a positive or negative impact on their well being and subsequent acceptance as comparison that highlighted improvement was seen as positive whereas comparison that emphasized differences could lead to negative emotions that were barriers to their acceptance.

Comparison with former self

Through comparison with their former selves, participants recognised loss of physical and cognitive abilities and loss of roles, activities or skills, in addition to acknowledging factors that they had retained. It was hypothesised that this process was used as a frame of reference for participants to try and understand what had happened to them.

“.... whereas I used to be so organised before, it was all gone”. (Participant 4)

Many participants reported loss of their job role following the injury, negatively impacting on their financial situation, as well as loss of formerly enjoyed hobbies due to an inability to partake in them. Participants also reported change to or loss of their relationships with others, often stating that partners now took on the roles that they
had previously undertaken, threatening previously held values, a factor that was particularly upsetting for individuals.

“Such a thing as, I was a man, as they say. Men don’t cry, sort of thing. Now I do”. (Participant 6)

Participants described their lives as being “slowed down” by the injury, with some feeling that they had regressed, comparing the experience to being a child again and needing to relearn things that they had previously known.

“It was like being a child, you know learn how to speak and things, it was, it was picking up things”. (Participant 3)

However, participants also acknowledged that there had been some positive changes in relation to the injury, and that they had gained positive attributes. For most this related to attributes or skills that they gained after the injury, and contributed to their changed perspectives on life.

“I felt so emotionally connected with what was going on. To me that’s a bit of a plus...Because it’s something you didn’t have before”. (Participant 1)

Comparison to self post injury
Some participants compared themselves to just after they had the injury, which allowed them to see the progress they had made and acted as a motivator for them to continue with their recovery and develop changed perspectives. This was often influenced by significant events that occurred following the injury, such as operations that led to improvement, or loss of a job role, which acted as poignant markers for comparison.

“If I look where I was 2 and a half years ago versus now, even I can sense a massive difference compared to how I was before, so that’s quite good for your sense of well-being, and feeling “I’ve recovered from this” and I’m going to be ok”. (Participant 1)

Comparison with others
Participants also compared themselves to others, which could have either a positive or negative impact on their acceptance, highlighting the fluctuating nature of the
process. Some participants normalised their difficulties stating that “everyone makes mistakes”, and that other people without a brain injury could have similar difficulties to their own, appearing to try and diminish their difficulties.

“One of your friends, you could suddenly not remember their name and yet you’ve been friends for 30 years. Now some of my friends were like that anyway and they’ve never had an accident, so (laughs) you kind of don’t feel too guilty in some ways”. (Participant 1)

However, other participants felt that mistakes highlighted their difficulties and thus impacted more on them than others who did not have an injury. Similarly, comparison with others could highlight things that they were not able to do that others could, leading to despair, a barrier to acceptance.

“Yes, if I compare myself with any of my peers, then I just feel an absolute failure, you know. And, you know, I can do so little in comparison, you know”. (Participant 11)

Comparison to others with a brain injury
Participants also compared themselves to others with a brain injury. It was hypothesised that this provided reassurance that they were not alone in their experiences and a sense that there were others who understood them. Those who were not in contact with other people with brain injuries, such as through support groups, expressed wonder at whether they went through similar experiences and felt that they could learn from them.

“... I think I need to go to (support group) or somewhere like that where other people have, or are going through relatively the same as me...... I think I’m, maybe I could get some tips, I don’t know some better strategies of dealing with everyday life...”. (Participant 5)

Comparison with others with brain injuries also provided participants with a frame of reference that highlighted the positives in their situation. Through comparison with others with brain injuries they realised that their injury could have been worse and felt grateful for the things they had been able to achieve post injury, with luck often cited as factor that contributed to changed perspectives.
“...there is people a lot, lot worse off than yourself. And you actually realise how lucky you are. And that’s when you’re actually thinking how pathetic am I being. This person has got this wrong with them”. (Participant 3)

Core Category 2: Changed Perspective

Participants described how, having gained an understanding of their limitations, they developed a changed perspective regarding themselves, their priorities in life and their perception of others in the process of moving towards acceptance.

a) Changed Perception of Self

This sub-category refers to the impact of the injury on participant’s identity. Some participants reported viewing themselves differently following the injury due to changes in ability.

“You sort of suddenly think, “wow, this is me now” and it would be like, I think my daughter sort of looked at me, cos I said, “Now I’m a different person”. I’m not a different person, I’m the same person I was before, but it’s like you’re a different person because you sort of approach things differently sometimes and, whereas at one point sometimes I used to be very quick witted, quite humorous, always very dry and frustratingly sometimes, it’s not there”. (Participant 4)

Another participant progressed this idea further and saw themselves as becoming a “new person” following the injury.

“So I’ve actually got to the point where there’s, I’m just a new person, I’m not, I’m not the old person anymore”. (Participant 3)

It was hypothesised that it was important for participants to reconcile the difference between their current and former selves. Acknowledgement of difference through formation of an altered identity was an important aspect of this to prevent participants from focusing on seeking to return to their former selves, which may have been unachievable. In order to create their altered identity it was necessary for participants to gain a balanced view on their lives, and to look forward, rather than to the past.
b) Balanced View

This sub-category related to participants gaining a balanced view of their lives following the injury, providing a positive perspective despite the impact of the injury. They appreciated the luck that they had experienced in surviving the accident and acknowledged the fragility of life, enhancing their commitment to adapting and working towards realistic goals.

“I’m very lucky to be alive, yes. So, erm, er, you know, I’m just very lucky and grateful that, you know, that’s why everyday when I look in my garden and I think what a fantastic, you know, experience...”. (Participant 9).

Participants reported that they could not know what life would have been like if they did not have the injury and therefore rumination or regret over what might have been was not helpful. They also reported a greater understanding and appreciation of others, particularly those who aided them in their recovery, including professionals and family members. These factors prevented them from descending below the threshold of acceptance, and led to them wanting to give back to aid others.

c) Looking forward not back

This sub-category refers to participants focusing on the positives in their lives, ensuring that they were making the most of their lives now, following the injury, facilitating their ability to adapt and work towards realistic goals.

“Life is important. Living a life. That’s what I want to do”. (Participant 6)

It was hypothesized that to do this they had to focus on the present or future rather than looking back. Participants commented on the importance of focusing on themselves, and noting small achievements as they happened, rather than dwelling on the past.

“The acceptance comes with you probably, looking forward rather than backwards. The sooner you can switch that direction as to where you’re going rather than where you’ve been and why you were there, which could go on forever, if you can kind of accept that somehow, sit on top of it and look at what’s coming, which is important and exciting, rewarding, then that’s probably where you get to...”. (Participant 1)
Core Category 3: Confirmation of Prognosis

This category relates to participants requiring confirmation of the likelihood of further improvement from others in order to make realistic aims and goals and accept the injury. Gaining this information could also contribute to changed perspectives.

For most participants confirmation of prognosis was provided by a medical professional, although for others family members would comment that regaining skills appeared unlikely. Some participants suspected that they would not make further improvement, whereas for others this was more unexpected and subsequently led to negative emotions.

“I think it was (Doctor) who said, ‘yeah, 12 months have passed, I don’t think there’s going to be any change now’ and that was a bit of a shocker”. (Participant 4)

As in the quote above, time was often cited as an indicator that no further improvement would be seen, although the length of time varied. It was hypothesised that confirmation of prognosis removed uncertainty and focus on past selves, leading participants to focus more on the future, and develop a changed perception of themselves. However, confirmation could also lead to barriers to acceptance due to the negative emotions evoked.

Core Category 4: Barriers to Acceptance

This category related to the barriers underlying the process that led participants to descend the threshold of acceptance, including negative emotions, feeling judged by others, and lack of trust in themselves, which often led to withdrawal. This could occur following comparison, confirmation of prognosis and if they set unrealistic goals. The support of others was required for participants to ascend back above the threshold of acceptance.

a) Negative Emotions

This sub-category refers to the negative emotions that participants experienced following the injury, which acted as a barrier to their acceptance. They reported self criticism, frustration, upset and hurt at situations that highlighted the things they
could no longer do, which could descend into feeling low if they withdrew and ruminated on their difficulties.

“I forget what I’m on about and I think oh god, don’t sound stupid (name). Just... go and make a card. It is frustrating”. (Participant 5)

Participants spoke of having “good days and bad days” following their injury, with bad days characterised by negative feelings and negative events attributed to the injury.

“I think if I’ve had a bad day,... I immediately I put it down, to the, to the (injury) and I’m thinking do you know what if I, if I wasn’t, this wouldn’t be happening if this hadn’t have happened. And then the problem is when you get down with a brain injury, then once you get, then you start to, then you start to think too much, and then you get really upset”. (Participant 3)

b) Others Judgements

This category refers to the participant’s reports that they felt others judged them negatively due to their brain injury, leading to negative emotions and impacting on their ability to accept. Other people’s perceptions of them changed compared to before the injury, due to an apparent lack of understanding.

“So a lot of people are doubting and scared, you know, what the, I suppose what the fear is you’ll be going up in a lift one day and you’ll suddenly lose your temper and just beat them up or something like that. Cause they don’t understand it”. (Participant 1)

Participants described how others had unrealistic expectations, either expecting them to be able to achieve things as they did before, or perceiving them to be functioning at a lower level than they were. Some found that others did not trust them due to their brain injury. This was frustrating and often led them to withdraw from others.

Many participants also cited difficulties due to the invisibility of the injury. They commented how visually, to others they would not appear to have difficulties, and
preferred not to disclose their injury outside of immediate contacts as they perceived that they would be viewed negatively by others.

“..the minute you tell somebody, you know I’ve got these cognitive, if they ask you, they suddenly start, they change. Their whole approach to you changes, I’ve noticed that”. (Participant 4)

c) Lack of Trust in Self

This sub-category related to participants questioning themselves and checking, either themselves or with others, due to an apparent lack of trust in their abilities. This included daily activities such as checking things were organised, and not trusting what they had, or might, say to others in social situations, which could lead them to withdraw from socialising.

“I gave directions one day and I pondered on it for ages after that. Was that right near there, was that right. And it ticks over”. (Participant 7)

Some participants were also uncertain of whether they were trying hard enough in their recovery, or whether they may do harm to themselves if they tried activities, leading them to refer to others for advice.

“Now it’s more of like, should I actually do this, or should I not? What would the consequences be if I didn’t do this, or would it result in something bad if I did this and didn’t think about what was going to happen? And now I’m kind of asking my relations, maybe should I do this or should I not and it’s like well, just get on with it, it’s alright now, or its, or that’s something you used to do anyway so just get on with it and do it”. (Participant 2)

d) Withdrawal

This sub-category related to participants withdrawing from others due to their difficulties, which resulted from negative emotions, judgement from others or lack of trust in themselves, and prevented acceptance. Participants reported difficulties in interacting with others led them to withdraw, as they did not feel understood and therefore ceased to continue trying to explain to others.
“I can’t do people, I don’t want to do people, I don’t want to have conversations with strangers, I can’t even..”. (Participant 5)

Another participant reported that it was easier if they withdrew as it removed them from responsibilities, which were difficult as they struggled to trust themselves.

