VOLUME I

RESEARCH COMPONENT

SPOUSAL RELATIONSHIPS AND IDENTITY FOLLOWING BRAIN INJURY

BY

DARRELLE VILLA

A thesis submitted to

The University of Birmingham

for the degree of

DOCTORATE IN CLINICAL PSYCHOLOGY

Department of Clinical Psychology
School of Psychology
The University of Birmingham
Sept 2013

Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes.

Volume 1

This volume comprises three chapters. The first chapter is a metasynthesis of qualitative research on the psychological and social processes contributing to experiences of identity change and reconstruction following traumatic brain injury. The second chapter is a qualitative study that investigates how spouses of people with acquired brain injury experience and make sense of their post-injury relationship, drawing on the concept of relationship continuity. It is intended that the literature review will be submitted to *Disability and Rehabilitation* and the empirical paper to *Neuropsychological Rehabilitation* for publication (See Appendices A and B for instructions for authors). The third chapter is a public domain briefing document, providing an accessible summary of the literature review and empirical paper.

Volume 2

Five Clinical Practice Reports (CPRs) are presented in this volume. The first report details the case of a 33-year old woman with depression, formulated from cognitive-behavioural and psychodynamic perspectives. The second report presents an evaluation of compliance with National Institute for Health and Clinical Excellence guidelines for borderline personality disorder in an adult community mental health team. The third report is a single-case experimental design evaluating the effectiveness of combined scanning training and functional electrical stimulation for unilateral spatial neglect in a 73-year old woman with a stroke. The fourth report presents a case study of a 15-year old girl with depression, formulated using an integrative model drawing on cognitive-behavioural and attachment perspectives. The fifth report is the abstract of an oral presentation of a case study of a 51-year old woman with learning disabilities showing challenging behaviour, comprising indirect work with the staff team using a cognitive-analytic approach.

All names and identifying features have been changed to ensure confidentiality.

Acknowledgements

I would like to thank my research supervisor, Gerry Riley, for his wisdom, rigorous eye, and sense of humour. I always left our meetings feeling better than when I went in. His ability to keep the person at the centre of his work is a real gift, and something I have learnt a great deal from. I would also like to thank Andrew Brennan, Louise Lorenc, and the staff at Headway Birmingham and Stoke for supporting this research and putting up with my pestering. Without the participants who shared their experiences, this project would not have been possible and so I give a heartfelt thanks to them.

Thank you also to my course saviours Ruchi, Becky, Zuhura, Jenny, Caroline and James for sharing in the moaning, panic, confusion and most of all the fun. I see many years of friendship ahead.

To all my other dearest friends, Emma, Michelle, Catherine, Gillian and Lucy for always being there and helping me remember what is important. To Emma, an especially big thank you for being my loyal proof-reader – could this be the last time? To Louise, Kate and Ruchi (once more with feeling) for the lifts, dinners, hours of chats, and for making Birmingham feel like home.

To mum, dad, Nerina, Sasha and Greener, for helping me keep my feet on the ground and for always being around.

Contents of Volume 1

Chapter One: Experiences of Identity Change and Reconstruction after Traumatic Brain Injury: A Metasynthesis of Qualitative Research

Chapter Two: Experiences of Couplehood and Continuity after Acquired Brain Injury: An Interpretative Phenomenological Analysis

List of Tables for Volume 1

Chapter One

Chapter Two

Chapter Three

List of Figures for Volume 1

Chapter One

Contents of Volume 2

Appendices Volume 2

Chapter One

Experiences of Identity Change and Reconstruction after Traumatic Brain Injury: A Metasynthesis of Qualitative Research

Background. A growing body of quantitative and qualitative research highlights the importance for well-being of sense of self and identity following traumatic brain injury (TBI). The current paper aims to integrate findings dispersed across the qualitative literature which shed light on the psychological and social processes that contribute to subjective experiences of identity change and reconstruction following TBI.

Method. Four databases were searched for qualitative research published between 1965 and 2013, investigating identity experiences following TBI. In total 1451 papers were screened. Included studies were evaluated using a qualitative quality framework to provide a context for interpretation of substantive findings. Data were extracted and synthesised using guidelines for metasynthesis outlined by Thomas and Harden (2008).

Results. From 33 papers, nine inter-related themes emerged which comprised processes contributing to appraisals of identity change and reconstruction following TBI: 1) loss of self-knowledge; 2) experiences of personal and social discrepancy; 3) discrepancies between self-experiences and the discourses and practices of others; 4) lack of legitimate social roles; 5) discourses and practices that deny personhood; 6) recovering self; 7) continuity amid change; 8) acceptance; 9) personal growth and meaning-making.

Conclusions. An in-depth understanding of the processes contributing to post-injury identity experiences can inform rehabilitation and intervention post-TBI to support individuals to negotiate these processes with less distress and reconstruct their identity in a positive way.

Keywords: *Traumatic brain injury, identity, personhood, qualitative research, metasynthesis*

Introduction

The concept of sense of self or identity is a complex one that encompasses our knowledge and understanding of ourselves, our relationships, and our position in the social world, as well as our self-evaluation. A number of factors contribute to our sense of self: understanding our personality (conceived as relatively stable and consistent patterns of feeling, thinking and behaving); understanding our motivations (including our goals, preferences, values etc.); understanding our abilities, strengths and limitations; knowing the roles we play within the social environment; knowing our personal history; as well as an evaluative component (self-worth and self-esteem). Construction of self-identity involves inter-personal as well as intra-personal processes (Gelech & Desjardins, 2011). The role of inter-personal processes in the development of identity is key to many approaches in psychology (e.g. psychodynamic approaches) which emphasise the role of social interaction and inter-subjectivity in the formation of the self.

Traumatic brain injury (TBI) can have a major impact on the components of self-identity (e.g. on personality, abilities and social roles) and a growing body of research highlights that TBI poses severe challenges to survivors' sense of self and identity (e.g. Biderman, Daniels-Zide, Reyes, & Marks, 2006; Coetzer, 2008; Gracey & Ownsworth, 2008; Segal, 2010). The concept of identity change has been used to refer to disruption in the continuity of the survivor's subjective sense of who they are post-injury and is considered to be a key feature of TBI (Moldover, Goldberg, & Prout, 2004; Segal, 2010). There is agreement in the field that the reconstruction of a positive and coherent identity is central to rehabilitation following TBI (Biderman et al., 2006; Coetzer, 2008; Heller, Levin, Mukherjee, & Reis, 2006; Morris, 2004; Ylvisaker, McPherson, Kayes, & Pellett, 2008).

Experiences of identity change following TBI are of particular interest because they are associated with a number of clinically relevant outcomes. Several quantitative studies have explored the relationship between perceived identity change following TBI and psychosocial outcomes, using self-rated discrepancies between pre- and post-injury self-concept as a measure of identity change. These studies report that survivors typically rate their current self significantly more negatively than their pre-injury self on a number of constructs (Carroll & Coetzer, 2011; Tyerman & Humphrey, 1984; Wright & Telford, 1996). Furthermore, greater perceived identity change (i.e. greater discrepancies between past and present self-ratings) has been reported to be significantly correlated with self-reported distress (Wright & Telford, 1996); depression (Cantor et al., 2005; Carroll & Coetzer, 2011; Vickery, Gontkovsky, & Caroselli, 2005); poor adjustment and poor self-esteem (Carroll & Coetzer, 2011); as well as poor subjective quality of life (Vickery et al., 2005).

Taking a slightly different approach, Jones and colleagues (Jones et al., 2011) reported that what they call “strength of personal identity” (measured by ratings on the self-statement, “Having had a brain injury has made me a stronger person”); “survivor identity” (measured by ratings on the self-statement, “I think of myself as someone who has survived a brain injury”); and “social identity” (measured by ticking off a list of “the relationships in your life that have improved since injury”) were positively associated with ratings of life-satisfaction in participants with acquired brain injury (ABI), the majority with TBI. Regression and bootstrapping analyses indicated that personal and social identity factors acted as a buffer between the negative effects of severity of injury and life-satisfaction. Taken together, these studies indicate a relationship between post-injury identity experiences, and well-being and adjustment.

Alongside this growing awareness of the clinical relevance of identity change following TBI, there are a growing number of discourses in the literature which highlight the importance of psychological and social *processes* that contribute to experiences of identity change post-injury (see reviews by Gracey & Ownsworth, 2012; Yeates, Gracey, & Collicutt McGrath, 2008). For example, using a biopsychosocial framework to deconstruct what they term 'personality change'[1] following ABI, Yeates et al. (2008) argue against purely biological explanations of post-ABI change which assume a direct link between neurological damage and 'personality change'. Instead, drawing on social constructionist theories of self and identity, they emphasise the importance of subjective experiences and social context in the development of sense of self following ABI. In particular, Yeates et al. (2008) discuss the centrality of language, social meanings and social roles, including family discourses and occupational roles, in the reconstruction of identity post-injury.

Also emphasising the importance of personal meaning and social context in the development of a coherent identity post-injury, Gracey and Ownsworth (2012) review the biological, psychological, and social factors which contribute to post-injury adjustment. The authors focus particularly on "self-discrepancy" between current and past self, or current and ideal self; the tendency to judge the self negatively relative to the pre-injury self and to others; and the negative judgement of others as key processes in adjustment and rehabilitation following brain injury.

A further strand of the brain injury literature which highlights the importance of psychosocial processes in the context of identity experiences is the small body of recent research on post-traumatic growth following brain injury. This literature highlights that, despite the dominant discourses of identity loss following injury, some individuals can

---

[1] While terms relating to personhood are often used interchangeably with lack of specificity (Segal, 2010), 'identity change/loss of self' tend to be used to refer to subjective experiences of change in sense of self, while the term 'personality change' tends to be used in reference to others' judgements that the person has changed.

experience an enhanced sense of self post-injury (Collicutt McGrath & Linley, 2006; Hawley & Joseph, 2008; Ownsworth & Fleming, 2011; Powell, Ekin-Wood, & Collin, 2007; Powell, Gilson, & Collin, 2012; Silva, Ownsworth, Shields, & Fleming, 2011). While the research is still in its infancy, psychological processes such as having a sense of personal meaning (including a sense of purpose and coherence), as well as aspects of the social environment (such as support, activity levels, employment, and stable relationships) have been found to predict post-traumatic growth (Powell et al., 2012).

Approaches to identity change which focus on psychological and social processes have been proposed to offer a way out of the “clinical dead end” (Yeates et al., 2008, p. 568) of explanations of identity change purely as a direct result of brain pathology, given that psychological and social processes are arguably more amenable to change than neurobehavioural disturbance. It is therefore likely that a richer understanding of the processes contributing to experiences of identity change and reconstruction will be useful in informing rehabilitation and intervention post-TBI. In particular, we may be better able to guide individuals through those processes so that they can negotiate experiences of identity change and loss with less distress and reconstruct their identity in a positive way. Despite the recognition of the potential importance of identity reconstruction to rehabilitation (Ben-Yishay, 2008; Coetzer, 2008; Gracey, Evans, & Malley, 2009; Gracey & Ownsworth, 2012; Ylvisaker et al., 2008), there are only a small number of small-*N* studies that specifically examine interventions that target identity change following brain injury (e.g. Dewar & Gracey, 2007). Increased understanding of post-injury identity processes may contribute to further intervention studies.

From the above discussion, it is clear that it is of clinical importance to examine the psychological and social processes that contribute to subjective experiences of identity change and reconstruction following TBI. The qualitative literature is well-placed to explore experience and process (Willig, 2008) and is therefore likely to provide rich data to contribute to our understanding of these processes. Indeed, there is a growing body of qualitative literature that explores experiences of self and identity following TBI that may shed light on the processes that contribute to subjective appraisals of post-injury identity change and reconstruction. However, the findings from these studies are dispersed across the qualitative literature.

While there are some excellent recent reviews of identity change in the context of TBI/ABI which draw on the qualitative literature (Gracey & Ownsworth, 2012; Segal, 2010; Yeates et al., 2008), there appears to be no review that systematically integrates the qualitative data relevant to processes contributing to appraisals of identity change and reconstruction following TBI. A recent metasynthesis of 23 qualitative studies of survivors' experiences of recovery following TBI identified a number of themes relating to identity (Levack, Kayes, & Fadyl, 2010). While Levack and colleagues' metasynthesis highlights the importance of the concept of identity change to survivors' experiences, it does not offer a sustained review and presentation of detailed data on the *processes* by which appraisals of identity change and reconstruction are made in individuals with TBI.

The purpose of the present study was to systematically locate, appraise, analyse and integrate the findings in qualitative studies of adults' experiences of identity following TBI, with a particular focus on the processes that contribute to appraisals of identity change and reconstruction post-injury.