“So I’m happy with not being asked a question. So don’t give me any authority or anything like that, just leave me alone in my bubble, and I’m happy”. (Participant 7)

Participants relied on the support and encouragement of others to overcome their withdrawal and partake in social activities, bringing them back over the threshold of acceptance.
Discussion

This study aimed to develop a theoretical model detailing the process of acceptance for individuals with a TBI. The use of grounded theory methodology facilitated participants in sharing their experiences and led to the creation of five core categories to account for the development of acceptance. This was not a fluid process, with barriers underlying individual’s experiences as they sought to move on with their lives and adapt to their changed circumstances. The model served to define acceptance for individuals with a TBI, with underlying concepts supporting existing literature within wider disability and physical health research, but also extends it, given that there were no previous studies focusing specifically on defining acceptance with this client group.

The participants spoke of the importance of understanding their limitations to acceptance, as they began from a position of lacking awareness, which is commonly seen following a TBI (e.g. Flashman & McAllister 2002). It has been acknowledged that focal lesions, particularly in frontal regions are associated with lack of awareness (e.g. Banks & Weintraub, 2009), and various models have been developed detailing the process of awareness, incorporating both neuropsychological and psychological factors (e.g. Ownsworth, McFarland & Young, 2002; Toglia & Kirk, 2000), with a focus predominantly on the former. However, while organic factors are evidently important, it is clear from this study that individual’s themselves were focused on the psychosocial aspects of understanding their limitations, emphasising that these aspects should not be overlooked.

The category of comparison was a pertinent theme conveyed by all participants, and appeared to be a complex process in serving to both facilitate and inhibit acceptance. Participant’s comparison with their former selves highlighted issues of loss and an understanding that they had changed. Existing research investigating self concept changes in individuals with acquired brain injuries has focused on comparison, (e.g. Tyerman & Humphrey, 1984; Wright & Telford, 1996), with individuals reporting a positive view of past selves in comparison to current, a view which can be inferred from participants accounts in the present study. Tyerman and Humphrey (1984) also reported that participants perceived themselves positively in relation to others with brain injuries, as in the current research.
Such findings are consistent with the notion of “loss of self” after brain injury, a commonly reported finding in brain injury research (e.g. Judd & Wilson, 1999; Myles, 2004; Nochi 1998). Myles (2004) identified that this is conceptualised in the literature as recognition by the individual that they are not the same as before, leading to negative evaluations, emotional distress and at times, denial. These factors were identified by participants in the present study as barriers to their acceptance. Cantor et al. (2005) developed this idea further, applying self-discrepancy theory (Higgins, 1987; Higgins, Klein & Strauman, 1985), to individuals with TBIs. The model proposes that emotional responses, such as depression and anxiety, are related to conflicting beliefs about aspects of the self, with inconsistencies between the actual self and the ideal, or ought self, resulting in emotional distress. Cantor et al. (2005) developed the theory to include self-appraised differences between pre and post injury self, a model which is consistent with the findings of the current study. This study also furthers these ideas, postulating that participants reconcile their changed selves through a change in focus and an altered appreciation of life, in order to accept what has occurred.

The participants changed perspective on life would fit with existing research regarding posttraumatic growth. This refers to the finding that positive effects can occur following a traumatic event (e.g. Helgeson, Reynolds & Tomich, 2006). Tedeschi and Calhoun (1996) identified that amongst the most common benefits reported following trauma were a greater appreciation of life, discovery of unexpected personal strengths and improved relationships with others going through the same experience, or who had been there to help. These were themes that were all evident in the current research. Studies focusing specifically on individuals with acquired brain injuries have identified that posttraumatic growth can occur with this population (e.g. Collicutt McGrath & Linley, 2006; Hawley & Joseph, 2007). Interestingly, posttraumatic growth has also been associated with reduced emotional distress in individuals with acquired brain injuries (e.g. Collicutt Mcgrath & Linley, 2006; Gangstad, Norman & Barton, 2009) a finding that the current study eludes to as changed perspectives were seen as part of acceptance, whereas negative emotions were viewed as a sign that individuals had not accepted the injury.

Posttraumatic growth has also been linked to the concept of altruism born of suffering (ABS; Staub, 2003, 2005), the notion of becoming helpful towards others after experiencing trauma. Staub and Vollhardt (2006) propose a model of ABS
which emphasises the role of help received from others, and suggests that greater awareness of suffering and increased perspective taking can lead to ABS. This would be consistent with the participant accounts of wanting to give back and help others and having a greater appreciation of others roles, in contributing to their acceptance.

The present research furthers existing literature in providing a model that incorporates not only the process of acceptance, but also barriers that underlie this process. Participant’s reports that they felt judged and not understood by others is reflected in the recognition that brain injuries are poorly understood by the general public (e.g. Hux, Schram & Goeken, 2006). Although the existing research in this area is limited, it is suggested that this can impact upon identity and adjustment following TBI (Willer, Johnson, Rempel & Linn, 1993). Social identity theory (Tajfel & Turner, 1979) is also relevant here as participants appeared to feel ostracized from former social groups, which impacted on their acceptance. There is also a plethora of research detailing the negative psychological outcomes that can occur following TBIs, including depression (e.g. Bryant et al., 2006; Koponen et al., 2002), consistent with participants accounts of negative emotions and withdrawal.

Limitations

While the findings highlight many pertinent issues relating to acceptance in individuals with a TBI, there are also limitations to the study that should be considered. There were issues with regard to bias in the sample as recruitment was limited in terms of geographical area, and there was limited variability in terms of age, ethnicity and cause of injury. Participants were also recruited from either healthcare settings or charities, and as such varied in terms of whether they were receiving active treatment at the time of the interviews, and at what stage this was at. The nature of the sampling method was self selected, which may have impacted on the external validity of the findings. There was also a broad range in terms of time since injury, and while this was beneficial to gain perspectives from individuals at different stages following the injury, it is possible that this overlooked nuances that occurred at particular times following the injury, and that perhaps acceptance had a different focus or meaning in earlier stages compared to latter. In addition, two participants chose to have their partners present during the interview which may have introduced a level of bias to their responses.
It should also be noted that there were difficulties recruiting from this population, which appeared in part to be due to difficulty locating individuals who would be able to participate in an interview and reflect on their experiences. Therefore all participants had either recovered or retained an ability to articulate their views and insights, which may have impacted on their ability to accept. Despite this, at times during the interviews participants struggled to elaborate on how or why they thought particular processes had occurred. This, in addition to time limitations, made it more difficult to adhere to the grounded theory principles of theoretical saturation and sampling.

A further limitation related to gaining details regarding the exact nature and severity of the injury. This relied on participant’s reports rather than accessing medical records therefore accuracy could not be confirmed. In addition the WMS IV BCSE, while a useful screening measure to gauge current level of cognitive functioning, did not provide detail regarding the nature of current cognitive difficulties which may have been beneficial to consider.

**Future research**

It would be beneficial to complete further investigation of acceptance in the area of TBI, with particular focus on acceptance at different stages post injury, and with a broader sample. It would also be useful for future research to collect data from the same participants over an extended time period, and to see whether views of acceptance change during recovery. Additionally, given the close link to identity change and acceptance, it would be useful to investigate this further.

Future research could also consider acceptance of family members. This study highlights the influential impact of family members and/or important referents on the acceptance process. The difficulties that participants reported if family members and others did not understand the impact of the injury highlights that a reciprocal acceptance process may occur.

**Clinical Implications**

The findings have important implications for services providing support and interventions for individuals with a TBI. Participants clearly stated that they were reliant on others support in order to gain an understanding of their limitations. Those who had information explained to them about the injury and what to expect as their recovery progressed found this beneficial. It is important for healthcare staff to
provide clear information to individuals, taking into account their cognitive difficulties when doing so to enhance their understanding. The inclusion of family members in this may well be important to ensure that they are aware and can continue to convey a consistent message to individuals.

Clarity over prognosis was vital in facilitating participant’s acceptance. Although prognosis is difficult to determine in the early stages, healthcare professionals should present a balanced view of likely outcomes, and be prepared to state clearly to the individual if no further improvement is expected. Involving individuals in realistic goal setting would perhaps facilitate this process. It was also notable that participants required the support of others to overcome barriers to acceptance, highlighting the important role of provision of psychological support after the injury to facilitate acceptance and recovery.

The findings also tentatively support the principles of ACT (Hayes et al., 1999) for individuals with a TBI, as acceptance was identified as an important aspect of recovery. The core components of ACT are to accept what an individual has and cannot be changed, choose valued life directions and take action to live a meaningful life (Hayes et al., 1999b), factors that would broadly adhere to the model. As Myles (2004) identified, ACT has potential utility in facilitating individuals with a TBI in regaining their sense of self, and it can be hypothesised from the current research that support to live a valued life, feeling emotions and bodily sensations without avoidance and gaining a more mindful view on thoughts and feelings related to the injury, would support recovery from a TBI.

Conclusion
In conclusion, this study highlights the complex process of acceptance in individuals with a TBI, and the importance of acceptance to this client group in maintaining psychological well being. Participant’s narratives focused on their attempts to understand their changed selves, and the changed perceptions and support from others that facilitated them to move forward and adapt to achieve acceptance, in the context of barriers that prevented them from progressing. Researching acceptance highlights a previously overlooked area of potential importance, and consideration of this factor is important in developing intervention and support for individuals with a TBI.
References


Critical Review

My Experience of Qualitative Research with Individuals with a Traumatic Brain Injury

Word Count:
5345
Introduction
This critical review describes my experience of carrying out a qualitative research project with individuals with a traumatic brain injury (TBI). Initially I will explain my interest in the research area, and selection of the methodology. I will then discuss my experiences of recruitment, conducting the interviews, and issues regarding measurement. Finally I will describe my experiences of the analysis. I will reflect on the knowledge and skills I gained throughout the process and how this has contributed towards becoming a qualified clinical psychologist.

Research Area
The research area was chosen due to the influence of my clinical interests. I worked predominantly in the area of learning disability prior to commencing clinical training and noted the influence of acceptance on clients and their families in this setting. At the time of developing the research topic I was working with a parent regarding acceptance of their child’s learning disability. The incongruence between the parental expectation and the child's ability appeared to significantly impact on their relationship and well-being, and they reported that they struggled to accept and recognise the child’s learning disability. This example is reflective of my wider experience of acceptance in this client group, with a lack of acceptance of the disability in individuals and their relatives appearing to have a detrimental effect on their relationships and well-being.

It has been suggested that following diagnosis of a learning disability in childhood parents go through an experience similar to grief for the loss of the “perfect” child who was expected (e.g. Hollins & Sinason, 2000). This led me to consider whether individuals with a TBI went through a similar process, especially as, in contrast to the majority of people with a learning disability, the individuals themselves are in a position where they may have awareness of the life they had previously led and how this contrasts to their life following the injury. I wondered whether those who were unable to progress past their feelings of grief were unable to accept the injury, especially as acceptance is cited as a stage in models of change regarding disability and loss (e.g. Kubler-Ross, 1967; Hollingsworth, Didelot & Levington, 2002).

During my subsequently work on a neurological rehabilitation ward I was struck by the sudden and unexpected nature of the injuries sustained in individuals with a TBI, and the change to their lives that may have been irrevocable. I wondered how individuals were able to reconcile this difference and about the psychological factors
differentiating clients who appeared resilient and focused when engaging in rehabilitation, and those that struggled to engage and were referred for psychological intervention. I also considered how individuals continued with their recovery after leaving the ward, where changes to their lifestyle were likely to become most apparent, particularly as they were often returning to different or adapted living environments and/or loss of roles.

In considering some of these issues I sought to find literature to aid in my clinical work, and also for the development of the study which following initial supervision meetings was conceptualised as a quantitative investigation of predictors of acceptance. I was surprised to find that the topic area appeared largely overlooked, both in wider clinical populations and with regard to TBI, with the exception of the emergent evidence base regarding acceptance and commitment therapy (ACT; Hayes, Strosahl & Wilson, 1999). Within this context it appeared that a qualitative investigation of acceptance in TBI would be more appropriate, to investigate perspectives of acceptance in individuals with a TBI, and factors that facilitated and hindered this process.

**Rationale for the Use of Grounded Theory**
Qualitative methodologies aim to generate detailed, rich descriptions and interpretations of investigated phenomena. Given the lack of clarity over definitions of acceptance in the literature it appeared important to gain an understanding of this concept. This could be achieved through seeking the perspectives of individuals who had experienced a TBI. Corbin and Strauss (2008) note that qualitative methods have been developed to investigate the inner experiences of participants and to determine how meanings are formed through and within culture. Consideration of these factors would lead to an understanding of the participant’s perspective of acceptance.

There are various qualitative methodologies, including interpretive phenomenological analysis (IPA) and grounded theory, both of which have been commonly used in studies with individuals with a TBI (e.g. O’Callaghan, Powell & Oyebode, 2006; Shotton, Simpson & Smith, 2007; Nochi, 1998a, 1998b). IPA aims to generate a rich description of lived experience and allows the researcher to develop an analytic interpretation of participants accounts (Smith, 2004). Grounded theory goes beyond this in that it provides an interpretive account but also develops a theoretical understanding of phenomena. The theory is grounded in participants
accounts, progressing research findings beyond detailed, rich accounts into a theoretical model that can be tested out and considered in future research. Grounded theory was therefore selected as an appropriate methodology for the present study as it aimed to investigate the process of acceptance, and development of a theory would serve to conceptualise this process.

Alternative perspectives of grounded theory methodology have developed since its inception by Glaser and Strauss in 1967. In fact, Glaser and Strauss subsequently proposed differing views of grounded theory (e.g. Glaser, 1992; Strauss & Corbin, 1998). A further alternative perspective is proposed by Charmaz (2000, 2006), who advocates a constructionist approach to grounded theory. Charmaz purports that both Glaser and Strauss’s approaches to grounded theory assume an objective external reality and therefore take a positivist and objectivist stance. Charmaz (2006) advocates a constructionist view that assumes multiple social realities, and believes that the studied world should be portrayed in an interpretive way as the researcher and interviewee together embark on a process of constructing reality. This approach was utilised in the current study to understand how individuals with a TBI understand and construct their acceptance of the injury in relation to their lived experiences.

**Recruitment**

When initially planning the project I had not anticipated significant difficulties in obtaining participants as two NHS sites and one charity were identified and agreed to recruit for the study, which appeared appropriate given the planned sample size. However, one of the NHS sites was a small service with a limited number of participants from which to recruit, and for the other the main contact for the study in the department left their post prior to recruitment commencing. Although assurances were received that recruitment could continue to commence at the latter site, and attempts made to build positive relationships with the clinicians there, it did not lead to any participants being identified from this department. It was considered that this was reflective of pressures on the service as this was a large and busy department, and that there were other research projects ongoing for which clinicians had greater investment due to being involved in their development.

The recruitment procedure also relied on clinicians in the departments to identify those who may be suitable to take part, placing a level of responsibility onto them. Additionally, they were required to provide potential participants with a recruitment
pack, either in person or via post, which may have been considered time consuming in comparison to a study in which these responsibilities were left to the researcher or if information was left in a reception area for participants to view and contact the researcher for further information if they wished.

Due to these difficulties, a further charity and an additional NHS site were approached and agreed to allow recruitment. Additionally, the inclusion criteria was amended to include participants up to 15 years post injury as opposed to 5 years, and to those who had been discharged from the services, following the advice of clinicians that this would open up a wider pool of participants from whom to recruit. It felt frustrating to be seeking approval from the ethics committee for these amendments, to be undergoing research and development procedures at a further trust, and to be going to present at regional meetings for the charity at what felt like the later stages of the research, when time pressures were more apparent.

Further factors regarding the sample also impacted on recruitment. When defining the characteristics of the sample for the study, consideration was given to the potential difficulties of interviewing individuals who may have cognitive difficulties. It was considered that due to concerns regarding ethics, individuals would be required to have capacity to give informed consent in order to take part. In addition, it was determined that participants would be required to be able to discuss and reflect on their experiences to participate in the interview, as is common in studies of this nature (Paterson & Scott-Findlay, 2002). However, clinicians reported that this significantly limited the number of potential participants within their services. Excluding a proportion of individuals with a TBI was a limitation, and there is a small body of research which would suggest that it is possible to include participants with cognitive difficulties, and that difficulties in expressive language can be overcome by the use of adaptive methods (e.g. Egan, Chenowth & Mcauliffe, 2006; Luck & Rose, 2007). On reflection, it may have been preferable to widen the inclusion criteria and gain the views of those with greater cognitive or expressive abilities than the inclusion criteria used allowed, as this would have provided a more representative sample.

However, despite difficulties in recruitment relating to gaining access to appropriate participants, the majority of participants who received the information packs contacted the researcher and expressed interest in taking part. I was struck when attending meetings at the charities by the genuine interest that individuals had in the
project, with even those who were aware that they would not have been eligible to
take part taking time to listen and ask questions. I was also impressed by the
participant’s commitment to partaking in the study, making time and overcoming
difficulties in transportation to attend, and their willingness to share their
experiences.

Interviews
Development of Questions
It was considered that semi-structured interviews would be an appropriate
methodology to gather data for the study, as this is one of the most commonly used
methods in qualitative research (e.g. Patton, 2002). An iterative process was used to
develop the interview, as ideas were changed and developed both during the initial
construction of the questions, and once the interviews had commenced. Questions
were devised through supervision and review of the type of questions used in
qualitative studies with individuals with a TBI. The interview was structured such that
the initial questions were based around the injury and changes that had occurred,
and then led to focus on acceptance of these changes, which was considered to be
an appropriate sequence.

In practice, I found that the majority of the interview was focused on the initial
questions, with participant’s comments about acceptance filtering through their
narratives regarding the occurrence of the injury and changes that had occurred as
a consequence. The later questions which specifically focused on acceptance were
still asked in this circumstance, and acted as an opportunity for topics that had been
discussed previously to be clarified.

Experiences of Interviewing
The location for the interview was discussed with each participant, to facilitate their
participation and ensure that it was convenient for them. The majority of participants
were seen at charity, university or NHS sites. For interviews in participant’s homes, I
consulted with referring clinicians with regard to any known risks of lone working in
the participant’s home, and followed University of Manchester and local NHS trust
policies on lone working. This included informing a designated individual of where I
was going and that I had completed the interview. I had anticipated when seeing
individuals in their homes that it may be difficult to conduct the interview in a quiet
place that was free from distractions. However, this did not occur as the participants
had specifically chosen times when they would be able to partake in the interview without interruption from other members of the household.

It was notable that for two interviews at NHS sites, participants requested that their partners remained with them during the interview. This was facilitated, although I was initially uncertain as to the impact that this may have on the interview process. I was concerned that participants may feel unable to be as open to discuss their experiences with their partners there. However, this did not appear to be the case, and although neither partner contributed in depth to the interview, their presence appeared to add to the data rather than remove from it. The partners were able to provide information regarding the injury that the individuals were not, and had a greater awareness of the chronology of events. Providing occasional prompts of this nature appeared to initiate a greater degree of reflection in the individual as they considered a particular time point. It was also interesting to see the level of dependence that the individuals had on their partners, with the reliance of the injured individual on their partner evident during the interview.

**Impact of Cognitive Difficulties**

Consideration was given during interviews to the participants level of understanding. I had no prior knowledge of the participants possible cognitive difficulties before meeting with them to carry out the interview. In this respect, carrying out the Wechsler Memory Scales IV Brief Cognitive Screening Examination (WMS IV BCSE; Wechsler, 2009) prior to the interviews was useful as it provided information as to areas of difficulty for the participant, such as memory. It was also beneficial to have had prior experience of working with individuals with cognitive difficulties and to be able to be flexible in phrasing of questions to ensure understanding.

Some participants would speak at length which could be difficult to follow, and appeared to talk quite broadly about their experiences such that it was difficult to determine if they were continuing to refer to the question asked. Initially I felt anxious that although they were providing a significant amount of information, it might not be relevant to the research question. It was also difficult in this circumstance to interject with further questions, or to clarify what was being said. However, following supervision and review of the transcripts I realised that participants were providing relevant information, and answering the questions asked, however the structure to their responses had made it difficult for me to follow this at the time. In fact, at times they had already provided responses to questions
that I later asked and were able to refer me to this. I learnt in this circumstance to allow participants to tell their story and to note down pertinent points for clarification afterwards, rather than to try and stop them during their narrative.

In contrast, other participants provided concise answers and required encouragement to elaborate on their responses. In this circumstance the interview schedule was followed more closely, however I was concerned that I was leading the participant and influencing their responses. It was also difficult at times to gain a greater depth of information from participants, as when the meaning of phrases were questioned, or participants were asked why they felt particular processes had occurred, they were not always able to elaborate.

Additionally, memory and attention difficulties were evident in some participants, as they would lose track of what they were saying and ask for clarification. I endeavoured to always respond with the last few words the participant had been saying, using their words. However, some participants required more information than this to regain their train of thought and I was conscious of trying not to put my own interpretation onto what had been said, whilst not always being able to recall the participants exact statements to relay back to them. With hindsight it may have been useful in this circumstance to have rewound the tape recorder for the participant to have heard back what they had said.

In these circumstances I was acutely aware of the power differential between myself and the participants. I was aware of my role as the researcher, and as an individual who had not experienced a TBI, and that participants may have felt compelled to present a picture of normality and state that they had accepted the injury. I was aware in some interviews that participants would describe how they felt they had accepted the injury in the context of achieving future goals, which drawing from my knowledge of working clinically in the area, I considered may not have been attainable for them.

I had not anticipated the aforementioned difficulties in the interview process and found them to be challenging. I also had not initially anticipated the emotional impact of the interviews. I was struck by the detrimental impact of the injury on the person’s life, and how their injuries had unexpectedly occurred in seemingly routine aspects of their lives. Some participants became upset when discussing the changes that the injury had caused to their lives, and I was often left with a sense of
hopelessness. I reflected that this was due to the different role of a researcher compared to that of a clinician, a role that was more familiar to me. It was difficult, particularly following my work in neurological rehabilitation not to step out of the researcher role and provide reassurance or clinical advice. However, the participants often commented that they had found the interview useful as they rarely had the opportunity to discuss what had happened following the injury, and that it had prompted them to think about the way that they had dealt with things. This led me to feel more positive about carrying out the interviews, especially as I was conscious that participants had provided their time and been willing to share their experiences.

Measures
Although standardised measures are not commonly used in qualitative research it was determined that it would be useful to gain information regarding the participants current cognitive abilities, to provide further information regarding the impact of the injury and the individuals current context. While psychometric testing is often viewed as integral to the discipline of neuropsychology, as Wilson, Evans and Gracey (2009) note, cognitive assessments do not provide information regarding the ability of the individual to cope with identified deficits in their everyday life. It could perhaps be considered that to gain information regarding a person’s coping abilities in the absence of the context of information regarding their cognitive abilities would be similarly limited. Therefore in gaining information regarding the individuals cognitive abilities, in addition to the qualitative interview, it was considered that this provided insight into both the individuals context and their views and experiences regarding the injury.