Method

Synthesising qualitative research. In recent years there has been a rapid increase in the publication of syntheses of qualitative studies (Dixon-Woods, Booth, & Sutton, 2007; Sandelowski & Barroso, 2007; Sandelowski, 2004). This trend relates to recognition of the need to integrate findings from the growing body of qualitative studies in order to increase their accessibility, usefulness and impact (Finfgeld, 2003; Sandelowski & Barroso, 2007; Thomas & Harden, 2008). In particular, it is recognised that syntheses of qualitative research, which combine the rigour, transparency and avoidance of bias of traditional systematic reviews, with the focus on complexity and context of qualitative research, are uniquely placed to contribute to evidence-based practice and policy (Dixon-Woods et al., 2007; Major & Savin-Baden, 2011; Mays, Pope, & Popay, 2005).

The present synthesis followed the procedures for synthesising qualitative research outlined by Sandelowski and Barroso (2007), and Pope, Mays and Popay (2007). It was also informed by guidance for undertaking systematic reviews of research developed by the Evidence for Policy and Practice Information and Co-ordination Centre (EPPI-Centre, 2010). The stages comprised:

1. Defining the research question/s;
2. Conducting the literature searches;
3. Specifying and applying the inclusion/exclusion criteria;
4. Appraising the quality of included studies;
5. Extracting the data;
6. Synthesising the findings.

In practice this was an iterative rather than linear process.

Research question. The aim of the qualitative synthesis was to systematically locate, appraise, analyse and integrate the findings in qualitative studies of adults' experiences of identity following TBI. The research question was: What psychological and social processes contribute to appraisals of identity change and reconstruction post-injury in individuals with TBI?

Literature searches. The following electronic databases were searched: PsycINFO, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. PsycINFO was chosen for its coverage of the psychological literature; MEDLINE and CINAHL for their coverage of the health literature; and Web of Science for its extensive coverage. No start date was entered but the earliest paper found was published in 1989.

A combination of keyword and subject heading searches was used to locate relevant references, with the Boolean operators *or* and *and* used to combine terms. Table 1 lists the search terms used and their combination. In order to identify subject headings by which relevant reports were likely to be indexed, the subject headings that had been used to index reports known to meet the inclusion criteria were identified for each database and included in the subject heading searches (known as 'pearl growing'; EPPI-Centre, 2010). This resulted in the addition of 'Life Experiences' to the subject headings searched.

Table 1

Keyword and Subject Heading Searches

Search number	Construct	Keyword terms (variations)	Subject terms (database)
1	Identity	Selfhood* (selfhood/s) Self-concept* (self-concept/s) Self-perception* (self-perception/s) Selves Personhood* (personhood/s) Personality change* (personality change/s) Identit* (identity/ies) Subjectivit* (subjectivity/ies) Combined with *or*	Self Concept, Self Perception, Subjectivity, Narratives, Personality Change, Identity Crisis, Identity Formation, Life Experiences (PsycINFO); Self Concept, Identity Crisis, Personhood (MEDLINE); Self Concept, Identity (CINAHL)
2	Traumatic brain injury	Brain injur* (acquired brain injury/ies, traumatic brain injury/ies) Head injur* (head injury/ies) ABI TBI Craniocerebral trauma* (craniocerebral trauma/s) Combined with *or*	Traumatic Brain Injury, Head Injuries (PsycINFO); Brain Injuries (MEDLINE); Brain Injuries, Head Injuries (CINAHL)
3	Searches 1 and 2 were combined with *and*		

Given the well-documented difficulties of locating qualitative research as a result of poor indexing (Flemming & Briggs, 2007), the EPPI-Centre recommends combining electronic database searching with the use of general search engines such as Google Scholar; citation tracking; and asking authors and experts in the field. These strategies were used to complement the electronic database searches. In addition, while time restraints did not allow for hand-searching of key journals as recommended (EPPI-Centre, 2010), special issues of the journals *Brain Impairment* and *NeuroRehabilitation* were searched for additional reports.

Inclusion criteria. Inclusion criteria were:

1. Studies published in a peer-reviewed journal.
2. Studies published in English language as the present study did not have resources for translation.
3. Studies reporting primary research using qualitative methods of data collection and analysis. Noblit and Hare's (1988) definition of qualitative research was used: the study was included if it sought to generate explanation and understanding of participants' subjective experiences and used an interpretative framework[2]. This broad definition was used as the aim was to include a range of qualitative research.
4. Studies whose participants were adults with TBI. Studies were excluded if insufficient information was provided to be confident it was a TBI sample. Studies were included if in addition to data from participants with TBI, they contained data from other participants (e.g. family members, professionals); however the data from these additional participants was not extracted or synthesised.
5. Studies containing findings relating to processes of identity change and reconstruction. As recommended by Ring and colleagues (Ring, Ritchie, Mandava, & Jepson, 2010) in their guide to synthesising qualitative research, it was decided to include all studies containing relevant data even if the focus of the study was different to that of the synthesis (i.e. studies whose focus was not identity change and reconstruction). This was because the

---

[2] Noblit and Hare's (1988) definition of "interpretative" is broad, proposing that qualitative research sits within an interpretative paradigm which attempts "to make clear, to make sense of an object of study... to bring to light an underlying coherence" (Taylor, 1982, cited in Noblit & Hare, 1988, p. 12, 17). They contrast this with quantitative research which sits in a positivist paradigm which is "causal and predictive". This definition of qualitative research as "interpretative" allows for the inclusion of a wide range of qualitative approaches, including both well-established methodologies (e.g. grounded theory) as well as less well-recognised or defined methods for sense-making. It is worth emphasising that the author is using the term "interpretative framework" broadly as used by Noblit and Hare (1988) and that use of this criterion does not imply any restriction of the review to qualitative approaches that specifically emphasise the interpretative aspect (e.g. interpretative phenomenological analysis).

value of synthesis was considered to be integrating data dispersed across the qualitative literature.

Tools available in the databases were used to limit searches by peer review journal article and availability in English language. On the other hand, the exclusion of papers based on methodology was done manually because it was considered that a number of reports would be missed otherwise due to poor indexing of methodology within databases.

The full list of the reports identified for each database, limited by peer review and English language, was imported into the reference management software, Zotero. In Zotero duplicates were removed and the remaining inclusion criteria applied. The title and abstract was read for each paper. If they did not provide sufficient information to make a decision regarding inclusion, the method section or full paper was read. For all decisions regarding whether the paper included data relevant to identity processes, the full paper was read.

Appraisal of quality. Some researchers argue against the use of quality checklists or frameworks for the appraisal of qualitative research, particularly in the context of a diverse range of qualitative designs and theoretical approaches (for discussion, see Carroll, Booth, & Lloyd-Jones, 2012; Dixon-Woods et al., 2006; Hannes, Lockwood, & Pearson, 2010; Spencer, 2003). However, systematic appraisal of quality was considered an essential component of the synthesis (Pope et al., 2007). Therefore each paper included was assessed for quality using a quality framework.

The Critical Appraisal Skills Programme (CASP) tool was selected from a number of frameworks available. The CASP comprises ten yes/no questions addressing the rigour, credibility, and relevance of qualitative studies, with prompts for the reviewer to consider when answering each question. The first two items are screening questions, while the remainder are detailed questions about study quality. See Appendix C for the CASP tool used.

The CASP was selected on the basis that it has been reported to be applicable to different qualitative approaches; it is free to use; and has been widely used (Hannes et al., 2010). In line with other reviewers (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012), it was found that the prompts provided for each question were a useful anchoring point to reduce ambiguity when answering the question.

It was decided a priori to exclude studies only if they did not meet the criteria within the CASP screening questions which ask whether there is a clear statement of the aims of the research and whether a qualitative methodology is appropriate. The further detailed questions were used only to provide information on study quality so their weight could be considered within the synthesis.

Data extraction. Data were first extracted on the general characteristics of each study including the focus of the study, reported methodology, sample, data collection and study setting. Following this, extraction of data from study findings was carried out. As recommended by Thomas and Harden (2008), study findings were considered to be all of the text labelled as ‘results’ or ‘findings’ in the reports. Extraction involved locating those sections of each paper.

Data synthesis. Thematic analysis (Thomas & Harden, 2008) was selected from the range of data synthesis approaches available (Major & Savin-Baden, 2011) for two reasons. Firstly, thematic analysis is an interpretative approach which goes beyond summarising to offer “novel interpretations of findings”; this interpretative approach is considered a key component of metasyntheses (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004, p. 1358). Secondly, Thomas and Harden (2008) provide detailed guidelines for conducting a thematic analysis; this was considered important given that a common critique of syntheses of qualitative research is the lack of clarity over how the synthesis was conducted (Hannes & Macaitis, 2012).

First, the findings sections were read and coded line by line for meaning and content. At the second stage, the researcher began the process of ‘translating’ concepts from one study to another: the researcher looked for similarities and differences between codes both within studies and across studies in order to develop higher level, but still fairly descriptive, themes. The researcher then looked for connections between themes and began to arrange them hierarchically such that some themes subsumed others and became superordinate themes. As part of this process, all study findings that related to the research questions[3] were entered into a Microsoft Excel spreadsheet, with similar codes grouped together (in columns) to form the higher level themes. Differences between concepts were also noted. The researcher took care to ensure data remained contextualised and continually referred back to original papers to ensure the synthesis was grounded in the data. The third stage involved developing analytic themes that went beyond the themes presented within each individual study. This process proceeded by using the descriptive themes to answer the research questions, thus developing a new set of higher order themes relevant to the synthesis. Emerging themes and the inter-relationships between them were discussed with the author’s supervisor who viewed all extracted data within the Excel table.

The author checked that the final themes included were present across a number of studies (a minimum of five studies). This was done in an effort to ensure that the themes were representative of a range of papers and that a small number of poor-quality papers did not over-contribute to the themes.

---

[3] Thomas and Harden (2008) recommend coding and translating all study findings. However, several studies included (whose focus was different to the synthesis focus) contained only minimal data relating to the research questions; therefore it was decided that only relevant data would be included in the table. This was considered justifiable given the large number of studies included in the synthesis.

Findings

Search strategy. Electronic database searches located 1996 potentially relevant papers. The removal of duplicates and application of inclusion criteria left 27 remaining papers for inclusion. See Figure 1 below for a flow chart of studies included. The title and abstract were read for all studies, while the full-text was read for 111 studies. Additional searches using Google Scholar, citation tracking, asking researchers in the field, and hand-searching special issues of two journals resulted in the addition of seven studies.