The WMS IV BSCE was chosen as a measure of cognitive abilities as it was specifically developed as a screening measure of global cognitive functioning, and it could be administered in 15 to 20 minutes. The timing of administration was important as a longer assessment might have led participants to become fatigued, and also detracted from the interview which was the principal focus of the study. Although other measures were considered, including the Addenbrooks Cognitive Examination-Revised (ACE-R; Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006) it was decided that as this was predominantly developed regarding screening for the early stages of dementia, the WMS IV BSCE was more appropriate for the purposes of the study.
Prior to carrying out the interviews I was concerned as to the potential impact of the assessment on engagement. As I would only be meeting with the participants on one occasion it was necessary to try and build rapport and ensure that the participant felt at ease quickly. I recognised the importance of providing a detailed explanation of the purpose and process of the demographic questions, cognitive assessment and interview, and discussed how long this would take and that during the interviews I may take notes at times as a prompt to remind myself if there was an aspect that I would like to follow up. At times it felt a little disjointed to complete the injury and demographic questions first, followed by administering the cognitive assessment, to then commence the interview which again focused on the injury. Participants often began to provide further details about the injury during the initial demographic and injury questions, and it may perhaps have been preferable to complete the cognitive assessment first.

With regard to the cognitive assessment, participants often commented that they had completed similar assessments in hospital, or with other professionals, particularly the orientation questions. They explained that they had often learnt the responses to many of these questions as they were asked them repeatedly over time. The other aspects of the assessment appeared less familiar to the participants which was perhaps reflective of the age of the measure as it was relatively new, providing greater validity to the scores.

Defining the severity of the participants TBIs was another factor that required consideration. As Sherer, Struchen, Yablon, Wang and Nick (2008) note, Glasgow Coma Scales (GCS; Teasdale & Jennett, 1974) are the most widely used clinical measure of TBI severity. However, limitations to this approach are noted due to a lack of clarity over the timing of the score used to denote severity (e.g. American Association of Neurological Surgeons, 2000; Eisenberg & Weiner, 1987). Scores are also usually recorded at the point of emergency department admission or following transfer to hospital wards. It was considered that gaining access to the relevant medical records to retrieve this information was questionable on ethical grounds. Therefore an alternative approach was utilised, in establishing length of post-traumatic amnesia, as defined by Russell and Smith (1961). To gain this information participants were questioned about the length of time they had been unable to recall following the injury. The accuracy of this information was questionable as it relied on participants accounts, and those who were at a longer time post injury in particular struggled to report this, often commenting they were unsure what they had
remembered, and what they had been told by other people. On reflection, it may have been preferable to have sent out the demographic questions prior to the interview, as this would have provided individuals with greater opportunity to consider their response to this question and possibly gain clarification from others.

**My experience of analysis**

Having never previously embarked on a qualitative research project, I had not anticipated the demanding and time consuming nature of the analysis process. Following each interview I began by transcribing the recordings. This was a lengthy process, however it was beneficial to hear each interview again and to listen intently, as I often noted factors that I had not considered to be pertinent at the time. I also realised how much of the information was lost when listening to the tapes, as the meaning behind pauses, body language and moments when participants became upset were not conveyed. This alerted me to the importance of noting down key thoughts about the interview, to try and ensure that the nuances in the conversation were not lost. Transcription also provided a time to reflect on possible alterations to the interview, and topics that required deeper exploration, in line with grounded theory principles. This was particularly pertinent in the current study due to the aforementioned impact of participants cognitive difficulties in the interviews.

In grounded theory is it suggested that analysis should occur simultaneously to further data being collected. It was difficult at times to progress with coding once transcription was complete. In the latter stages of the research, having acknowledged the time consuming nature of transcription I prioritised this, as it appeared logical that if the interviews were not transcribed I could not the code. On reflection, this was perhaps due to my own anxieties about how to progress with coding, and it would have conversely felt more manageable to have adhered more closely to coding while still collecting data.

Time pressures also impacted on my ability to simultaneously collect data and code. The difficulties I experienced with recruitment meant that I was still interviewing participants in the later stages of the research process. On occasion I saw more than one participant in a day which could be quite demanding as I sought to capture my thoughts regarding one interview prior to commencing the next, and found that issues from the previous interview appeared pertinent if similar concepts were mentioned in the subsequent one. I was concerned that I was placing too much emphasis on such concepts and found the interview schedule useful here in
ensuring that while endeavouring to gain greater depth regarding the apparently pertinent concepts, I did not overly focus on such topics at the expense of the participants other narratives.

Prior to commencing coding I had anticipated that due to my experience of family therapy approaches and as a member of reflecting teams where pertinent themes are identified, that I would not find coding to be overly difficult, although I was daunted at the length of the interviews. However, my assumptions were incorrect as I quickly established that the level of detail required was significantly greater than providing reflections in a therapy context.

I began with line by line coding, which refers to naming each line of the written data (Glaser, 1978). I found that I struggled to determine the appropriate level of closeness to the data, at times feeling as though I was just re-writing what the participant had said, while at others I felt that I had introduced a level of interpretation to the data and was concerned that I was too far removed from what the participant may have meant. This led me to gain a greater understanding of the different levels to coding, with Charmaz (1990) noting that the initial stages of coding are concerned with keeping the researcher examining the collected data “rather than lapsing entirely into theoretical flights of fancy which have little connection to the data”.

Therefore following initial line by line coding in which I endeavoured to remain close to the data, I progressed to focused coding, which Glaser (1978) defines as more directed, selective and conceptual than line by line coding. I found that at this point I gained a greater sense of the information being conveyed in the data and that although I had multiple codes, it felt manageable to synthesise and explain larger excerpts of the data. I was also mindful that it is identified in the literature that there is a risk in excessively emphasising identification of codes, as opposed to explaining how they are related to each other (e.g. Glaser, 1992; Stern, 1994). I found that theoretical coding was important here, to consider how substantial codes may relate to each other (Glaser, 1978).

In practice the different types of coding were not carried out in an entirely linear pattern, as I tended to note my thoughts about possible links between codes during the initial stages. Initially, I did not realise that these took the form of memos, and was confused as to the role of memos in the grounded theory process. I was
concerned that the examples of memos provided in Charmaz (2006) appeared to be long and detailed and that I was missing what was purported to be a vital part of the research process. However, I realised that my own style of memo writing was to note down my personal reflections, ideas, theoretical insights and my interpretation of which codes may be significant and developed into categories, and the relationships between them. These insights were important in the early stages as they prompted me to constantly compare participant’s narratives, adhering to the constant comparative approach, a key principle in grounded theory. In the later stages memos formed the basis of my descriptions of categories in my write up and I realised how important they were. I gained the confidence to write them in my own style and considered that although they were not overly detailed, they prompted me to reflect in detail about the categories when writing up.

Charmaz (2006) states that “memo writing leads directly to theoretical sampling” (p.103). However, this was the area of grounded theory methodology that I found most difficult to adhere to. Theoretical sampling refers to collection of further data to gain information to elaborate on emerging concepts, in order to develop categories and achieve saturation. Due to difficulties in recruitment it was not possible for me to seek out particular participants to illuminate and define early findings. However, altering my interview schedule did allow me to gain further information regarding my emerging categories with future participants.

I also found the issue of saturation difficult to conceptualise. Categories are seen to be saturated when collection of further data does not lead to new theoretical insights or new properties. Due to limitations in time available and the scope of the project, it was decided that the concept of “theoretical sufficiency” (Dey, 1999) would be used as an alternative. Dey (1999) is critical of the concept of saturation and proposes that researchers should focus instead on the ability of data to create a sufficient theoretical account. It was considered that this was achieved in the current study, although I found it difficult to determine the point at which I should stop collecting data and sought supervision regarding this.

Reflexivity
A reflective journal was used as a tool to enhance reflexivity in the research process. Reflexivity is important to qualitative methods due to the influence of the researcher in the research process. As Charmaz states, the “theory depends on the researcher’s view; it does not and cannot stand outside it”. (p.130, 2006). Reflexivity
led me to consider what I brought to the study and my own influence on the research. I became aware of how my previous experiences and knowledge may impact on my interpretations of the data. I considered this to be a vitally important aspect of the research process and had not previously considered my own influence in the context of research.

However, initially I was sceptical about the use of a reflective journal and did not see the value in it. Entries were predominantly based around recording work completed as part of the research process, and actions from supervision meetings, with few reflections or insights documented. However, as the research progressed and recruitment commenced I found the journal to be a useful tool in which to document and reflect on successful recruitment strategies and those that were less effective. When I conducted interviews, initial thoughts and insights were all recorded, which served as memo’s in the analysis stage. I began to see that the journal served as an important aspect of the research, bringing together personal reflections and insights and evidencing decisions made. The journal also had a cathartic purpose, allowing me to record frustrations, particularly around recruitment. At times when the research felt overwhelming it was beneficial to look back through the journal and acknowledge the amount of progress that had already been made.

**Conclusion**

As Lloyd, Gatherer and Kalsy (2006) note, there is a relatively small number of published studies including qualitative interviews with individuals with a TBI. Neuropsychology as a discipline has been criticised for its over focus on diagnosis of cognitive deficits at the expense of the individuals lived experience of them. The current research was converse to this view as it sought the experiences of individuals with a TBI, allowing them to express their views, which contributes to improved understanding of the experiences of individuals with a TBI.

The process of conducting a qualitative research project with individuals with a TBI was a challenging process. At times I experienced feelings of frustration and despair, and found it difficult to see how the project would ever be completed. However the factor that kept me going through the process was the individuals with a TBI who had generously volunteered their time and shared their experiences. I learnt a great deal from the experience, both in terms of use of qualitative methodology and research skills, and about myself, and the factors that influence my work, which has enhanced my development as a clinical psychologist.
References


Appendix 1: Summary of Neuropsychological Rehabilitation Journal Manuscript Guidelines
Neuropsychological Rehabilitation considers all manuscripts on the strict condition that they have been submitted only to Neuropsychological Rehabilitation, that they have not been published already, nor are they under consideration for publication or in press elsewhere. Authors who fail to adhere to this condition will be charged with all costs which Neuropsychological Rehabilitation incurs and their papers will not be published.

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Manuscript preparation

1. General guidelines

- Papers are accepted only in English. British English spelling and punctuation is preferred. Any consistent spelling style may be used. Please use double quotation marks, except where “a quotation is ‘within’ a quotation”.
- There is no word limit for manuscripts submitted to this journal. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendices (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- Abstracts of 150-200 words are required for all papers submitted. Avoid abbreviations, diagrams, and references to the text in the abstract.
- Each paper should have 5 keywords.
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here.
- All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the
manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the article is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

- Biographical notes on contributors are not required for this journal.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
- Authors must adhere to SI units. Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors should supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Section headings should be concise and should not contain numbering.
- Acknowledgements should be gathered into a brief statement at the end of the text. All sources of financial sponsorship are to be acknowledged, including the names of private and public sector sponsors. This includes government grants, corporate funding, trade associations and contracts.
- Tables should be kept to the minimum. Each table should be typed double spaced on a separate page, giving the heading, e.g., "Table 2", in Arabic numerals, followed by the legend, followed by the table. Make sure that appropriate units are given. Instructions for placing the table should be given in parentheses in the text, e.g., "(Table 2 about here)".
- Results of statistical tests should be given in the following form:

"... results showed an effect of group, $F(2, 21) = 13.74, MSE = 451.98, p < .001$, but there was no effect of repeated trials, $F(5, 105) = 1.44, MSE = 17.70$, and no interaction, $F(10, 105) = 1.34, MSE = 17.70$." Other tests should be reported in a similar manner to the above example of an $F$-ratio. For a fuller explanation of statistical presentation, see the APA Publication Manual (6th ed.).

- Abbreviations that are specific to a particular manuscript or to a very specific area of research should be avoided, and authors will be asked to spell out in full any such abbreviations throughout the text. Standard abbreviations such as RT for reaction time, SOA for stimulus onset asynchrony or other standard abbreviations that will be readily understood by readers of the journal are acceptable. Experimental conditions should be named in full, except in tables and figures.

2. Style guidelines

- Description of the Journal’s reference style
- Guide to using mathematical symbols and equations
3. Figures

- It is in the author's interest to provide the highest quality figure format possible. **Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.**
- Figures must be saved separate to text. Please do not embed figures in the paper file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the paper (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

4. Publication charges

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There is no submission fee for Neuropsychological Rehabilitation.

**Page charges**

There are no page charges for Neuropsychological Rehabilitation.

**Colour charges**

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6. Supplemental online material

Authors are welcome to submit animations, movie files, sound files or any additional information for online publication.

- Information about supplemental online material
Appendix 2: Search Terms Used In Metasynthesis
## Search Terms Used in Metasynthesis

### Words Related to Traumatic Brain Injury

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Words Related to Traumatic Brain Injury</th>
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</thead>
<tbody>
<tr>
<td>“Traumatic brain injury”</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>“TBI”</td>
<td>Head Injury</td>
</tr>
<tr>
<td>“head injur*”, “closed head injur*”</td>
<td>Brain trauma</td>
</tr>
<tr>
<td>“brain trauma”, “head trauma”, “cranial trauma”</td>
<td>Brain injury</td>
</tr>
<tr>
<td>“brain injur*”, “cranial injur*”</td>
<td>Brain damage</td>
</tr>
<tr>
<td>“brain damage”, “head damage”, “cranial damage”</td>
<td>Brain disorder</td>
</tr>
<tr>
<td>“brain disorder*”, “head disorder*”, cranial disorder*</td>
<td>Brain contusion</td>
</tr>
<tr>
<td>“brain contusion”</td>
<td>Brain concussion</td>
</tr>
<tr>
<td>“diffuse axonal injur*”</td>
<td>Diffuse axonal injury</td>
</tr>
<tr>
<td>“brain edema”, “brain oedema”</td>
<td>Brain edema</td>
</tr>
<tr>
<td>“crainocerebral injur*”, “craniocerebral damage”, “crainocerebral trauma”</td>
<td>Crainocerebral injury</td>
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</table>

### Words Related to Study Design

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Words Related to Study Design</th>
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</thead>
<tbody>
<tr>
<td>“qualitative”, “qualitative research”, “qualitative stud*”</td>
<td>Qualitative</td>
</tr>
<tr>
<td>“focus group*”</td>
<td>Focus groups</td>
</tr>
<tr>
<td>“interview*”, “semi structured interview*”</td>
<td>Interviews</td>
</tr>
<tr>
<td>“narrative”</td>
<td>Narrative</td>
</tr>
<tr>
<td>“thematic”, “theme*”</td>
<td>Thematic</td>
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<tr>
<td>“discourse analysis”</td>
<td>Discourse analysis</td>
</tr>
<tr>
<td>“content analysis”</td>
<td>Content analysis</td>
</tr>
<tr>
<td>“ethnograph*”</td>
<td>Ethnography</td>
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<tr>
<td>“constant comparative method”</td>
<td>Constant comparative method</td>
</tr>
<tr>
<td>“observational method”</td>
<td>Observational method</td>
</tr>
<tr>
<td>“phenomenolog*”, “phenomenolog* research”, “phenomenolog* stud*”, “interpretive phenomenolog*”</td>
<td>Phenomenology</td>
</tr>
<tr>
<td>“grounded theor*”, “grounded stud*”, “grounded stud*”</td>
<td>Grounded theory</td>
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</table>

### Words Relating to Family

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<th>Search Term</th>
<th>Words Relating to Family</th>
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<td>“famil*”</td>
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<td>“relative*”</td>
<td>Relative</td>
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<td>“partner*”, “spouse”</td>
<td>Partner</td>
</tr>
<tr>
<td>“husband*”</td>
<td>Husband</td>
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<tr>
<td>“wife”, “wives”</td>
<td>Wife</td>
</tr>
<tr>
<td>“child*”</td>
<td>Child</td>
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<tr>
<td>“significant other*”</td>
<td>Significant other</td>
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<tr>
<td>“carer*”, “caregiver”</td>
<td>Carer</td>
</tr>
<tr>
<td>“sibling*”, “brother*”, “sister*”</td>
<td>Sibling</td>
</tr>
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</table>
Appendix 3: Critical Skills Appraisal Programme (CASP; 2006)
This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is not a definitive guide and extensive further reading is recommended.

**How to use this appraisal tool**

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour**: has a thorough and appropriate approach been applied to key research methods in the study?
- **Credibility**: are the findings well presented and meaningful?
- **Relevance**: how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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Screening Questions

1. Was there a clear statement of the aims
   □ Yes □ No of the research?
   Consider:
   – what the goal of the research was
   – why it is important
   – its relevance

2. Is a qualitative methodology appropriate?  □ Yes □ No
   Consider:
   – if the research seeks to interpret or illuminate
   the actions and/or subjective experiences of
   research participants

Is it worth continuing?
Detailed questions
.................................................................................................................................

Appropriate research design
3. Was the research design appropriate to address the aims of the research?
   Consider:
   – if the researcher has justified the research
design (e.g. have they discussed how they
decided which methods to use?)
.................................................................................................................................

Sampling
4. Was the recruitment strategy appropriate to the aims of the research?
   Consider:
   – if the researcher has explained how the
   participants were selected
   – if they explained why the participants they
   selected were the most appropriate to provide
   access to the type of knowledge sought by the
study
– if there are any discussions around recruitment
(e.g. why some people chose not to take part)

Data collection
5. Were the data collected in a way that addressed the research issue?
Consider:
– if the setting for data collection was justified
– if it is clear how data were collected (e.g. focus
group, semi-structured interview etc)
– if the researcher has justified the methods
chosen
– if the researcher has made the methods explicit
(e.g. for interview method, is there an indication
of how interviews were conducted, did they
used a topic guide?)
– if methods were modified during the study. If so,
has the researcher explained how and why?
– if the form of data is clear (e.g. tape recordings,
video material, notes etc)
– if the researcher has discussed saturation of
data

Reflexivity (research partnership relations/recognition of researcher bias)
6. Has the relationship between researcher and participants been adequately
considered?
Consider whether it is clear:
– if the researcher critically examined their own
role, potential bias and influence during:
– formulation of research questions
– data collection, including sample recruitment
and choice of location
– how the researcher responded to events during
the study and whether they considered the
implications of any changes in the research design

Ethical Issues

7. Have ethical issues been taken into consideration?
Consider:
– if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
– if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
– if approval has been sought from the ethics Committee

Data Analysis

8. Was the data analysis sufficiently rigorous?
Consider:
– if there is an in-depth description of the analysis process
– if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
– whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
– if sufficient data are presented to support the findings
– to what extent contradictory data are taken into account
– whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation
Findings

9. Is there a clear statement of findings?

Consider:
– if the findings are explicit
– if there is adequate discussion of the evidence both for and against the researcher’s arguments
– if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
– if the findings are discussed in relation to the original research questions

Value of the Research

10. How valuable is the research?

Consider:
– if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
– if they identify new areas where research is necessary
– if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
### Quality Appraisal Checklist (Walsh & Downe, 2006)

#### Summary criteria for appraising qualitative research studies

<table>
<thead>
<tr>
<th>Stages</th>
<th>Essential Criteria</th>
<th>Specific Prompts</th>
</tr>
</thead>
</table>
| **Scope and purpose**| Clear statement of, and rationale for, research question/aims/purposes | • Clarity of focus demonstrated  
• Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing  
• Link between research and existing knowledge demonstrated  
• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both |
|                      | Study thoroughly contextualised by existing literature  |                                                                                                                                                  |
| **Design**           | Method/design apparent, and consistent with research intent | • Rationale given for use of qualitative design  
• Discussion of epistemological/ontological grounding  
• Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)  
• Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims  
• Setting appropriate  
• Were data collection methods appropriate for type of data required and for specific qualitative method?  
• Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?  
• Was triangulation of data sources used if appropriate? |
|                      | Data collection strategy apparent and appropriate      |                                                                                                                                                  |
| **Sampling strategy**| Sampling strategy and method appropriate               | • Selection criteria detailed, and description of how sampling was undertaken  
• Justification for sampling strategy given                                                                 |


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<tr>
<th>Analysis</th>
<th>Analytic approach appropriate</th>
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<td></td>
<td>• Thickness of description likely to be achieved from sampling</td>
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<td>• Any disparity between planned and actual sample explained</td>
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<td>• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</td>
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<td></td>
<td>• Was it appropriate for the qualitative method chosen?</td>
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<td>• Was data managed by software package or by hand and why?</td>
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<td></td>
<td>• Discussion of how coding systems/conceptual frameworks evolved</td>
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<td></td>
<td>• How was context of data retained during analysis</td>
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<td></td>
<td>• Evidence that the subjective meanings of participants were portrayed</td>
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<td></td>
<td>• Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</td>
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<tr>
<td></td>
<td>• Did research participants have any involvement in analysis (e.g. member checking)</td>
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<td>• Evidence provided that data reached saturation or discussion/rationale if it did not</td>
</tr>
<tr>
<td></td>
<td>• Evidence that deviant data was sought, or discussion/rationale if it was not</td>
</tr>
</tbody>
</table>
| Interpretation | Context described and taken account of in interpretation | • Description of social/physical and interpersonal contexts of data collection  
• Evidence that researcher spent time “dwelling with the data”, interrogating it for competing/alternative explanations of phenomena  
• Sufficient discussion of research processes such that others can follow “decision trail”.  
• Extensive use of field notes entries/verbatim interview quotes in discussion of findings  
• Clear exposition of how interpretation led to conclusions |
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<tr>
<td></td>
<td>Clear audit trail given</td>
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<td></td>
<td>Data used to support interpretation</td>
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</table>
| Reflexivity | Researcher reflexivity demonstrated | • Discussion of relationship between researcher and participants during fieldwork  
• Demonstration of researchers influence on stages of research process  
• Evidence of self-awareness/insight  
• Documentation of effects of the research on researcher  
• Evidence of how problems/complications met were dealt with |
| Ethical dimensions | Demonstration of sensitivity to ethical concerns | • Ethical committee approval granted  
• Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants  
• Evidence of fair dealing with all research participants  
• Recording of dilemmas met and how resolved in relation to ethical issues  
• Documentation of how autonomy, consent, confidentiality, anonymity were managed |
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<tr>
<th>Relevance and transferability</th>
<th>Relevance and transferability evident</th>
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<tr>
<td></td>
<td>• Sufficient evidence for typicality specificity to be assessed</td>
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<tr>
<td></td>
<td>• Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</td>
</tr>
<tr>
<td></td>
<td>• Discussion of how explanatory propositions/emergent theory may fit other contexts</td>
</tr>
<tr>
<td></td>
<td>• Limitations/weaknesses of study clearly outlined</td>
</tr>
<tr>
<td></td>
<td>• Clearly resonates with other knowledge and experience</td>
</tr>
<tr>
<td></td>
<td>• Results/conclusions obviously supported by evidence</td>
</tr>
<tr>
<td></td>
<td>• Interpretation plausible and „makes sense“</td>
</tr>
<tr>
<td></td>
<td>• Provides new insights and increases understanding</td>
</tr>
<tr>
<td></td>
<td>• Significance for current policy and practice outlined</td>
</tr>
<tr>
<td></td>
<td>• Assessment of value/empowerment for participants</td>
</tr>
<tr>
<td></td>
<td>• Outlines further directions for investigation</td>
</tr>
<tr>
<td></td>
<td>• Comment on whether aims/purposes of research were achieved.</td>
</tr>
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</table>
Appendix 5: Quality Rating Scoring of Included Studies
### Quality Rating of Included Studies