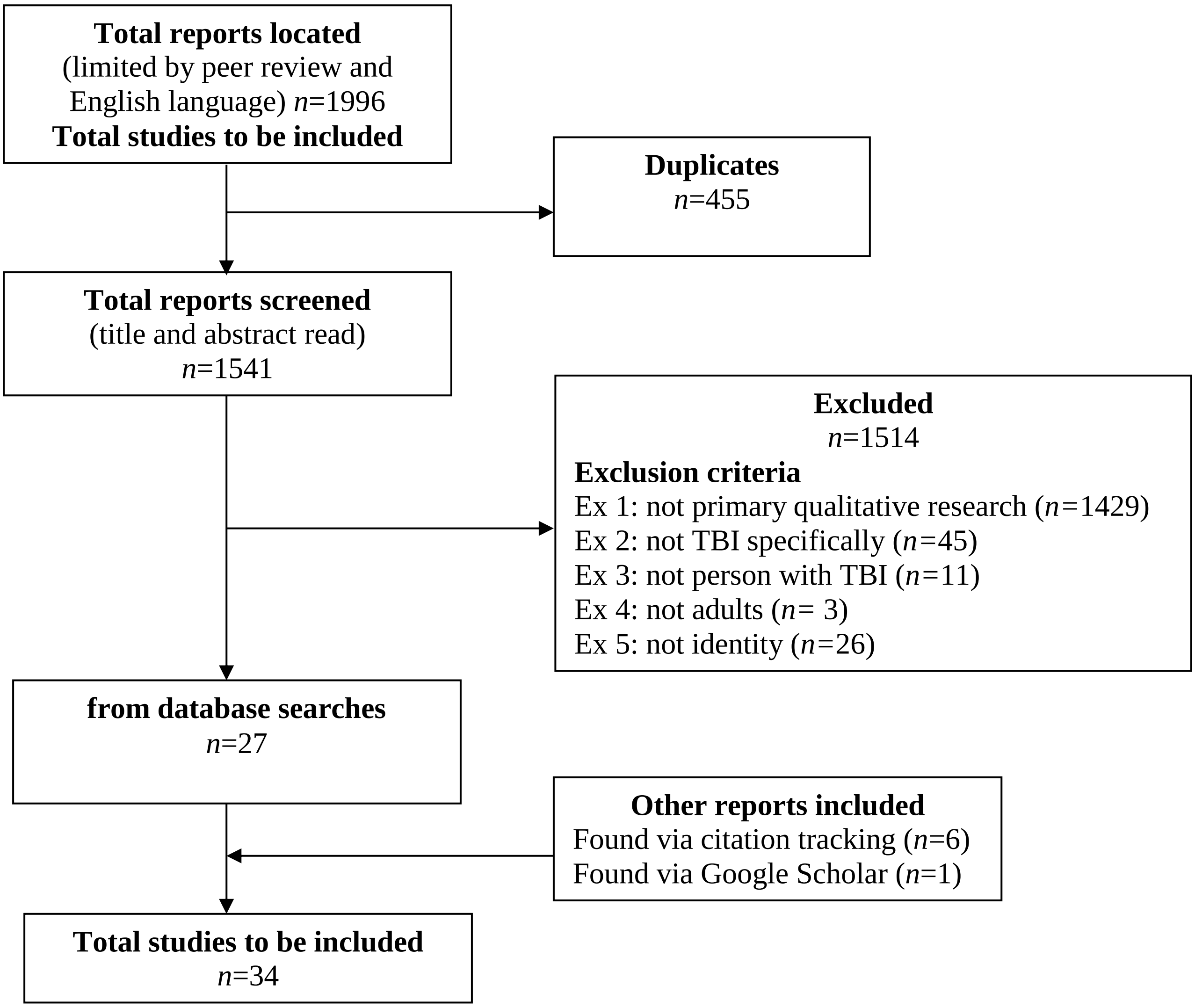

Figure 1. Flow chart for inclusion of studies in synthesis

Study quality. An overview of study quality, based on application of the CASP tool, is presented in Table 2. It is worth noting that the appraisal was necessarily based on the quality of the reporting of the research rather than its actual conduct. One paper (Landau & Hissett, 2008) was excluded on the basis that it did not meet the criteria in the CASP screening questions. Specifically, a qualitative methodology was not appropriate for the study's research questions. Therefore, a total of 33 studies met criteria for inclusion in the synthesis. They were subject to detailed appraisal using the CASP tool, with the main findings for each of the quality criteria assessed summarised below.

***Appropriateness of research design*.** Twenty of the 33 papers provided a clear rationale for the research design, including the theoretical framework and specific methods used. Those studies which used approaches that guided the entire study, such as interpretative phenomenological analysis (IPA), grounded theory (GT), discourse analysis (DA), ethnography, or narrative approaches, for the most part provided a justification for the approach used. Two studies provided a rationale for the use of qualitative methods in general but not the specific theoretical framework used.

The remaining 11 papers did not provide a rationale for the research design. Of these, two papers provided no indication of the qualitative approach used (in terms of either theoretical framework or specific methods) which is considered a significant weakness, given the range of qualitative approaches available. Six studies stated the specific methods of data analysis (e.g. comparative analysis, thematic analysis) but not the wider theoretical framework guiding the study, and provided no rationale. The remaining three studies indicated that GT had been used but provided no justification for their choice.

***Sampling*.** All but two of the studies stated how participants were recruited, with 22 studies providing some rationale for the participants selected (nine of these explicitly stating inclusion/exclusion criteria). Only four studies provided information on non-responders, with an additional three studies indicating that all individuals approached participated.

Data collection. The method of data collection was clear in all studies and all but three of the studies made clear the form of the data (e.g. transcripts). However, there were two main weaknesses within reporting of data collection. Firstly, only 14 of the studies provided justification for choices made in the data collection method, while only seven made any reference to data saturation or justification of sample size, with one additional study acknowledging that data saturation had not been reached.

Reflexivity. Reflexivity was an area of weakness across several of the studies reviewed. Twenty-one of the papers reviewed made some reference to reflexivity, the majority citing the use of a reflexive journal or diary to capture their impressions, assumptions and biases. However, many of these studies did not indicate how this impacted on the trustworthiness of data. In nine studies researchers made an attempt to situate themselves either culturally, professionally or academically and discuss the impact of this on the research process. Two studies discussed avoiding imposing preconceived ideas or theories on the data but did not indicate how this was achieved.

Ethical issues. The majority of studies reviewed provided little detail about ethical procedures (e.g. informed consent, confidentiality) with 16 papers not stating whether ethical approval had been obtained and only two papers discussing consideration of potential consequences for participants and debriefing. These findings are likely to relate to the gap between recording and actual conduct, rather than to ethical misconduct.

Data analysis. All but seven of the studies provided a reasonably in-depth description of the analysis process. Credibility and bias was discussed in 24 studies, with reported use of independent researchers, multiple researchers independently analysing the data, member checking, triangulation of methods, and use of field logs, journals and memos to track decision-making process. For three studies, the quotations did not always appear to support the themes, while one study presented lengthy quotations with little analysis. Only four studies discussed contradictory data, with two of these citing use of negative case analysis.

Findings. All but four studies had a clear statement of findings, discussed in relation to the original research questions.

Value of the research. The majority of the studies reviewed discussed the contribution of their research to practice, policy or research, with several studies also indicating the need for future research.

Table 2

Critical Appraisal of Study Quality Using the CASP

Criteria		Chamberlain, 2006	Cloute, Mitchell, & Yates, 2008	Conneeley, 2002	Conneeley, 2012	Crisp, 1993	Douglas, 2013	Gelech & Desjardins, 2011	Glover, 2003	Gutman & Napier-Klemic, 1996	Hoogerdijk, Runge, & Haugboelle, 2011	Howes, Benton, & Edwards, 2005	Jones & Curtin, 2011	Jumisko, Lexell, & Söderberg, 2005	Klinger, 2005	Kovarsky, Shaw, & Adingono-Smith, 2007	Krefting, 1989	Landau & Hissett, 2008	Lawson, Delamere, & Hutchinson, 2008	Muenchenberger, Kendall, & Neal, 2008	Nochi, 1997	Nochi, 1998a	Nochi, 1998b	Nochi, 2000	O'Callaghan, Powell, & Oyebode, 2006	Padilla, 2003	Parsons & Stanley, 2008	Petrella, McColl, Krupa, & Johnston, 2005	Price-Lackey & Cashman, 1996	Roscigno & Van Liew, 2008	Roundhill, Williams, & Hughes, 2007	Sabat, Moodley, & Kathard, 2006	Shotton, Simpson, & Smith, 2007	Soeker, 2011	Strandberg, 2009
1	Clear statement of aims?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2	Qualitative approach appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3	Research design appropriate to address aims?	?	✓	x	✓	?	✓	?	x	x	✓	✓	?	x	?	x	✓	x	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	?	✓
4	Recruitment strategy appropriate to address aims?	?	?	✓	✓	?	✓	✓	?	?	✓	✓	✓	✓	?	x	✓	x	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	x	?	✓	✓	✓	✓	?
5	Data collected in way that addressed research issue?	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	?	?	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓
6	Researcher-participant relationship considered?	?	✓	✓	✓	x	✓	x	x	✓	✓	x	?	x	✓	x	?	x	✓	?	?	x	?	?	x	?	?	x	?	?	✓	?	x	?	?
7	Ethical issues considered?	✓	x	✓	✓	x	✓	?	x	?	✓	✓	?	✓	x	x	x	?	✓	✓	x	x	x	x	x	?	✓	x	x	✓	✓	✓	✓	✓	✓
8	Data analysis rigorous?	✓	✓	x	✓	?	✓	✓	x	x	?	✓	✓	✓	✓	x	?	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	x	x	✓	x	✓	?	✓
9	Clear statement of findings?	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	?	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
10	Valuable research?	✓	✓	?	✓	✓	✓	✓	?	?	✓	✓	?	?	✓	?	✓	?	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	?	✓	✓	✓	✓	✓	?

Key: ✓ = yes, x = no, ? = unsure

Study characteristics. Table 3 shows the characteristics of the studies included. Two articles (Conneeley, 2002; Conneeley, 2012) presented data from one study, while a further four articles (Nochi, 1997; Nochi, 1998a; Nochi, 1998b; Nochi, 2000) appeared to have some overlap in the data, although they reported different numbers of participants; it appears that the later articles report an extended version of the study. As the articles reported different (although overlapping) themes and included different quotations, they were treated separately. Accounting for these overlaps, collectively, the studies presented data from 277 participants (202 men, 75 women) with mild to very severe TBI, ranging in age from 17 to 81 years. Participants were recruited from hospitals, outpatient clinics, residential services, support groups, charities and the community, and ranged from seven months to 40 years post-injury. While a number of different qualitative approaches were used, the majority of studies used individual interviews as the method of data collection.