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<tr>
<td>1. The study includes family members of individuals with a TBI as the primary respondents.</td>
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<tr>
<td>2. There is a clear statement of the aims and objectives of the research, and a rationale for this.</td>
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<tr>
<td>3. An appropriate research design and methodology is used to address the aims and purpose of the project.</td>
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<td>4. A clear description of, and justification for, the sampling strategy used, including explanation for any disparity between the planned and actual sample.</td>
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<tr>
<td>5. Method of data collection explicitly stated, including form (e.g. tape/video recording), and details of topic guides or semi structured interviews if used.</td>
<td>0.5</td>
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<tr>
<td>6. Method of data analysis explicitly stated, including information on evolution of coding systems, use of software packages, &amp; discussion regarding data saturation.</td>
<td>0.5</td>
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<td>7. Reference to reflexivity, including acknowledgement of the relationship between researcher and participants, &amp; potential sources of bias and influence during the study.</td>
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<td></td>
<td>Consideration of ethical issues, including approval from an ethics committee, &amp; how consent was sought, &amp; confidentiality &amp; anonymity maintained.</td>
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<td>9</td>
<td>A clear statement of the findings, including reference to the initial research question. There should be sufficient detail in description of the analysis process such that it is clear how conclusions were reached, &amp; sufficient data presented to support findings so it is evident that the results and conclusions are clearly grounded in the data.</td>
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<td>A discussion of the relevancy and transferability of the research. The findings should be discussed with regard to how they add to existing knowledge or understanding and should outline future directions for investigation. Limitations and weaknesses of the study should be clearly outlined</td>
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</table>
Appendix 6: Guidance for Metasynthesis (Noblit & Hare, 1988)
Guidance for Metasynthesis (Noblit & Hare, 1988)

This approach consists of a process of seven stages that overlap and repeat as the metasynthesis progresses:

(a) Getting started and deciding on a phenomenon of study.

(b) Deciding what qualitative studies are relevant to the initial interest.

(c) Reading the qualitative studies.

(d) Determining how the studies are related to each other. In this phase, the synthesizer makes a list of the key metaphors in each study and their relations to each other. The term metaphor refers to themes, concepts, or phrases. Three different assumptions can be made about the relationships between the studies to be synthesized. These key assumptions are: “(1) the accounts are directly comparable as "reciprocal" translations; (2) the accounts stand in relative opposition to each other and are essentially refutational; or (3) the studies taken together present a „line of argument” rather than a reciprocal or refutational translation” (Noblit & Hare, 1988, p. 36).

(e) Translating the studies into one another.

(f) Synthesizing translations. This involves creating a whole as something more than the individual parts imply. The translations as a group are one level of a metasynthesis. Next, the translations can be compared to decide if the same metaphors/themes or concepts can be encompassed into those of others. This is a second level of synthesis.

(g) Expressing the synthesis through the written word, plays, art, videos, or music.
Appendix 7: Guidance for Metasynthesis (Walsh & Downe, 2005)
Guidance for Metasynthesis (Walsh & Downe, 2005)

Practically, this process begins with the first reading of the studies and is completed with the creation of a grid of key concepts. These findings are then juxtaposed to both identify homogeneity of categories/codes/themes and, crucially, to note discordance and dissonance. Jensen and Allen (1996) identify two processes here. The first, or hermeneutic, aspect consists of accurately capturing individual or cultural constructions. This is the art of respecting and representing context as intended through the original research. Second is the dialectic aspect, which relates the studies to each other. This can be achieved through juxtaposition of the parameters identified by the compare and contrast exercise.

Reciprocal translation

The next phase begins the translation of one study’s findings into another, using metaphors and concepts that could be applied to both. Sometimes commonalities will be only too apparent and reciprocal translations are relatively straightforward. At other times they will stand in opposition as a “refutational translation” (Noblit & Hare 1988), or they may overlap without being substitutional. Refutation and overlap may contribute to another, emergent, category or understanding which has not been identified in the original accounts. It is crucial to the method that differences are not glossed over or subsumed. Deviant data may be the raw material of another perspective, making a new space for understanding. In fact the absence of divergent or deviant data may arouse suspicion as to the rigour of the reciprocal translation, as qualitative inquiry rarely results in complete congruence of meaning.

Synthesis of translation

The final phase is synthesizing the translations to elucidate more refined meanings, exploratory theories and new concepts. Clusters of metaphors become progressively more refined and a consensus emerges as to core themes or explanatory, mid-level, or substantive theory (Sherwood 1997b, Strauss & Corbin 1998, Campbell et al. 2003). The synthesis needs to reflect the tension between contradictory or alternative explanations if reciprocal translations suggest a lack of congruence. Ultimately, the final synthesis will be the grounds on which the value of meta-synthesis is judged and it therefore needs to convey explicitly how the whole is greater than the sum of the constituent parts.
15 August 2012

Ms Melissa Robertshaw, Trainee Clinical Psychologist
University of Manchester
Second Floor, Zochonis Building
Brunswick Street
Manchester
M13 3PL

Dear Ms Robertshaw

REC reference: 12/NW/0458
IRAS ref no: 98708

Thank you for your e-mail of 10 August 2012, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence of insurance or indemnity</td>
<td></td>
<td>25 May 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>21 May 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>CI</td>
<td>21 May 2012</td>
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<tr>
<td>Investigator CV</td>
<td>Student</td>
<td>25 April 2012</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
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<td>25 May 2012</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>1</td>
<td>05 July 2012</td>
</tr>
<tr>
<td>Other: Academic Supervisor CV</td>
<td></td>
<td></td>
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<tr>
<td>Other: Field Supervisor CV</td>
<td></td>
<td></td>
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<tr>
<td>Other: Internal Research Ethics Subcommittee Approval Letter</td>
<td></td>
<td>19 December 2011</td>
</tr>
<tr>
<td>Other: Signature of Dr John Fox</td>
<td></td>
<td>29 June 2012</td>
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<td>Participant Consent Form: Consent to Contact Form</td>
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<td>Participant Consent Form</td>
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<td>05 July 2012</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>2</td>
<td>05 July 2012</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>21 May 2012</td>
</tr>
<tr>
<td>Questionnaire: Brief Cognitive Status Exam Record Form (from WMS-IV)</td>
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<td></td>
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<tr>
<td>Questionnaire: Demographic/Injury Questions</td>
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<tr>
<td>REC application</td>
<td></td>
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<tr>
<td>Response to Request for Further Information</td>
<td>1</td>
<td>10 August 2012</td>
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</tbody>
</table>

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0458  Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

Mr Francis Chan
Chair

Email: elaine.hutchings@northwest.nhs.uk

Enclosure: “After ethical review – guidance for researchers”

Copy to: Ms Lynne MacRae, R&D, University of Manchester
02 January 2013

Ms Melissa Robertshaw, Trainee Clinical Psychologist
University of Manchester
Second Floor Zochonis Building
Brunswick Street
Manchester
M13 3PL

Dear Ms Robertshaw

REC reference: 12/NW/0458
Amendment number: Substantial amendment 1
Amendment date: 19 December 2012
IRAS project ID: 98708
Summary: To amend the inclusion/exclusion criteria to aid recruitment.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

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<thead>
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<th>Document</th>
<th>Version</th>
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<tbody>
<tr>
<td>Protocol</td>
<td>2</td>
<td>19 November 2012</td>
</tr>
<tr>
<td>Notice of Substantial Amendment (non-CTIMPs)</td>
<td>Substantial amendment 1</td>
<td>19 December 2012</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>1</td>
<td>19 November 2012</td>
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</table>
Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

12/NW/0458: Please quote this number on all correspondence

Yours sincerely

[Signature]

Mr Francis Chan
Chair

E-mail: nrescommittee.northwest-gmsouth@nhs.net

Enclosure: List of names and professions of members who took part in the review
Appendix 10: Research and Development Approval Letter 1
Dear Ms Robertshaw

Study Title: Exploring Acceptance Post Traumatic Brain Injury: A Grounded Theory Approach

REC Reference: 12/NW/0458
EuDraCT Reference: N/A
R&D Reference: 2012/118neuro

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS SalfoR+D and has gained NHS R&D approval from the following NHS Trust:

- Salford Royal NHS Foundation Trust

All clinical research must comply with the Health and Safety at Work Act, [www.hse.gov.uk](http://www.hse.gov.uk) and the Data Protection Act. [http://www.hmso.gov.uk/acts](http://www.hmso.gov.uk/acts)

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The ‘Research Passport Application Form’. This can be obtained from web addresses: [http://www.gmregroup.nhs.uk/researchers/passports.html](http://www.gmregroup.nhs.uk/researchers/passports.html) and [http://www.hope-academic.org.uk/academic/salfordrd/Research%20Passports.html](http://www.hope-academic.org.uk/academic/salfordrd/Research%20Passports.html) This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.

It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study. [http://www.nres.npsa.nhs.uk/applications/after-ethical-review/annual-progress-reports/]
Where clinical trials of investigational medicinal products are sponsored by Salford Royal NHS Foundation Trust or Salford Primary Care Trust, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within Salford Royal NHS Foundation Trust and Salford Primary Care Trust, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor's Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. Where Salford Royal NHS Foundation Trust or Salford Primary Care Trust is acting as Sponsor then amendments or changes MUST be discussed with the Sponsor prior to REC submission. On completion of the study you are required to submit a 'Declaration of End of Study' form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

[Signature]

Rachel Georgiou
NHS SalfoR+D Associate Director
Dear Melissa,

Re: Research Governance Decision Letter

SPEAR/Trust Project Reference: 1148
Project Title: Exploring Acceptance Post Traumatic Brain Injury: A Grounded Theory Approach
REC No.: 12/NW/0458

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study on condition you comply with the Trust’s Argyll (Lone Working Policy) System (details of this will be emailed to you). Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

Trust R&D approval covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached ‘Information for Researchers – Conditions of Research Governance Approval’ leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research.
We can confirm that in this instance we will not charge for these. However we would like to remind you that Trust costs should be considered and costed at the earliest stage in the development of any future proposals. Please find enclosed an example invoice of study costs incurred with research for your information.

You will need to contact us before any new researchers join your team as they will need Trust permission before they start work on the project.