Table 3

Characteristics of Included Studies

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Chamberlain, 2006	To explore the experience of surviving TBI; to explore the experiences of self within survival and recovery.	Qualitative content analysis	*N*=60; 40 men, 20 women; 18-81 years; mild to critical TBI as a result of RTA[a] (*n*=47) or unstated cause (*n*=13); one year post-injury; living with family (*n*=50), nursing home (*n*=7) or other (*n*=3); 25 were in employment. One family member per participant was also interviewed.	Adelaide, Australia. Individuals who had been admitted to Intensive Care Unit at participating hospitals one year previously.	Interviews. One interview with each participant (together with family member); 45-60 minutes per interview; interviews conducted in participants' homes. Interviews audio-recorded and transcribed.
Cloute, Mitchell, & Yates, 2008	To explore the interpretative repertoires used by individuals with TBI and significant others; to explore how interpretative repertoires are used to construct social identity.	DA	*N*=6; 5 men, 1 woman; 22-60 years; severe TBI as a result of RTA (*n*=2), fall (*n*=2) or assault (*n*=2); 4-20 years post-injury; all living in the community; no participants were in employment, prior to injury all were employed or studying. 1-2 significant others per participant were also interviewed.	Devon, UK. Participants recruited via Social Services Adult Disability Teams and local branch of Headway.	Semi-structured interviews. One interview with each participant (together with significant other); duration not stated; majority of interviews conducted in participants' homes. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Conneeley, 2002	To gain insight into the issues perceived as relevant for individuals with TBI re-entering their social environment.	Qualitative methodology – not stated	*N*=18; 13 men, 5 women; 17-60 years; severe TBI as a result of RTA (*n*=12), assault (*n*=3), fall (*n*=1), accident at work (*n*=1), or sporting injury (*n*=1); one year post-injury; all participants discharged to home environment with family support; employment status not stated. Significant other and professional staff were also interviewed.	UK. Patients consecutively discharged from the ward of a neurological rehabilitation unit.	Semi-structured interviews. Three interviews with each participant: on discharge, six months and one year post-discharge; duration of interviews not stated; interviews conducted in participants' homes or at the rehabilitation hospital. Significant other and professional staff also interviewed.
Conneeley, 2012	To explore the journey of individuals with brain injury and their families. To explore the views of the individual with brain injury, their family member, and the rehabilitation team over a period of one year following discharge from a neurological rehabilitation ward.	Interpretative phenomenological approach, thematic analysis	*N*=18; 13 men, 5 women; 17-60 years; severe TBI, as a result of RTA (*n*=12), assault (*n*=3), fall (*n*=1), accident at work (*n*=1), or sporting injury (*n*=1); recruited on discharge from post-acute neurological rehabilitation ward; all living in the community supported by a family member; employment status not stated. Significant other and professional staff were also interviewed.	UK. Participants recruited through neurological rehabilitation ward as they were discharged from the ward.	Semi-structured interviews. Three interviews with each participant: on discharge, six months and one year post-discharge; duration of interviews not stated; most interviews conducted in participants' homes. Significant other and healthcare professional also interviewed. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Crisp, 1993	To explore the experience of living with TBI and the meaning it has for the person with TBI. To explore psychosocial responses to TBI.	Comparative analysis	*N*=10; 6 men, 4 women, 22-50 years; mild to severe TBI, cause not stated; 3-20 years post-injury; all living in the community; four participants were in paid full-time employment, two were full-time students, two were part-time volunteers, and two were unemployed.	Victoria, Australia. Participants recruited from Headway and via rehabilitation professionals working with individuals with TBI.	Unstructured and semi-structured interviews. 7-10 interviews with each participant; 40-75 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.
Douglas, 2013	To explore the way in which adults who have sustained a severe-very severe TBI view themselves/conceptualise themselves several years after the injury	GT	*N*=20; 16 men, 4 women; 21-54 years; Moderate to very severe TBI as a result of RTA; 5-20 years post-injury; all participants living in the community with various levels of paid and unpaid support; no participants in paid employment, four were volunteers, and two were in vocational training programmes.	Australia. Participants recruited from metropolitan community disability agencies that provide services to people with TBI.	In-depth interviews. One interview with each participant; 90-180 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed. Field notes.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Gelech & Desjardins, 2011	To explore the construction of self following ABI.	Thematic, syntactic and deep-structure analysis	*N*=4; 3 men, 1 woman; 37-55 years; moderate to severe TBI all as a result of RTA; 4-21 years post-injury; two participants living independently and two in assisted living centres; no participants in employment, all employed prior to injury.	Saskatoon, Saskatchewan, Canada. Local rehabilitation centre.	Life history and semi-structured interviews. Two interviews with each participant; 35-90 minutes per interview; interviews conducted in rehabilitation centre or participants' homes. Interviews audio-recorded and transcribed.
Glover, 2003	To explore perceptions of quality of life following TBI; the effects of the injury on family, social and working life; and the effects of Headway on quality of life.	Qualitative case history. Data analysed using 'framework' analytic approach	*N*=4; all men, 34-53 years; TBI as a result of RTA (*n*=2) and fall (*n*=1) or other (*n*=1); severity of injury not stated; 6-11 years post-injury; living situation and employment status not stated.	Essex, UK. Headway.	Conversational interviews. Number, duration and location of interviews not stated. Interviews audio-recorded.
Gutman & Napier-Klemic, 1996	To explore the disruption of gender identity and gender role after TBI.	GT	*N*=4; 2 men, 2 women; 33-46 years; TBI as a result of RTA; severity of injury not stated; 10-18 years post-injury; living in a residential facility; three participants employed, all employed pre-injury.	Northeast USA. Residential facility for people with head-injury.	Open-ended interviews. Six interviews with each participant; 60 minutes per interview; interviews conducted in private informal settings such as the participant's residence or an empty recreational room at the facility. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Hoogerdijk, Runge, & Haugboelle, 2011	To explore how individuals with TBI make sense of their adaptation process and the performance of occupations within the process.	Narrative analysis	*N*=4; 3 men, 1 woman; 33-61 years; TBI, cause not stated; severity of injury not stated; 20-27 months post-injury; all married and living with partner; one in employment.	Netherlands. Participants discharged from inpatient treatment programme at a rehabilitation centre at least six months previously.	Interviews. Two interviews with each participant; 50-90 minutes per interview; interviews conducted in participants' homes. Interviews audio-recorded and transcribed.
Howes, Benton, & Edwards, 2005	To investigate the experience of ABI.	IPA	*N*=6, all women; 30-51 years; mild to severe TBI, cause not stated; 7 months to 15 years post-injury; living situation and employment status not stated.	UK, recruited via referrals made to a Clinical Neuropsychologist at a district general hospital.	Semi-structured interviews. Two interviews with each participant; duration not stated; interviews conducted in a private consultation room at the hospital. Interviews audio-recorded and transcribed.
Jones & Curtin, 2011	To explore masculine identity and participation of men with TBI living in rural Australia; to explore the impact of role changes on identity and participation satisfaction.	GT	*N*=21; all men; 24-66 years; severe-extremely severe TBI as a result of RTA (*n*=14), fall (*n*=4), or assault (*n*=3); 2-31 years post-injury; living situation not stated; participants unemployed (*n*=8), retired (*n*=4), doing voluntary or unpaid work (*n*=2), or in paid work (*n*=7).	New South Wales, Australia. Participants were recruited from one of eight rural Brain Injury Rehabilitation Programmes.	Semi-structured interviews. One interview with each participant (together with partner or support person); 60-90 minutes per interview; interviews conducted in participants' homes or convenient location. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Jumisko, Lexell, & Söderberg, 2005	To explore the meaning of living with TBI as narrated by people with moderate or severe TBI.	Phenomenological hermeneutic method	*N*=12, 10 men, 2 women; 23-50 years; moderate to severe TBI, caused by RTA (*n*=7), fall (*n*=3), or assault (*n*=2); 4-13 years post-injury; two participants lived with their parents, two with their partners, and eight alone or with their children; employment status not stated.	Sweden. Participants recruited by a psychologist and a nurse working in two different hospitals.	Interviews. Two interviews with each participant; 60-75 minutes on average; interviews conducted in participants' homes (*n*=11) or work place (*n*=1). Interviews audio-recorded and transcribed.
Klinger, 2005	To explore experiences of the process of occupational adaptation after TBI. To explore occupation and identity following TBI.	Constant comparative method	*N*=7; 6 men, 1 woman; 29-45 years; TBI as a result of RTA (*n*=4), accident at work (*n*=2), or assault (*n*=1); severity of injury not stated; 2-16 years post-injury; living situation not stated; six participants unemployed, one employed.	Ontario, Canada. Participants were recruited via the director of a local brain injury association and by the director of a clubhouse programme for individuals with TBI.	In-depth, semi-structured interviews. One interview with each participant; 90 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.
Kovarsky, Shaw, & Adingono-Smith, 2007	To gain insight into how identity was ascribed and managed during face-to-face interactions between speech-language pathologists and their clients during therapy	Not clear	*N* not stated. Adults with TBI attending therapy sessions with speech and language therapist at rehabilitation hospital, 2-6 patients per group plus speech and language therapist. No further information given.	USA. Participants recruited from rehabilitation hospital.	Six group therapy sessions; 45-65 minutes per session; sessions conducted in rehabilitation hospital; sessions video-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Krefting, 1989	To explore the life experiences of people with TBI and their family to gain an understanding of disability.	Ethnographic study. Thematic and content analysis	*N*=21; 14 men, 7 women; 17-41 years; moderate to severe TBI, cause not stated; 2-22 years post-injury; all participants living in the community; one participant in employment, remainder supported by income from insurance settlement, social security or allowances from parents. Family members and neighbours, teachers, friends also interviewed.	Urban community, Southwest USA. Participants were recruited via leaders of the local branch of the National Head Injury Foundation, or by others in the study.	Non-structured interviews with individual, family members and friends. Not clear if interviews were joint or separate. 80 interviews in total; 60-240 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed. Participant observation at family support group meetings, treatment sessions, and family time. Document review.
Lawson, Delamere, & Hutchinson, 2008	Experience of recovery and rehabilitation following brain injury	Autoethnography	*N*=1, female; age and number of years not stated. Moderate TBI as a result of RTA. Living in the community.	Montreal, Canada. Participant recruited through social connection.	Four years of poetry and journal entries, interview. Number, duration and location not stated.
Muenchenberger, Kendall, & Neal, 2008	To explore turning points and processes that define the experience of identity change for people with TBI.	Interpretative qualitative research design using a phenomenological approach. Thematic analysis of data.	*N*=6; 4 men, 2 women; 22-42 years, TBI all as a result of RTA; severity of injury not stated; 1-25+ years post-injury; participants had attained 'positive productive outcomes' following brain injury (e.g. return to work, study).	Australia. Participants had received formal inpatient and outpatient brain injury rehabilitation but were not current rehabilitation clients.	In-depth narrative/life-story interviews with critical incident technique. Two interviews with each participant; duration and location of interviews not stated. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Nochi, 1997	To explore the self-images of people with TBI and how they experience psychological distress.	Constant comparison	*N*=4; 3 men, 1 woman; 24-40 years; TBI as a result of RTA (*n*=3), or fall (*n*=1); severity of injury not stated; 3-12 years post-injury; all participants living in the community either independently (*n*=3) or with parents (*n*=1); all participants either in employment (*n*=3) or study (*n*=1).	New York, USA. Participants were recruited from an independent living centre or TBI support group.	In-depth interviews and observations. Two interviews with each participant; 30-45 minutes per interview; interviews conducted in participants' homes, independent living centre, or university. Interviews audio-recorded and transcribed.
Nochi, 1998a	To explore experiences of self after TBI.	GT	*N*=10; 6 men, 4 women, 24-49 years, TBI, caused by RTA, or sports injury; severity of injury not stated; 2-12 years post-injury; all participants lived in the community by themselves or with their families; three participants worked full-time, three worked part-time, three were unemployed and one was a graduate student.	Northeast USA. Participants recruited from a TBI support group (*n*=7). Additional data collected from e-mail written on the TBI Support List on the internet (*n*=3).	Semi-structured interviews conducted with the seven participants recruited from the support group. Two or more interviews with each participant; 45-60 minutes per interview. Interviews audio-recorded and transcribed. Participant observation. Also reviewed text from TBI e-mail discussion board for three participants.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Nochi, 1998b	To explore loss of sense of self experience in relation to the sociocultural context; to identity the images or labels that individuals with TBI feel they receive from society by examining their self-narratives.	GT	*N*=10; 8 men, 2 women; 24-54 years; TBI caused by RTA (*n*=8), sporting injury (*n*=1), or fall (*n*=1); severity of injury not stated; 3-28 years post-injury; all participants were living in the community; four were unemployed, four were employed and two were students. Additional data obtained from 13 participants, 5 men, 8 women, 2-61 years; 1-34 years post-injury.	Northeast USA. Participants recruited from a TBI support group. Additional data collected from e-mail written on the TBI Support List on the internet.	Semi-structured interviews. Two to three interviews with each participant; 45-60 minutes per interview; interviews conducted in place familiar to participant. Interviews audio-recorded and transcribed. Participant observation. Also reviewed text from TBI e-mail discussion board of 13 additional participants.
Nochi, 2000	To explore the self-narratives of coping for people with TBI.	GT	*N*=10; 8 men, 2 women, 24-54 years; TBI as a result of RTA (*n*=8), fall (*n*=1), or sporting injury (*n*=1); severity of injury not stated but length of coma from 0-4 months; 3-28 years post-injury; living in the community; four unemployed, four employed and two students.	USA. Participants recruited from a TBI support group.	Semi-structured interviews. Two or more interviews with each participant; 45-60 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed. Participant observation.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
O'Callaghan, Powell, & Oyebode, 2006	To explore experiences of gaining awareness of deficits after TBI.	IPA	*N*=10; 7 men, 3 women; 21-60 years; moderate to severe TBI as a result of RTA (*n*=6) or fall (*n*=4); seven living at home with family and three lived alone with support.	Birmingham, UK. Patients attending an outpatient post-acute rehabilitation service.	Semi-structured interviews. One interview with each participant; ~60 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.
Padilla, 2003	To investigate the lived experience of disability for a woman who sustained a head injury 20 years ago.	Phenomenology	*N*=1; female; ~40 years; TBI as a result of train accident; severity not stated; 21 years post-injury; living at home and working.	Nebraska. Recruited through social contact.	Interviews and e-mail conversation. Eleven interviews and 72 e-mail message exchanges; 60-90 minutes per interview; interviews conducted in participant's work place or home. Two interviews audio-recorded and transcribed; interview notes for remaining interviews.
Parsons & Stanley, 2008	To explore the experience of occupational adaptation and strategies used by people with ABI living in a rural area.	Phenomenological approach	*N*=2; both men; 30 and 44 years; mild to moderate TBI, as a result of RTA; 1 and 15 years post-injury; both living in their own home in rural Australia.	Rural South Australia. Participants recruited via Brain Injury Rehabilitation Services.	Semi-structured interviews. One/two with each participant; 60 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Petrella, McColl, Krupa, & Johnston, 2005	To explore the process of returning to productive activities from the perspective of people with longstanding ABI; to understand how intrinsic and extrinsic factors enable or limit productive involvement over time.	GT, constant comparative method	*N*=6; 4 men, 2 women; 33-78 years; severe TBI caused by RTA; 13-15 years post-injury; all participants living in the community; one participant was a part-time student and volunteer; one worked part-time, and the remainder worked in a vocational rehabilitation programme.	Ontario, Canada. Participants recruited from an outreach community programme for people with brain injuries.	Semi-structured interviews. Two-three interviews with each participant; 18-90 minutes per interview; interviews conducted in participants' homes. Interviews audio-recorded and transcribed.
Price-Lackey & Cashman, 1996	To explore how a person experiences and adapts to head injury. Initial interview focused on occupational satisfaction after the TBI, second interview focused on adaptation to ‘turnings’ in her life.	Narrative analysis used for data-analysis. Also ‘narrative smoothing’ – process in which investigator decides which story will be told.	*N*=1; female; 43; states moderately severe TBI due to RTA; 5 years post-injury.	California. Not stated how participant was recruited.	Life history interviews. Two interviews; 3 hours and 4 hours; one year apart; location of interviews not stated. Interviews audio-recorded and transcribed.
Roscigno & Van Liew, 2008	To highlight one man's personal writings about his life after experiencing severe TBI. To provide preliminary understanding of the nature of social interactions for people with TBI. To explore the social processes that influenced the assignment of meaning to his life.	Symbolic interactionism	*N*=1, male, 35 years, severe TBI as a result of RTA; 18 years post-injury.	USA. Not clear how participant was recruited.	Written journal, written retrospectively. In person and telephone discussions. Duration and location of 'discussions' not stated.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Roundhill, Williams, & Hughes, 2007	To explore the process of loss; to explore how individuals experience grief following TBI and how they view themselves and their lives in light of these losses.	IPA	*N*=7; 6 men, 1 woman; 32-60 years; severe TBI as a result of RTA (*n*=6), or assault (*n*=1); 3-40 years post-injury; living situation and employment status not stated.	UK. Participants recruited through Headway.	Semi-structured interviews. One interview with each participant; duration and location of interviews not stated. Interviews audio-recorded and transcribed.
Sabat, Moodley, & Kathard, 2006	To explore the construction of identity pre and post TBI.	Life history methodology and narrative analysis	*N*=1, male, 31 years; severe TBI sustained in an explosion while in the army; 12 years post-injury; living situation and employment status not stated.	KwaZulu, South Africa. Participant recruited from rehabilitation institution for individuals with stroke and head injury.	In-depth semi-structured interviews. Three interviews with each participant; 90 minutes per interview; interviews conducted at rehabilitation institution. Interviews audio-recorded. Document review of personal journal and photograph album.
Shotton, Simpson, & Smith, 2007	To explore appraisal, coping and adjustment in individuals with a TBI.	IPA	*N*=9, 7 men, 2 women; 21-59 years; moderate to severe TBI as a result of RTA (*n*=4), fall (*n*=3), assault (*n*=2); 2-6 years post-injury; three unemployed, one attending day centre, four in education, one employed; all employed prior to brain injury.	UK. Participants recruited via database of neurological rehabilitation unit.	Semi-structured interviews. One interview with each participant; 54-87 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Soeker, 2011	To explore the difficulties in resuming and maintaining worker roles, adaptation following TBI, and the relationship between competence and identity in TBI.	Data analysis methods described by Morse and Field (1996): comprehending, synthesising, theorising and recontextualising	*N*=10, 9 men, 1 woman; 31-64 years; mild to moderate brain injury, cause not stated; number of years post-injury not stated; living situation not stated; all participants in employment (inclusion criteria).	South Africa. Participants recruited from statistical records of Hospital Occupational Therapy Department and Road Accident Fund Organization.	In-depth interviews. One interview with each participant; 60 minutes per interview; location of interviews not stated. Interviews audio-recorded and transcribed.
Strandberg, 2009	To explore how individuals with TBI experience the changeover process that arises after the trauma.	Critical interpretation perspective. Qualitative content analysis	*N*=15; 10 men, 5 women; 19-53 years; mild to moderate TBI as a result of RTA (*n*=11), fall (*n*=3), or assault (*n*=1); 5 months to 17 years post-injury; living situation and employment status not stated.	Örebro, Sweden, outreach team of University hospital of Örebro.	In-depth interviews. One interview with each participant; 1-2 hours per interview; interviews conducted in participants' homes, workplace or at the university. Interviews audio-recorded and transcribed.

[a] Road traffic accident

Study findings. A number of themes emerged from the synthesis of study findings, which grouped around three overarching themes: 1) processes contributing to experiences of identity change or loss post-injury; 2) processes contributing to negative reconstruction of identity post-injury; and 3) processes contributing to adaptive and coherent reconstruction of identity post-injury. At least five studies contributed to each theme (range = 5-21, mean = 14). Furthermore, studies of a range of quality, including those rated to be of higher quality contributed to each theme. For a list of study themes and the number of studies contributing to that theme, see Table 4. For a list of themes; studies contributing to each theme; and key quotations, see Table A1 in Appendix D. The main themes that emerged are discussed below.

Table 4

List of Study Themes

Overarching theme	Theme (number of studies contributing)
Processes contributing to appraisals of identity change or loss post-injury	Loss of self-knowledge (10) Experiences of personal and social discrepancy (19) Discrepancies between self-experiences and the discourses/practices of others (5)
Processes contributing to negative reconstruction of identity post-injury	Lack of legitimate social roles and unmet milestones (6) Discourses and practices that deny personhood (16)
Processes contributing to adaptive and coherent reconstruction of identity post-injury	Recovering self (17) Continuity amid change (12) Acceptance and letting go (21) Personal growth and meaning-making (20)

1) Processes contributing to appraisals of identity change or loss post-injury:

Loss of self-knowledge. Gaps in autobiographical memory and lack of access to an accurate self-history as a result of brain injury were highlighted as impacting on identity experiences post-injury. In particular, memory deficits were considered to hinder the construction of continuous and coherent self-narratives, central to a sense of knowing who one is as a person, as described by one participant:

> I don’t remember myself in my later years with this amnesia. [...] I am now only just getting to know this person in the mirror. I don’t even look anything like I remembered. I don’t feel, somehow, like I am anything like I was. (Krefting, 1989, p. 76)

For some participants, loss of self-history was experienced as having a profound impact on their global sense of personhood:

> I don’t remember anything about my life before the accident... [W]hen I woke up, I couldn’t identify my mother, my brothers, and sisters, I couldn’t identify anything. ...I didn’t know I was an almost 18-year-old girl. ...I didn’t know what one should do as a human being. (Jumisko, Lexell, & Söderberg, 2005, p. 44)

Alongside gaps in autobiographical memory, another facet to loss of self-knowledge is loss of knowledge about one’s capabilities and skills post-injury (“I had no idea what I could do any more”; Conneeley, 2012, p. 78).

Other narratives did not refer to loss of autobiographical memory or knowledge about capabilities but spoke to the concept that some fundamental knowledge about who one is as a person had been lost (“I felt as though I didn’t even know that I had a personality to start with. I felt really sort of empty”; Roundhill, Williams, & Hughes, 2007, p. 247).

Loss of self-knowledge contributed to feelings of uncertainty and unpredictability ("I live my life without a certainty I must admit, of most things without a certainty of making the right decisions or thinking the right way or doing the right thing..."; Muenchenberger, Kendall, & Neal, 2008, p. 985-986). A sense of alienation from the self was also apparent in some participant narratives ("I still, after two years, am trying to redefine myself. I don't know this person any more. She is not reliable and cannot be trusted as my best friend"; Nochi, 1998a, p. 872).

Experiences of personal and social discrepancy. Across a number of studies, a powerful process identified as contributing to judgements of identity change was the experience of discrepancy between pre- and post-injury self. Typically, return to pre-injury environments prompted participants to compare their current self-image with that of their pre-injury self-image and make appraisals of identity change, with the current self viewed negatively in comparison:

> I don't feel like I did about myself when I didn't have this incapacity. I don't feel like I used to be, I feel, if you like, like a lesser person than I used to be because I used to be an assistant general manager... so now things are different. (Conneeley, 2012, p. 80)

Changes identified were: cognitive ("I have lost my identity [...] that which I value so much – my mind – it doesn't work like it used to. I don't think it will ever be the same"; Chamberlain, 2006, p. 411); functional ("I was always brought up that 'if you start a job you finish it' and that's what I can't do at the moment"; Jones & Curtin, 2011; p. 1575); and affective ("After the accident... my son was three years old, and I knew he was my son. But the feeling like we were connected was gone", Nochi, 1998a, p. 873). As the quotations above highlight, several participant narratives indicated that the extent to which perceived discrepancies are experienced as threatening to sense of self was influenced by what the individual values (e.g. their mind, the way they were brought up, their emotional experience as a father).

The most widely discussed factor contributing to appraisals of loss of identity by comparison was changes in social functioning following injury, in particular participants' realisation that they were unable to fulfil pre-injury roles. Again it was the value attributed to these roles and the extent to which they were considered to be self-defining that often seemed to impact on participants' experiences of loss of identity:

> Part of what exacerbated my profound sense of loss of self was the loss of my role as a valued member of the healthcare team. [...] A fundamental part of how I defined myself was associated with my previous work. I defined myself – and my sense of competence and compassion – in that role. (Lawson, Delamere, & Hutchinson, 2008, p. 242)

While loss of occupational roles was frequently cited within this theme, changes in other social roles such as that of parent, spouse and friend were also considered to impact on identity experiences ("I want to do something, like he is moving all his girlfriend's furniture now. Normally I would do it but they've taken over that role [...]. I did everything. It was always me, the main man."; Soeker, 2011, p. 84).

Without previously valued roles to contribute to their sense of self, some participants described having no clear sense of who they were:

> When they ask me what I do, for the last couple of years I have said 'nothing'. After that 75% of people don't want to talk to you. But if you are working, then you are one of the guys. If not, who knows what you are. (Krefting, 1989, p. 77)

Discrepancies between participants’ potential/imagined pre- and post-injury futures also contributed to appraisals of identity change. Participants discussed loss of what they “could-a been; should-a been” (Klinger, 2005, p. 12) as a result of the head-injury:

> I should have already fallen in love and gotten married, had a family, gone down that route. I know I would have been in an executive level position at work by now. [...] It just feels like part of my life was not fulfilled. (Gutman & Napier-Klemic, 1996, p. 540)

In summary, perceived discrepancies between valued or defining aspects of pre- and post-injury cognition, functioning, emotional experience, social roles, and imagined futures prompted participants to reflect on their identity and make judgements of post-injury identity change and loss.

Discrepancies between self-experiences and the discourses/practices of others. A further process contributing to appraisals of identity change was discrepancies between the survivors’ own self-experiences and the information and responses given by others. Often it was family or friends who had known the person prior to their injury who pointed out changes in their personality, temperament, and capabilities which contradicted participants’ sense of a stable inner self and thus made them question their identity (“maybe I’m not seeing myself properly”; Howes, Benton, & Edwards, 2005, p. 135). The attitudes and actions of friends and family towards the survivor, including breaking off friendships, ending relationships and treating them differently (e.g. with pity, wariness, or like a child), also contributed to survivors’ perceptions that they had changed (“How I get on with people I don’t think has particularly changed but I think people must obviously have a different view of me because they’re assessing, you know, does he really understand this, this sort of thing”; Muenchenberger et al., 2008, p. 360).

Beyond family and friends, treatment by employers and unknown others highlighted discrepancies between how the individual sees themself and others' perception of them. One participant describes returning to work: "I personally thought it went really well, but then work suspended me on grounds of not being able to do the job, so there was my perception and their perception and they were completely different..." (Howes et al., 2005, p. 135).

One set of discourses considered to have a particularly powerful impact on identity experiences post-injury were authoritative medical and professional discourses. Frequently these discourses indicated change and damage to the self which contradicted survivors' felt experience and threatened notions of a stable and intact self. One strand of these discourses is neuropsychological assessments which indicate changes to cognition or personality:

> Yeah, like I think, I think I'm okay. But yet I have tests, I have cognitive tests and they all prove that, no, you're not what you used to be. I had tests done, you know, and he said, 'Well according to what we have on your information, your standards and stuff, you're down considerably'. But I don't consider myself a dimwit really. (Gelech & Desjardins, 2011, p. 67)

These authoritative discourses frequently caused participants to question their self-knowledge and instead defer to medical and professional knowledge ("I don't feel anything wrong with my brain, [but] they insist I'm brain injured. Well wouldn't they know?"; Gelech & Desjardins, 2011, p. 68). Furthermore, professional discourses of change and deficit were frequently co-opted by family and friends in ways that undermine the credibility of the participant's own experiences of self:

> [another challenge] is when you actually get over certain things but people around you are still thinking that you're still the person that's got the injury and that injury will always be with you because doctors or support workers or whoever, have told the

> people around you that this is how they will react, they'll be like this forever, they'll be this way, they can't they're just thinking that they can. (Muenchenberger et al., 2008, p. 988)

To summarise, the discourses and practices of family, friends, employers and others, as well as authoritative medical discourses, frequently contradicted survivors' self-experiences. In particular, discourses of change, damage and deficit threatened survivors' experiences of a stable and intact inner self.

2) Processes contributing to negative reconstruction of identity post-injury: The themes presented within this overarching theme relate to the negative reconstruction of identity following TBI; however, they also relate to the preceding overarching theme of awareness of identity change and loss. It is not easy to separate out these two strands as frequently they were interwoven within participant narratives. For example, participants made appraisals of a diminished sense of self and simultaneously reconstructed their identity as someone lacking self-worth.