It is your responsibility to contact us a week prior to the expiry date we have recorded for this project to let us know if you wish to extend it, as we will need to send a new approval letter. You will also need to let us know immediately if for any reason the project finishes earlier.

It is a condition of our Trust approval that on completion of this study we are in receipt of an end of study report summary and a copy of the Ethics letter confirming that they have closed the study, we will remind you of this nearer the time. You will also be asked to complete an audit form for each year your study is supported by this Trust (including the year of its completion) this approval requirement and failure or refusal to complete it may result in Trust approval being withdrawn.

By beginning your research you are agreeing to all the terms and conditions as stated within this letter.

May I wish you every success with your research and if you have any queries do not hesitate to contact the R&D Team.

Yours sincerely,

[Signature]

Dr. Andy Mee
Research & Development Manager
Dear Melissa

Re: Research Governance Decision Letter

Project Reference: Trust ID 266
Project Title: Acceptance in Traumatic Brain Injury

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study. With regard to your study, we would like you to note that it is required to acknowledge the Trust when publishing your work and this also applies to any posters that maybe produced. The form of acknowledgement should be as described on the 5 Boroughs website. Please note when contacting the Research Office about your study you must always provide the project reference numbers provided above.

Trust research approval covers all locations within the Trust; however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached ‘Information for Researchers – Conditions of Research Governance Approval’ leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the Research Office should you require any further information. You may need this letter as proof of your approval.

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research. We can confirm that in this instance we will not charge for these. However we would like to remind you that Trust costs should be considered and costed at the earliest stage in the development of any future proposals.
May I wish you every success with your research.

Yours sincerely

Anthony Hodgson
Head of Research
**Acceptance in Traumatic Brain Injury – Participant Information Sheet**

**Please read this sheet carefully**

You are invited to take part in a research study. The research study is looking at acceptance in traumatic brain injury. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. This leaflet has been designed to provide you with information about the study so that you can make an informed decision about whether you would like to take part. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that you do not understand or if you would like more information.

**What is the study about?**

The study aims to investigate how individuals who have experienced a traumatic brain injury make sense of, and accept what has happened to them. It aims to find out if there are things that make it easier for people to accept what has happened to them, and if there are things that make it more difficult.

**Do I have to take part?**

It is up to you to decide whether or not to take part. You do not have to take part in the project if you do not want to. If you do not want to take part you do not have to give a reason for this. If you do decide to take part you will be asked to sign a consent form. However, you can still change your mind and withdraw from the study at any time without giving a reason. Whether you decide to take part in the study or not, it will not affect the care that you receive.

**What will I have to do if I agree to take part?**

The study involves completing some short tasks (e.g. answering questions involving memory, drawing or general knowledge), and answering some short questions about the injury that will last for approximately 15 minutes. This will be followed by being interviewed about your experiences after the traumatic brain injury for approximately 45 minutes. With your agreement, this interview will be recorded, and your words transcribed. Everyone taking part will only be interviewed once.

If you fill in the attached “Consent to Contact” form and return it in the envelope provided, you will be contacted via telephone to answer any questions that you may have about the study and discuss whether you would like to take part. If you
decide that you would like to take part a time during the day for the interview to take place will be arranged. This will be at a location convenient for you.

You will be reimbursed for your travel expenses on provision of the appropriate receipts.

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

The study will add to our understanding of traumatic brain injury. It will help to indicate more clearly the difficulties that people who have experienced traumatic brain injuries encounter, and what kinds of help are likely to be most useful to them.

**Are there any risks to taking part?**

The study will involve being interviewed about your experiences after the traumatic brain injury, which some participants could potentially find upsetting. Should this occur, you will be asked if you wish to take a break or end the interview. Your decision will be respected and you will be encouraged to contact an appropriate source of support. This would include:

1. Informing your GP, who will be able to speak to you about your options for further help.
2. If you are currently a patient of a Clinical Psychology or Clinical Neuropsychology department you can contact them to arrange an appointment to talk about any difficult emotions you are experiencing.
3. You can also call The Samaritans on 0161 236 8000. They will be able to speak to you and are available 24 hours a day, every day.

**Confidentiality**

All of the information collected from you during the study will be kept strictly confidential and will only be used for the purposes of this research. The results from the study will be kept strictly anonymous and although quotations from the interviews may be used, they will not contain personally identifiable information. If the results of the project are published in scientific journals, this information will be kept anonymous – this means that your results will not be linked to your name.

As stated, the interview will be confidential; however, if you say anything about harm to yourself or harm to others during the interview, your GP may have to be informed. If you reveal information during the interview to indicate that you or others may be at risk, the researcher has a duty of care to inform an appropriate person. The researcher will endeavour to keep you informed if this is going to happen.
What if I change my mind?

Participation in the study is completely voluntary; you do not have to take part. If you do decide to take part you are able to withdraw at any time without providing a reason.

Who has reviewed the study?

Research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by NRES Committee North West - Greater Manchester East Research Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to researchers who will do their best to answer your questions. If they are unable to resolve your concern or wish to make a complaint regarding the study, please contact the University of Manchester Research Practice and Governance Coordinator on 0161 275 8093 or by email to research-governance@manchester.ac.uk.

What happens once the study is over?

If you would like to be posted an information sheet on the results of the study once the study has finished, please initial the relevant box on the consent form.

Who can I talk to for further information?

If you would like further information regarding the study please complete the attached “Consent to Contact” form and return it in the envelope provided. Once this is received the researcher will contact you via telephone to discuss any questions you may have and whether you would like to take part. Completing this form does not mean that you have to take part in the study.

Thank you for your interest. Please do not hesitate to contact us via the details provided below if you have any questions.

Melissa Robertshaw - Trainee Clinical Psychologist
Melissa.robertshaw@postgrad.manchester.ac.uk
Dr Penny Bunton – Clinical Lecturer
Penny.bunton@manchester.ac.uk
Dr John Fox – Clinical Lecturer
John.fox@manchester.ac.uk
Division of Clinical Psychology
Tel: 0161 306 0400
Second Floor, Zochonis Building, Brunswick Street, Manchester, M13 9PL
Appendix 14: Cover Letter to Participants
Dear Sir/Madam,

We are contacting you as you are currently, or have previously attended (recruitment site). We are writing to see whether you would be interested in contributing to a research study that is being carried out by researchers in the Department of Clinical Psychology at the University of Manchester.

The research study looks at acceptance in traumatic brain injury. In particular we are interested in finding out about people’s experiences after the injury and how they make sense of, and understand what has happened to them. It aims to find out if there are things that make it easier for people to accept what has happened to them, and if there are things that make it more difficult.

The study would involve meeting with the researcher on one occasion. First, you would complete some short tasks (e.g. answering questions involving memory, drawing or general knowledge), and answer some short questions about your injury. Then you would be interviewed by the researcher about your experiences after the traumatic brain injury. A participant information sheet about the study is enclosed with this letter.

We would very much appreciate your involvement in this research but understand that you may not wish to be involved or may have other commitments at this time. Participating in the study will not have any bearing on any current or future treatment you may receive.

If you would like to find out more information about the study you can complete the “Consent to Contact” form enclosed with this letter and return it in the envelope provided.

You do not have to take part in the study and you do not have to complete the enclosed “Consent to Contact” form. You also do not have to take part in the study if you complete the “Consent to Contact” form. Even if you agree to take part you are completely free to withdraw from the project at any time without needing to give us a reason.

Yours faithfully,

Melissa Robertshaw  Dr Penny Bunton  Dr John Fox
Trainee Clinical Psychologist  Clinical Lecturer  Clinical Lecturer
Appendix 15: Consent to Contact Form
Study Consent to Contact Form

Study: Acceptance in Traumatic Brain Injury

Researchers:
Melissa Robertshaw
Dr Penny Bunton
Dr John Fox
Dr Stephen Mullin

Thank you for your interest in this study. If you would like further information regarding the study please complete the form below and return it in the prepaid envelope provided. The researcher will not contact you unless this form is completed and returned to them. If you complete and return the form you do not have to take part in the study.

Please read each point and put your initials in the box provided if you agree:

1. I understand that this study is looking at acceptance in people who have experienced a traumatic brain injury.

2. I would like further information regarding this study and agree that a researcher can contact me via the details I have provided below.

3. I understand that in agreeing that a researcher can contact me about the study I do not have to take part.

Name:________________________________________
Telephone Number:______________________________

I confirm that I consent for a researcher from the above named study to contact me to discuss the study and answer any questions that I may have.

Signed:_______________________________________

Print Name:_____________________________________
Date:___________________________________________

Thank you for your interest in the study. You will be contacted by a study researcher via telephone as soon as possible upon receipt of this form.
Thank you for your interest in this study. If you have any further questions about the study, please ask the researcher.

Please read each point and put your initials in the box provided if you agree:

Please Initial Box

1. I understand that this study is looking at acceptance in people who have experienced a traumatic brain injury by interviewing participants about their experiences.

2. I have been given a copy of the participant information sheet which I have read and understood. In addition, I have been given the opportunity to ask questions about the study.

3. I understand that my participation in the study is voluntary and that I do not have to take part. I also understand that I can withdraw from the study at any time without giving a reason, and this will not affect any care that I receive.

4. I understand that although a record will be kept of my participation in the study, all of the data collected from my participation will be treated confidentially.

5. I understand that data collected during the study will be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.

6. I give permission for the study results to be published as long as my results are not linked to me personally and no one can tell that they are mine.

7. I agree to take part in the study.

8. I would like to be posted an information sheet on the results of the study once the study has finished.

Participant:
Name: ___________________ Signed: _______________ Date: ___________

Researcher:
Name: ___________________ Signed: _______________ Date: ___________
Appendix 17: Demographic/Injury Questionnaire
Demographic/Injury Questions

Age: ........................................................................

Gender: Male ☐ Female ☐

Ethnicity: .................................................................

Lead Clinician:
GP ☐
Clinical Psychologist ☐
Neurosurgeon ☐
Neurologist ☐
Occupational Therapist ☐
Physiotherapist ☐
Other (please state) ☐

Lead Clinician Name:
........................................................................

Lead Clinician Address
........................................................................

Other services accessed:
GP ☐
Inpatient Rehab ☐
Community Rehab Team ☐
Physiotherapy ☐
Occupational Therapy ☐
Speech and Language ☐
Clinical Psychology ☐
Other (please state) ☐

Date of Injury:
........................................................................
Date of last memory before injury?

- Same day ☐
- One day before ☐
- 2 days before ☐
- 3 days before ☐
- 4 days before ☐
- 5 days before ☐
- 6 days before ☐
- 7 days plus ☐

Date of first memory after the injury?

- Same day ☐
- 1-3 days ☐
- 3-6 days ☐
- 7-10 days ☐
- 11-14 days ☐
- 15 days plus ☐

Nature of Injury

- Skull fracture ☐
- Bleeding ☐

Cause of Injury

- Assault ☐
- Fall ☐
- Road traffic accident ☐
- Other (please state) ☐

Did you receive surgery on your head due to the injury?

- Yes ☐
- No ☐

Any other comments:

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
Appendix 18: Interview Schedule
**Interview Schedule:**

**Aim:** To develop an understanding of acceptance after a traumatic brain injury, and factors that hinder or facilitate this process.

In this interview I would like to gain an understanding of your experiences after you sustained the traumatic brain injury. I am interested about hearing all of your feelings and views, both positive and negative, so that I can get an understanding of how it’s been for you. I will be recording the interview to make sure I capture everything that you say, but I might also take a few notes. If you want to stop for a break at any point that is fine.