Lack of legitimate social roles and unmet milestones. It was not only loss of previously valued/self-defining roles but also lack of opportunity to fulfil legitimate roles in society generally, or to achieve social milestones, that contributed negatively to post-injury identity experiences. Several narratives indicated that lack of access to social roles impacted on survivors' appraisals of themselves such that they reconstructed their identity as someone lacking self-worth ("I felt absolutely useless because you're a survivor if you like but you're not... you feel worthless, you aren't profitable you just feel a spare part sitting there doing nothing, watching everyone else do it round you"; Glover, 2003, p. 753). Similarly, not meeting socially validated milestones, such as marriage and children, were considered to have a negative impact on self-worth and were linked to appraisals of the self as inferior ("everyone's got to have a girl... you feel really inferior without a partner... not good about yourself, frustrated, annoyed"; Muenchenberger et al., 2008, p. 986).

For several participants the process of making appraisals of diminished self-worth centred on comparisons made between oneself and family, friends or colleagues:

> I'm an idiot, I'm unmarried... I'm the only failure in the family... I don't feel like a brother. They [brother and sister] have made it, I have not. They have spouses, children, money... [my] self-esteem goes down and down... I feel useless. (Crisp, 1993, p. 397)

In summary, lack of access to meaningful roles, unmet social milestones and social comparison contributed to negative reconstructions of participants' identity as inferior or lacking self-worth.

Discourses and practices that deny personhood. A particular subset of discourses and practices which impacted negatively on post-injury identity experiences are those which denied the uniqueness of the individual and instead associated them with a homogenous, marginalised, low-status, dependent group.

Narratives indicated that the discourses and practices of others contradicted their own experience of themselves as a unique individual and denied them full personhood ("I guess one of the fears now is this. If I say, 'Oh, I had a head trauma', then people are going to think that I'm, you know, beyond whole person"; Nochi, 1998b, p. 670). Terms such as "TBI", "brain injury", and "disability" were considered by some participants to contribute to this process of denying individuality and personhood ("I don't, I don't like the word 'disability'. I, I just, you know, that's just society's way of saying, you know. They [people with TBI] are more unique"; Nochi, 1997, p. 547). These terms were also considered a barrier that prevented others from getting to know them as a person ("I don't like the term 'TBI' because it just puts another stigma. It puts things on people. It’s just a title (...) [Suppose I say] ‘I have TBI’, and that’s going to stop people from getting to know me”; Nochi, 1998a, p. 873).

While this dehumanising process was linked to stigma and prejudice in society, it was also linked to clinical discourses and practices, with participants suggesting that being a patient or a client was at odds with being a full person (“When is my life going to be my own and not [that of] a client. If you’re a client, you’re not a person. You’re looked at in a very clinical way”; Gutman & Napier-Klemic, 1996, p. 541). One participant’s description powerfully captured the experience of having one’s personhood stripped away within institutional environments (“To the staff we are all the same, one body is just like the next”; Gelech & Desjardins, 2011, p. 69).

One particular strand of discourses and practices that deny the survivors’ full personhood are those that position the individual as dependent or lacking autonomy, frequently through infantilising or paternalistic practices and systems. One participant spoke of her relationship: “We planned to be together alone at night. ...We were found [by staff members] and separated. Do you know how that makes me feel? I’m 46 and she’s 43. I feel like we’re children” (Gutman & Napier-Klemic, 1996, p. 541). Medical discourses particularly contributed to loss of agency (“Now that I have diabetes they’re really watching out for me. Which is a good thing for my own health, but I don’t feel like I am in control of my own body, of my own self”; Gelech & Desjardins, 2011, p. 70).

In summary, discourses, including medical discourses, which denied the personhood of the individual contributed to survivors’ negative reconstruction of themselves as a member of a homogenous, low-status, dependent group.

3) Processes towards an adaptive and coherent reconstruction of identity post-injury:

Recovering self. A number of participant narratives spoke to the concept of recovering parts of the self that were deemed to have been lost or changed following the injury as a strategy for re-establishing a sense of self ("...all you want to go and do is be the person you can... cause you're brought up with the 'self' you know"; Muenchenberger et al., 2008, p. 985). Hope for a future when one is closer to one's pre-injury self was a central part of these narratives ("I'll keep improving, with hard work of course, for the next… 10 years, or 20 years, no matter what. It's going to be difficult… never being 100% again. But I think I'm going to be close, eventually"; Chamberlain, 2006, p. 413).

Return to pre-injury social roles featured as particularly important within the re-establishment of a sense of identity ("Well, the best aspect is it gave you an identity back. That a person's back in the workforce"; Gelech & Desjardins, 2011, p. 67). In particular, returning to social roles was presented as a strategy to develop self-esteem/self-worth in part through social validation ("it wasn't about the job itself it was about getting it. It was about the acknowledgement that I could do something... someone said I could do it"; Muenchenberger et al., 2008, p. 987). Achieving social milestones and fitting into social norms were considered a central part of this process ("What society might class as 'normal' is what I was trying to fit into in the last 2 years to make sure I was being a part of society and behaving the right way"; Muenchenberger et al., 2008, p. 986).

However, while several studies highlighted that the opportunity to engage in meaningful occupation and to re-establish social roles was central to identity reconstruction, there was some ambivalence within participant narratives about the value of trying to *recover* one's pre-injury self. Striving towards and imagining a future where one is closer to one's image of pre-injury self was presented as a way of protecting against loss of self by comparison with pre-injury self by allowing survivors to "cling on" to "who they were before" (O'Callaghan, Powell, & Oyebode, 2006, p. 587). However, within some participant narratives, this was equated with denial of loss and change:

> For many months after the accident I completely denied there was anything wrong [...] I just thought if people would let me get back to work, let me get back to my house, let me get on with my life then it'd be ok. (O'Callaghan et al., 2006, p. 586)

As such, it was considered by some participants to be a "block to getting better" (O'Callaghan et al., p. 587). Furthermore, several studies also presented findings suggesting that a retrospective focus could hinder the development of a coherent post-injury identity, as will be explored in the theme 'Acceptance' below.

Similarly, a focus on achieving socially accepted milestones was understood by some participants as indicating a lack of a secure sense of one's own personal identity. As one participant described his decision to get married following his injury: "I suppose this [chapter] describes someone who was lost, who was trying to show the world that he wasn't lost by doing things like getting married" (Muenchenberger et al., 2008, p. 986).

In summary, being able to reoccupy meaningful social roles was considered an important part of identity reconstruction. In contrast, a narrow retrospective focus centred on striving towards and hoping for a return to pre-injury identity was considered to protect against loss of self in the short-term but be aligned to denial of change that may hinder post-injury identity reconstruction.

Continuity amid change. An overlapping but distinct theme, recognising continuity of selfhood, emerged as a key means of reconstructing a sense of self coherent with one's pre-injury self. Participants highlighted continuity in their pre- and post-injury interests, activities and lifestyles for example their occupational roles ("The jewellery course I'm doing [is] an extension of my trade as a Fitter and Turner; I'm working with metal still. So it's great"; Jones & Curtin, 2011, p.1573). In this way, participants constructed coherent self-stories in which the present was seen as a continuation of the past or "just another chapter" (Parsons & Stanley, 2008, p. 234).

For other participants, the process comprised recognition of a more fundamental sense of continuity of internal characteristics and how the self is experienced ("I haven't undergone extreme personality change... I feel the same as I've always been"; Crisp, 1993, p. 399). Participants described a stable inner core or essence that was experienced as unchanged *despite* significant changes in their functioning, social roles, and the way others perceived them ("I have changed in other people's eyes for sure, 'cause every time my mom sees me she cries. Yeah. But I still feel like the same person"; Gelech & Desjardins, 2011, p. 68-69). Other narratives indicated that participants recognised continuity of the self *because of* change, with one participant describing the process of discovering her core self when other superficial elements of the self were stripped away:

> And I discovered that...who I was as a core person wasn't lost and wasn't damaged. And that was really an amazing discovery to come too. So then I would look at moments like that and say, 'I couldn't have achieved this level of discovery without having lost everything that was a part of my self-definition'. (Price-Lackey & Cashman, 1996, p. 311)

In a number of narratives, the process of recognising continuity of self relates to a realisation that in order to meet the challenge of the brain injury, survivors have drawn on their pre-injury characteristics, such as determination or sense of humour ("One thing that I did not lose when I received the head injury is [...] my sense of humor. If I had lost my sense of humor, having to go through these traumatic experiences probably would have been impossible"; Roscigno & Van Liew, 2008, p. 215).

It is worth emphasising that the process of recognising continuity in selfhood is distinct from the process of 'recovering self'. In particular, recognition of continuity does not require a return to pre-injury self, hope of recovery in the future, or denial of change/loss/deficit. Instead there is more flexible recognition of elements of continuity amid change, thus this process accommodates change in a way that the process of recovering self cannot.

Acceptance and letting go. Alongside narratives about recovering pre-injury self and recognising continuity of the self, a well-represented theme within the studies related to the need to 'let go' of the old self and 'accept' change and loss in order to move forward and reconstruct a positive sense of identity in the present. In particular, narratives spoke to the idea that rigidly holding on to past identity hindered the development of a positive identity in the present ("Keeping your hand clenched on the past doesn't let you accept anything new"; Padilla, 2003, p. 419). Letting go and acceptance of loss and change were seen as necessary to developing an openness to new experiences upon which to build a positive sense of identity in the present:

> [I]f I was going to assume that I was going to be back playing soccer or whatever, I would never have taken up Tai Chi… [...] But you have to lay those things to rest, before you get started on the new things. (Klinger, 2005, p. 12)

In several narratives, grieving for the loss of past selves was highlighted as a necessary stage of acceptance. One participant explicitly used the metaphor of bereavement to make sense of the acceptance process:

> I started thinking about my creative process as being like a husband who died and ... if I was ever going to move on with my life ... I had to be open to new relationships... I could grieve and let go and accept a new relationship. (Price-Lackey & Cashman, 1996; p. 312)

Like grieving the loss of loved one, several narratives indicated that acceptance was a gradual process ("Maybe I needed this time to go by so I could finally be ready to let go"; Padilla, 2003, p. 419).

Perhaps unsurprisingly, given its intrinsic link to loss, acceptance was described as a difficult process ("But it's hard to lay all those things to rest because that is what you've been doing your whole life"; Klinger, 2005, p. 12). There was some ambivalence around the process of acceptance ("I know it's impossible to get back to the way I was. I often dream about it. I'm trying to. Then again, the world has opened up more to me. Things I know now I didn't then. I'm more independent"; Crisp, 1993, p. 398). For some participants acceptance was seen as "giving up" on returning to one's pre-injury self ("I should understand that I've got this injury and that I will never be normal again, but on the other hand it's difficult for me to think in that way; it is like giving up"; Jumisko et al., 2005, p. 46).

For some participants acceptance was a balance between accepting loss and trying to retain parts of one's pre-injury identity, as captured within one participant narrative:

> And I guess the real key was trying to deal with the fact that okay that old self was, I don't know, almost put it to rest and leave it behind, and you have to start a whole new person. So that doesn't happen overnight that's for sure, that takes some time… And you're struggling to get a new identity or at least retain what's left of the old one. And kind of adapt it. (Klinger, 2005, p. 12)

Personal growth and meaning-making. Several studies presented findings relating to a sense of personal growth experienced by participants as a result of the injury. This theme had several facets to it. A number of participants highlighted that although much had been lost, the injury had contributed positively to their lives and contributed to positive change in the self, often negatively evaluating aspects of their pre-injury life and personal characteristics ("[The accident] did me a favour [...] I was the most important thing on this planet, I wasn't a very nice person. Some people say I'm better now [...]"; Glover, 2003, p. 755).Within these narratives, a sense of meaning or purpose was attributed to the accident such that it was seen as part of a coherent life-story ("The motor bike accident fitted in well with me trying to put my life back together"; Jones & Curtin, 2011, p. 1573).

Within several narratives, personal growth was linked to reflection and reassessment of one's values and increased clarity over what is important ("The most important things in life, things that really matter, I think the head injury has made me realise what they actually are. And they should be worked on. The other stuff shouldn't be bothered with"; Roundhill et al., 2007, p. 250). In particular, several narratives spoke to the idea that the injury and associated losses (particularly in aspects of the social self) facilitated a separating of one's own values and priorities from those of wider society which were often seen as superficial or materialistic ("A person's world maybe revolves too much around financial and having. That can happen too. And, you know, it's easy to get involved in that"; Gelech & Desjardins, 2011; p. 70). As such the identity constructed was seen as being based on core values rather than societal norms. As one participant expressed it, "Being in my position you tend not to follow the crowd" (Crisp, 1993, p. 397).

Personal growth was frequently linked to moral growth, which centred on an increased appreciation of other people ("I'm glad I had my accident because it's made me into a better person. It’s made me help people. If I see a lady across the road with shopping I will run over and help her”; Douglas, 2013, p. 68) and especially of difference and disability (“Now when I see someone walking down the street, I don’t necessarily think they’re retarded, I have a lot more tolerance and a lot more appreciation for somebody that might look a little different; what they might have been through”; Klinger, 2005, p. 12).

In these ways, participants reconstructed a sense of self associated with personal and moral growth, rather than loss, and were able to draw positive meaning from their experiences (“I think I’ve developed a lot because of my suffering. I’ve got more from it I think. ...so, there is more good than bad”; Jumisko et al., 2005, p. 47).

Discussion

Summary of findings. The present synthesis presented a number of themes relating to processes of identity change, loss and reconstruction following TBI. The studies reviewed were all cross-sectional so it is not possible to know how these processes occur across time. However, although by no means suggesting a linear stage model, it is possible to propose a temporal sequence with different processes typically occurring at different stages post-injury and some processes providing the building blocks for others. *Loss of self-knowledge* was associated within the studies with the early post-injury phase when survivors had not made clear appraisals of what had been changed or lost. Increased awareness of these changes and losses was typically described as occurring around time of return to pre-injury environments and roles, through the process of comparing pre-injury self-image with current self-image (*Experiences of personal and social discrepancy*), and through comparison of self to peers and societal norms (*Lack of legitimate social roles and unmet milestones*). The responses of other people on return to pre-injury environments, particularly those which contradicted their image of their identity as stable and intact (*Discrepancies between self-experiences and discourses and practices of others*) and denied their personhood (*Discourses and practices that deny personhood*), also contributed to appraisals of identity as changed and diminished. While these processes were experienced as having a negative impact on identity experiences, it is likely that some increased awareness of changes and loss is a necessary pre-requisite for adaptive identity reconstruction.

Indeed the themes relating to adaptive reconstruction suggest that while at earlier stages post-injury, survivors may focus on striving to recover their pre-injury self (*Recovering self*), some participants later express this to be an unhelpful strategy associated with denial and propose adaptive strategies to be more flexible recognition of continuity of selfhood

(*Continuity amid change*) and acceptance of change and loss (*Acceptance and letting go*). *Personal growth and meaning making* was associated with later stages post-injury when survivors had an awareness of both what had been lost and what had been gained.

Limitations of the synthesis. The limitations of this synthesis relate in part to decisions made regarding study inclusion. The decision to include studies whose focus was not the processes of identity change and reconstruction but contained relevant data made it more difficult to locate papers containing relevant findings because potentially relevant material could be contained within any qualitative study of TBI. It is likely that some papers containing relevant material, but with a different focus, will have been missed.

Furthermore, the inclusion of studies with a different focus to that of the synthesis introduced some uncertainty regarding how well the issues of identity change and reconstruction were covered within those studies. Indeed, as mentioned, several included studies did not contain sustained exploration of themes relating to identity. This factor also impacted on the degree of interpretation required by the researcher. This could be considered to be a more general limitation of syntheses of qualitative research, which are an interpretation of an interpretation. These limitations notwithstanding, the inclusion of studies with a different focus to the synthesis was considered justifiable in order to integrate information dispersed across the qualitative literature. Review of the findings extracted from the contributing studies and discussions of the emerging themes and their inter-relationships with the study supervisor supported the process of grounding themes in the data.

A further limitation relates to the process of critical appraisal of study quality. As no studies were independently rated by a second reviewer, it was not possible to provide inter-rater reliability data on study quality, which would increase confidence in the reported quality appraisal.

The synthesis would have been expanded by the inclusion of findings from studies comprising mixed ABI samples including participants with TBI. Indeed, the researcher is aware of studies containing findings relevant to the processes reviewed which included mixed samples but were excluded (e.g. Gracey et al., 2008; Medved & Brockmeier, 2008). However, given the large number of studies included, the addition of further studies is likely to have resulted in an unmanageably large dataset to synthesise, which in turn could impact negatively on the depth of analysis (Finfgeld, 2003). Similarly, the inclusion of data from sources other than peer-reviewed journal articles could have expanded the present review but were not included for similar reasons.

Wider implications. The present synthesis indicated that there is a large body of research on survivors' experiences post-TBI, a conclusion also drawn by Levack et al. (2010) in their metasynthesis of experiences and outcomes following TBI. However, there are fewer qualitative studies which directly target the processes contributing to appraisals of identity change and reconstruction. With regards to identity change/loss, while a number of studies report findings on the *content* of appraisals of identity change and loss (i.e. data indicating that participants experience identity change/loss), fewer studies explore the *processes* which contribute to this. With regards to identity reconstruction, although a number of studies contained relevant data, it was the focus of few studies, therefore sustained detailed investigation of the processes contributing to identity reconstruction was lacking. Given the clinical implications of post-injury identity for well-being, further sustained investigation of these issues would be valuable to inform clinical practice.

Despite these limitations within the data, the present review indicated that a number of processes have been identified as contributing to post-injury identity experiences. These include both intrapersonal and interpersonal processes as well as wider systems and practices.

Understanding these processes may help rehabilitation services guide survivors and their families more effectively through experiences of identity change and loss, avoiding undue distress and inadvertently contributing to negative post-injury experiences, to achieve more positive outcomes. In particular, the review suggests that using the broad language of “identity/personality change” within rehabilitation, may be less helpful and more disempowering for survivors than identifying specific impairments in cognitive, emotional and social functioning. In addition, the review suggests that useful goals for rehabilitation or psychotherapy post-injury are likely to include supporting individuals to redefine and accept their post-injury identity, as well as to integrate aspects of their pre- and post-injury identity and find meaning in the occurrence and consequences of their injury. The review also highlighted the importance of supporting survivors to develop and access meaningful social roles on which to reconstruct an adaptive and purposeful sense of identity post-injury.

A number of themes within the synthesis relate to the processes by which others, including family members, can contribute to narratives of identity loss and change following TBI. This finding speaks to the value of a joint understanding and reconstruction of experiences between survivors and significant others. Arguably then, it is of value to examine the experiences of personhood and relationship contained within the narratives of significant others in the survivor’s life, which is the focus of the empirical chapter which follows.

References

Ben-Yishay, Y. (2008). Foreword. *Neuropsychological Rehabilitation, 18*, 513-521. doi:10.1080/09602010802141525

Biderman, D., Daniels-Zide, E., Reyes, A., & Marks, B. (2006). Ego-identity: Can it be reconstituted after a brain injury? *International Journal of Psychology*, *41*, 355-361. doi:10.1080/00207590500345963

Cantor, J., Ashman, T., Schwartz, M., Gordon, W., Hibbard, M., Brown, M., … Cheng, Z. (2005). The role of self-discrepancy theory in understanding post-traumatic brain injury affective disorders: A pilot study. *Journal of Head Trauma Rehabilitation*, *20,* 527-543. doi:10.1097/00001199-200511000-00005

Carroll, C., Booth, A., & Lloyd-Jones, M. (2012). Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qualitative Health Research*, *22*, 1425-1434. doi:10.1177/1049732312452937

Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*, *21*, 289-305. doi:10.1080/09602011.2011.555972

Chamberlain, D. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*, *54*, 407-417. doi:10.1111/j.1365-2648.2006.03840.x

Cloute, K., Mitchell, A., & Yates, P. (2008). Traumatic brain injury and the construction of identity: A discursive approach. *Neuropsychological Rehabilitation, 18,* 651-670. doi:http:10.1080/09602010701306989

Coetzer, R. (2008). Holistic neuro-rehabilitation in the community: Is identity a key issue? *Neuropsychological Rehabilitation*, *18*, 766-783. doi:10.1080/09602010701860266

Collicutt McGrath, J., & Linley, P. (2006). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury, 20,* 767-73. doi:10.1080/02699050600664566

Conneeley, A. (2002). Social integration following traumatic brain injury and rehabilitation. *Journal of Occupational Therapy*, *65*, 356-362.

Conneeley, A. L. (2012). Transitions and brain injury: A qualitative study exploring the journey of people with traumatic brain injury. *Brain Impairment*, *13*(Special Issue 01), 72-84. doi:10.1017/BrImp.2012.3

Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study. *Disability, Handicap & Society, 8,* 393-404. doi:10.1080/02674649366780371

Dewar, B. K., & Gracey, F. (2007). ‘Am not was’: Cognitive-behavioral therapy for adjustment and identity change following herpes simplex encephalitis. *Neuropsychological Rehabilitation, 17,* 602-620. doi:10.1080/09602010601051610

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., … Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, *6,* 27-44. doi:10.1177/1468794106058867

Dixon-Woods, M., Booth, A., & Sutton, A. (2007). Synthesizing qualitative research: A review of published reports. *Qualitative Research*, *7,* 375-422. doi:10.1177/1468794107078517

Douglas, J. M. (2013). Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury, 27,* 60-74. doi:10.3109/02699052.2012.722254

Evidence for Policy and Practice Information and Co-ordinating Centre, Social Science Research Unit, Institute of Education, University of London. (2010). *EPPI-Centre Methods for Conducting Systematic Reviews.* Retrieved from http://eppi.ioe.ac.uk/cms/

Finfgeld, D. L. (2003). Metasynthesis: the state of the art--so far. *Qualitative Health Research*, *13*, 893-904. doi:10.1177/1049732303253462

Flemming, K., & Briggs, M. (2007). Electronic searching to locate qualitative research: evaluation of three strategies. *Journal of Advanced Nursing*, *57*, 95-100. doi:10.1111/j.1365-2648.2006.04083.x

Gelech, J., & Desjardins, M. (2011). I am many: The reconstruction of self following acquired brain injury. *Qualitative Health Research*, *21*, 62-74. doi:10.1177/1049732310377454

Glover, A. (2003). An exploration of the extent to which attending Headway enhances quality of life after traumatic brain injury. *Disability & Rehabilitation*, *25*, 750-760. doi:10.1080/0963828021000058503

Gracey, F., Evans, J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A ‘Y-shaped’ model. *Neuropsychological Rehabilitation*, *19*, 867-890. doi:10.1080/09602010903027763

Gracey, F., & Ownsworth, T. (2008). Editorial. *Neuropsychological Rehabilitation*, *18*, 522-526. doi:10.1080/09602010802141509

Gracey, F., & Ownsworth, T. (2012). The experience of self in the world: The personal and social contexts of identity change after brain injury. In J. Jetten, C. Haslam, & S. A. Haslam [Eds.]. *The social cure: identity, health and well-being* (pp. 273-295). Sussex: Psychology Press.

Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O'Dell, J., ... & Mohamed, S. (2008). “Feeling part of things”: Personal construction of self after brain injury. *Neuropsychological Rehabilitation, 18*, 627-650. doi:10.1080/09602010802041238

Gutman, S., & Napier-Klemic, J. (1996). The experience of head injury on the impairment of gender identity and gender role. *American Journal of Occupational Therapy, 50,* 535-544. doi:10.5014/ajot.50.7.535

Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments’ ability to assess validity in qualitative research. *Qualitative Health Research, 20,* 1736-1743. doi:10.1177/1049732310378656

Hannes, K., & Macaitis, K. (2012). A move to more systematic and transparent approaches in qualitative evidence synthesis: Update on a review of published papers. *Qualitative Research, 12,* 402-442. doi:10.1177/1468794111432992

Hawley, C. A., & Joseph, S. (2008). Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury, 22,* 427-435. doi:10.1080/02699050802064607

Heller, W., Levin, R. L., Mukherjee, D., & Reis, J. P. (2006). Characters in contexts: Identity and personality processes that influence individual and family adjustment to brain injury. *The Journal of Rehabilitation, 72,* 44-49.