**Can you tell me about how you came to have the injury?**
- When did it happen?
- Where did it happen?
- Were other people involved?

**How would you describe the person you were before the injury?**
- What was going on in your life at that time?
- How did you spend your time – e.g. did you work, family/friend relationships, living arrangements?
- Did you have any hobbies or interests?
- How did you feel?

**How would you describe the person you are now?**
- Do you think you have changed at all since the injury – how/why did it affect you, how did you notice?
- What has been the impact of the injury on your life?
- Any different roles e.g. work, family?
- Do you enjoy the same things that you used to?
- How do you feel (about that/about what you described)? How do you view this?

**Do you think that you have been able to understand, or make sense of what happened to you?**
- What is your understanding of what has happened to you?
- How have you coped?
- What did it mean to you to have had the injury?
- Any particular examples or experiences?
- What was helpful/unhelpful in understanding what had happened to you? Tell me what would have helped/What was it you felt you needed then?

**You might have heard people talk about accepting the injury. I would be really interested to hear what you think it means to accept the injury?**
- How would a person know when they had accepted the injury?
- How would a person who has accepted the injury feel?
- What would a person who has accepted the injury do (would they work? pursue particular interests?)
What do you think about your own acceptance of the injury?
- Why/how they think they have/have not accepted?
- Can you think of any examples?
- How have feelings changed over time?
- What makes it easier or more difficult?
- Do they do things differently/see things in a different way?
- Do they think things might change in the future?

Have there been/are there times when you feel you have not accepted that you have had the injury?
- How do you know this?
- What does it mean to you?
- How has it affected you?
- Can you tell me more about x experience?
- Can you think of any examples?

What do you think other people (e.g. family, friends) would say about your acceptance of the injury?
- Why/how they think they have/have not accepted?
- What experiences relate to this.
- How have feelings changed over time?

Ending Questions:

Is there anything else that you would like to add about your acceptance of the TBI?

Or anything that we have not discussed today about your experience of having a TBI that you think is important to mention?

Do you have any questions?

General Prompts:
- Can you say more about that?
- Can you tell me about that in more detail?
- Can you describe what that was like for you/family etc
- I would be interested to hear more about..
- What did you mean by?
Appendix 19: Extract from Anonymised Coded Transcript
<table>
<thead>
<tr>
<th>Transcript</th>
<th>code</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. I wonder how you feel you have accepted</strong></td>
<td>Reliant on wife</td>
</tr>
<tr>
<td><strong>2. some of these changes?</strong></td>
<td>Friends visited</td>
</tr>
<tr>
<td>3. When I erm, when I first had my</td>
<td></td>
</tr>
<tr>
<td>4. accident, within erm the first few weeks</td>
<td>Friends focused on former abilities</td>
</tr>
<tr>
<td>5. my wife took my phone off me which</td>
<td></td>
</tr>
<tr>
<td>6. was probably a smart move. Erm, but</td>
<td></td>
</tr>
<tr>
<td>7. when my friends used to come in to see</td>
<td></td>
</tr>
<tr>
<td>8. me we only ever talked about going on</td>
<td></td>
</tr>
<tr>
<td>9. another bike ride to another mad</td>
<td></td>
</tr>
<tr>
<td>10. destination. In fact we’ve organised</td>
<td></td>
</tr>
<tr>
<td>11. one. But I’ve finally worked out that I’m</td>
<td></td>
</tr>
<tr>
<td>12. not actually going to ride that because I</td>
<td></td>
</tr>
<tr>
<td>13. have no control over my body properly.</td>
<td></td>
</tr>
<tr>
<td>14. So physically I kind of know that I’m not</td>
<td></td>
</tr>
<tr>
<td>15. going to go, well I might one day be able</td>
<td></td>
</tr>
<tr>
<td>16. to do something, but not like I used to.</td>
<td></td>
</tr>
<tr>
<td>17. Erm, and I don’t have any concentration</td>
<td></td>
</tr>
<tr>
<td>18. either. Like reading is terrible. I bought</td>
<td></td>
</tr>
<tr>
<td>19. loads of books and I’ve opened one.</td>
<td></td>
</tr>
<tr>
<td>20. And I got to the first page, I went ‘sigh’.</td>
<td></td>
</tr>
<tr>
<td>21. And when I do some stuff; I sometimes</td>
<td></td>
</tr>
<tr>
<td>22. help them in our office by just trying to</td>
<td></td>
</tr>
<tr>
<td>23. point them in the right direction, stuff</td>
<td></td>
</tr>
<tr>
<td>24. that I, just, you know, they ask me</td>
<td></td>
</tr>
<tr>
<td>25. questions. And I can do that for like</td>
<td></td>
</tr>
<tr>
<td>26. about, most of about an hour, then I get</td>
<td></td>
</tr>
<tr>
<td>27. really, really tired. Erm, and it takes me</td>
<td></td>
</tr>
<tr>
<td>28. a long time to warm up, so I’m kind of</td>
<td></td>
</tr>
<tr>
<td>29. warming up now to sort of, you know,</td>
<td></td>
</tr>
<tr>
<td>30. our conversation. You know, I feel a</td>
<td></td>
</tr>
<tr>
<td>31. little bit more in control. Not in control;</td>
<td></td>
</tr>
<tr>
<td>32. that’s the word I keep saying, don’t I? I</td>
<td></td>
</tr>
<tr>
<td>33. mean just a bit more comfortable. Erm.</td>
<td></td>
</tr>
</tbody>
</table>
| Comparison to self just after injury | 34. I don’t burst out into tears as much as I used to. But that was really weird. I just, in the middle of a, just a conversation with someone the other day, I was just pah. It was just kind of weird.  
35. Yes.  
36. I mean, even our conversation just then, when we first started I was really, probably about 30 seconds away from just ... but I’ve finally accepted that. I don’t feel as embarrassed as I used to.  
37. Is that you think just the passage of time that that’s got easier, or...?  
38. I think whenever I get into anything that’s slightly stressful, just slightly stressful, I can’t make phone calls anymore as well. I used to make phone, you know I used to phone people up all the time. People I didn’t even know. Because for my job, it’s sort of finding new clients and stuff and I, you know, and one of my key strengths was just to pick the phone up and talk to people and, you know, if a bill comes in the house and it needs someone to ring up, I don’t do that at all. I have to get my wife to do that. I just don’t, you know; I wanted to change our television subscription and it took me 5 weeks to pick up the nerve to pick the phone up.  
39. Kind of weird that. |
<p>| Emotions uncontrollable |
| Accepted crying as not embarrassed? |
| Concern regarding others opinion? |
| Critical of self |
| Contrast to before |
| Change in roles |</p>
<table>
<thead>
<tr>
<th>Changed to things can do?</th>
<th>Changed to things can do?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>68. Do you find yourself comparing yourself to how you use to be?</strong></td>
<td><strong>68. Do you find yourself comparing yourself to how you use to be?</strong></td>
</tr>
<tr>
<td>70. Yeah. I can’t. I’ve moved into different,</td>
<td>70. Yeah. I can’t. I’ve moved into different,</td>
</tr>
<tr>
<td>71. what I’ve done is I’ve like, the garden</td>
<td>71. what I’ve done is I’ve like, the garden</td>
</tr>
<tr>
<td>72. has never been nicer. So my number 1</td>
<td>72. has never been nicer. So my number 1</td>
</tr>
<tr>
<td>73. task, you know my gardener loves me</td>
<td>73. task, you know my gardener loves me</td>
</tr>
<tr>
<td>74. cos he, and, you know, I’ve always got a</td>
<td>74. cos he, and, you know, I’ve always got a</td>
</tr>
<tr>
<td>75. job to do and a task that he has to do.</td>
<td>75. job to do and a task that he has to do.</td>
</tr>
<tr>
<td>76. Well, I don’t do any of the tasks, but,</td>
<td>76. Well, I don’t do any of the tasks, but,</td>
</tr>
<tr>
<td>77. you know, erm. So I’ve kind of, I</td>
<td>77. you know, erm. So I’ve kind of, I</td>
</tr>
<tr>
<td>78. suppose, changed what I did before and</td>
<td>78. suppose, changed what I did before and</td>
</tr>
<tr>
<td>79. pushing it into something else.</td>
<td>79. pushing it into something else.</td>
</tr>
<tr>
<td>80. Right, I see.</td>
<td>80. Right, I see.</td>
</tr>
<tr>
<td>81. Yeah.</td>
<td>81. Yeah.</td>
</tr>
<tr>
<td><strong>82. Is it important for you to still kind of have a hand in the business?</strong></td>
<td><strong>82. Is it important for you to still kind of have a hand in the business?</strong></td>
</tr>
<tr>
<td>84. Erm, (sigh), yeah, but I meddle and I get</td>
<td>84. Erm, (sigh), yeah, but I meddle and I get</td>
</tr>
<tr>
<td>85. in everyone’s way and I can tell that</td>
<td>85. in everyone’s way and I can tell that</td>
</tr>
<tr>
<td>86. they don’t really want me to be saying</td>
<td>86. they don’t really want me to be saying</td>
</tr>
<tr>
<td>87. things that I say, or, you know, my</td>
<td>87. things that I say, or, you know, my</td>
</tr>
<tr>
<td>88. opinion, which then, you know, you</td>
<td>88. opinion, which then, you know, you</td>
</tr>
<tr>
<td>89. kind of feel as if you, you know. An</td>
<td>89. kind of feel as if you, you know. An</td>
</tr>
<tr>
<td>90. example of that was my PA, who had</td>
<td>90. example of that was my PA, who had</td>
</tr>
<tr>
<td>91. been my PA for many years nearly, she,</td>
<td>91. been my PA for many years nearly, she,</td>
</tr>
<tr>
<td>92. I sent her an email to do something, cos</td>
<td>92. I sent her an email to do something, cos</td>
</tr>
<tr>
<td>93. I thought, “oh, why don’t we do this”,</td>
<td>93. I thought, “oh, why don’t we do this”,</td>
</tr>
<tr>
<td>94. and then she referred it to one of my</td>
<td>94. and then she referred it to one of my</td>
</tr>
<tr>
<td>95. colleagues. It was like, you know,</td>
<td>95. colleagues. It was like, you know,</td>
</tr>
<tr>
<td>96. ‘turncoat’.</td>
<td>96. ‘turncoat’.</td>
</tr>
<tr>
<td>97. Oh, I see.</td>
<td>97. Oh, I see.</td>
</tr>
<tr>
<td>98. It was kind of weird really. But I know</td>
<td>98. It was kind of weird really. But I know</td>
</tr>
<tr>
<td>99. that that’s really probably the best, it’s</td>
<td>99. that that’s really probably the best, it’s</td>
</tr>
<tr>
<td>100. not my, you know, kind of decision</td>
<td>100. not my, you know, kind of decision</td>
</tr>
<tr>
<td>101. really. So, I suppose also now, I don’t</td>
<td>101. really. So, I suppose also now, I don’t</td>
</tr>
<tr>
<td>Huge contrast – but acknowledging deficits and trying to put energies into something else (adapt and overcome)</td>
<td>102. know what to do, you know. Can’t 103. really do the gardening all the time 104. and, you know. Bought myself a pair 105. of walking boots. That’s about it 106. really.</td>
</tr>
</tbody>
</table>