Hoogerdijk, B., Runge, U., & Haugboelle, J. (2011). The adaptation process after traumatic brain injury An individual and ongoing occupational struggle to gain a new identity. *Scandinavian Journal of Occupational Therapy, 18,* 122-132. doi:10.3109/11038121003645985

Howes, H., Benton, D., & Edwards, S. (2005). Women’s experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health, 20,* 129-142. doi:10.1080/0887044042000272903

Jones, J., & Curtin, M. (2011). Reformulating masculinity: Traumatic brain injury and the gendered nature of care and domestic roles. *Disability & Rehabilitation, 33,* 1568-1578. doi:10.3109/09638288.2010.537803

Jones, J. M., Haslam, S. A., Jetten, J., Williams, W. H., Morris, R., & Saroyan, S. (2011). That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychology & Health, 26,* 353-369. doi:10.1080/08870440903440699

Jumisko, E., Lexell, J., & Söderberg, S. (2005). The meaning of living with traumatic brain injury in people with moderate or severe traumatic brain injury. *Journal of Neuroscience Nursing, 37,* 42-50. doi:10.1097/01376517-200502000-00007

Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, *12*, 9-16. doi:10.1080/14427591.2005.9686543

Kovarsky, D., Shaw, A., & Adingono-Smith, M. (2007). The construction of identity during group therapy among adults with traumatic brain injury. *Communication & Medicine, 4*, 53–66. doi:10.1515/CAM.2007.029

Krefting, L. (1989). Reintegration into the community after head injury: The results of an ethnographic study. *Occupational Therapy Journal of Research, 9*, 67-83.

Landau, J., & Hissett, J. (2008). Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health, 26*, 69-85. doi:10.1037/1091-7527.26.1.69

Lawson, S., Delamere, F., & Hutchinson, S. (2008). A personal narrative of involvement in post-traumatic brain injury rehabilitation: What can we learn for therapeutic recreation practice? *Therapeutic Recreation Journal, 42*, 236-250.

Levack, W., Kayes, N., & Fadyl, J. (2010). Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disability & Rehabilitation*, *32*, 986-999. doi:10.3109/09638281003775394

Major, C. H., & Savin-Baden, M. (2011). Integration of qualitative evidence: Towards construction of academic knowledge in social science and professional fields. *Qualitative Research*, *11*, 645-663. doi:10.1177/1468794111413367

Mays, N., Pope, C., & Popay, J. (2005). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research & Policy*, *10*(Suppl 1), 6-20. doi:10.1258/1355819054308576

Medved, M. I., & Brockmeier, J. (2008). Continuity amid chaos: Neurotrauma, loss of memory, and sense of self. *Qualitative Health Research*, *18*, 469-479. doi:10.1177/1049732308315731

Moldover, J. E., Goldberg, K. B., & Prout, M. F. (2004). Depression after traumatic brain injury: A review of evidence for clinical heterogeneity. *Neuropsychology Review*, *14*, 143-154. doi:10.1023/B:NERV.0000048181.46159.61

Morris, S. (2004). Rebuilding identity through narrative following traumatic brain injury. *Journal of Cognitive Rehabilitation*, *22*, 15-21.

Muenchenberger, H., Kendall, E., & Neal, R. (2008). Identity transition following traumatic brain injury: A dynamic process of contraction, expansion and tentative balance. *Brain Injury*, *22*, 979-992. doi:10.1080/02699050802530532

Newton, B. J., Rothlingova, Z., Gutteridge, R., LeMarchand, K., & Raphael, J. H. (2012). No room for reflexivity? Critical reflections following a systematic review of qualitative research. *Journal of Health Psychology*, *17*, 866-885. doi:10.1177/1359105311427615

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies*. California: SAGE.

Nochi, M. (1997). Dealing with the ‘Void’: Traumatic brain injury as a story. *Disability & Society, 12,* 533-555. doi:10.1080/09687599727119

Nochi, M. (1998a). ‘Loss of self’ in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine*, *46*, 869-878. doi:10.1016/S0277-9536(97)00211-6

Nochi, M. (1998b). Struggling with the labeled self: People with traumatic brain injuries in social settings. *Qualitative Health Research, 8*, 665-681. doi:10.1177/104973239800800507

Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science & Medicine*, *51*, 1795-1804. doi:10.1016/S0277-9536(00)00111-8

O’Callaghan, C., Powell, T., & Oyebode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation*, *16*, 579-593. doi:10.1080/09602010500368834

Ownsworth, T., & Fleming, J. (2011). Growth through loss after brain injury. *Brain Impairment*, *12*, 79-81. doi:10.1375/brim.12.2.79

Padilla, R. (2003). Clara: A phenomenology of disability. *The American Journal of Occupational Therapy, 57*, 413-423. doi:10.5014/ajot.57.4.413

Parsons, L., & Stanley, M. (2008). The lived experience of occupational adaptation following acquired brain injury for people living in a rural area. *Australian Occupational Therapy Journal*, *55,* 231-238. doi:10.1111/j.1440-1630.2008.00753.x

Petrella, L., McColl, M., Krupa, T., & Johnston, J. (2005). Returning to productive activities: Perspectives of individuals with long-standing acquired brain injuries. *Brain Injury, 19*, 643-55. doi:10.1080/02699050410001671874

Pope, C., Mays, N., & Popay, J. (2007). *Synthesizing qualitative and quantitative health research: A guide to methods*. Maidenhead: McGraw Hill & Open University Press.

Powell, T., Ekin-Wood, A., & Collin, C. (2007). Post-traumatic growth after head injury: A long-term follow-up. *Brain Injury*, *21*, 31-38. doi:10.1080/02699050601106245

Powell, T., Gilson, R., & Collin, C. (2012). TBI 13 years on: factors associated with post-traumatic growth. *Disability & Rehabilitation*, *34*, 1461-1467. doi:10.3109/09638288.2011.644384

Price-Lackey, P., & Cashman, J. (1996). Jenny's story: Reinventing oneself through occupation and narrative configuration. *Journal of Occupational Therapy*, *50*, 306-314. doi:10.5014/ajot.50.4.306

Ring, N., Ritchie, K., Mandava, L., & Jepson, R. (2010). *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews.* Retrieved from http://www.healthcareimprovementscotland.org/our_work/clinical__cost_effectiveness/programme_resources/synthesising_research.aspx

Roscigno, C., & Van Liew, K. (2008). Pushed to the margins and pushing back: A case study of one adult's reflections on social interactions after a traumatic brain injury sustained as an adolescent. *Journal of Neuroscience Nursing, 40*, 212-21. doi:10.1097/01376517-200808000-00005

Roundhill, S., Williams, W., & Hughes, J. (2007). The experience of loss following traumatic brain injury: Applying a bereavement model to the process of adjustment. *Qualitative Research in Psychology, 4*, 241-257. doi:10.1080/14780880701473540

Sabat, A., Moodley, L., & Kathard, H. (2006). Identity construction following traumatic brain injury: A case study. *South African Journal of Communication Disorders, 53,* 17-26.

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research, 14*, 1366-1386. doi:10.1177/1049732304269672

Sandelowski, M., & Barroso, J. (2007). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.

Segal, D. (2010). Exploring the importance of identity following acquired brain injury: A review of the literature. *International Journal of Child, Youth and Family Studies, 1*, 293-314.

Shotton, L., Simpson, J., & Smith, M. (2007). The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: A qualitative investigation. *Brain Injury, 21*, 857-869. doi:10.1080/02699050701481621

Silva, J., Ownsworth, T., Shields, C., & Fleming, J. (2011). Enhanced appreciation of life following acquired brain injury: Posttraumatic growth at 6 months post-discharge. *Brain Impairment, 12*, 93-104. doi:10.1375/brim.12.2.93

Soeker, M. (2011). Occupational adaptation: A return to work perspective of persons with mild to moderate brain injury in South Africa. *Journal of Occupational Science*, 81-91. doi:10.1080/14427591.2011.554155

Spencer, L. (2003). Quality in qualitative evaluation: A framework for assessing research evidence : a quality framework.

Strandberg, T. (2009). Adults with acquired traumatic brain injury: Experiences of a changeover process and consequences in everyday life. *Social Work in Health Care*, *48*, 276-297. doi:10.1080/00981380802599240

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 45. doi:10.1186/1471-2288-8-45

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qualitative health research*, *14*, 1342-1365. doi:10.1177/1049732304269888

Tyerman, A., & Humphrey, M. (1984). Changes in self-concept following severe head injury. *Journal of Rehabilitation Research*, *7*, 11-23. doi:10.1097/00004356-198403000-00002

Vickery, C., Gontkovsky, S., & Caroselli, J. (2005). Self-concept and quality of life following acquired brain injury: A pilot investigation. *Brain Injury*, *19*, 657-665. doi:10.1080/02699050400005218

Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method.* Maidenhead: McGraw Hill & Open University Press.

Wright, J. C., & Telford, R. (1996). Psychological problems following minor head injury: A prospective study. *The British Journal of Clinical Psychology*, *35*, 399-412. doi:10.1111/j.2044-8260.1996.tb01194.x

Yeates, G. N., Gracey, F., & Collicutt Mcgrath, J. C. (2008). A biopsychosocial deconstruction of ‘personality change’ following acquired brain injury. *Neuropsychological Rehabilitation*, *18*, 566-589. doi:10.1080/09602010802151532

Ylvisaker, M., McPherson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping: Facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychological Rehabilitation, 18*, 713-741. doi:10.1080/09602010802201832

Chapter Two

Experiences of Couplehood and Continuity after Acquired Brain Injury: An Interpretative Phenomenological Analysis

Background. Within the dementia literature, it has been suggested that spouses differ in terms of whether they see their relationship as continuous with the premorbid relationship or radically different, and that perceptions of continuity may be associated with more positive responses to caregiving and more person-centred care. The aim of this qualitative study was to explore spouses' experiences of their relationship and caregiving following acquired brain injury and to consider the relevance of the concept of relationship continuity in understanding their post-injury relationship and caregiving experiences.

Method. Six spouses of people with acquired brain injury were interviewed regarding their experiences of their relationship and of caregiving. Transcripts were analysed using interpretative phenomenological analysis.

Findings. Three overarching themes are presented: participants' sense of continuity with the past was suggested to influence their post-injury experiences of their spouse; relationship; and caregiving role.

Conclusions. Broadly, experiences of relationship continuity were associated with a better sense of adjustment and more person-centred approaches to caregiving.

Keywords: *Brain injury, caregivers, spousal relationships, adjustment, qualitative research*

Introduction

Following acquired brain injury (ABI)[4], family becomes the primary support system for many individuals in the long-term (Gan & Schuller, 2002). It is generally accepted within the ABI literature that family relationships are important for the well-being (Kendall & Terry, 2009; Palmer & Glass, 2003) and rehabilitation outcomes (Clark & Smith, 1999; Evans et al., 1987; Sander et al., 2002) of individuals following ABI, as well as the well-being of the uninjured spouse (Anderson, Parmenter, & Mok, 2002; Epstein-Lubow, Beevers, Bishop, & Miller, 2009). Alongside this research, there is a substantial body of evidence which reports that ABI places a strain on the very family relationships which are central to the well-being of both parties. Decades of research have reported significant burden and distress for families (Brooks, Campsie, Symington, & Beattie, 1987; Gillen, Tennen, Affleck, & Steinpreis, 1998; Kreutzer et al., 2009; Rigby, Gubitz, & Phillips, 2009; Rivera, Elliott, Berry, Grant, & Oswald, 2007; Rosenbaum & Najenson, 1976) and elevated rates of unhealthy family functioning (Gan, Campbell, Gemeinhardt, & McFadden, 2006; Gan & Schuller, 2002; Schönberger, Ponsford, Olver, & Ponsford, 2010).

Spousal[5] relationships appear to be placed under particular strain. Early studies reported high rates of marital breakdown following ABI (Tate, Lulham, Broe, Strettles, & Pfaff, 1989; Thomsen, 1974) although more recent, larger *N* studies report rates of separation and divorce comparable with the general population (Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007). However, although couples appear to be staying together, the literature consistently reports lower levels of marital quality or satisfaction (Blais & Boisvert, 2005; Burridge, Williams, Yates, Harris, & Ward, 2007; Godwin, Kreutzer, Arango-Lasprilla, &

---

[4] The author is using the UK definition of ABI: a non-degenerative injury to the brain occurring since birth. The term includes traumatic brain injuries caused by an external physical force as well as non-traumatic injuries such as strokes and other vascular accidents, hypoxia, infections, and tumours (The United Kingdom Brain Injury Forum).

[5] The term “spouse” is used to refer to both those formally married and those living as partners.

Lehan, 2011; Gosling & Oddy, 1999; Peters, Stambrook, Moore, & Esses, 1990; Peters et al., 1992; Ponsford, 2003), as well as reduced life satisfaction for couples (Eriksson, Tham, & Fugl-Meyer, 2005; Forsberg-Wärleby, Möller, & Blomstrand, 2004; Ostwald, 2008) following ABI.

Given that relationships are fundamentally important for the well-being of both parties and the strain that ABI can place on those relationships, it is important to understand what happens to relationships following ABI. The majority of the literature has focused on characteristics of the injury or injured spouse that predict relationship breakdown (Arango-Lasprilla et al., 2008; Kreutzer et al., 2007; Wood & Yurdakul, 1997) or relationship satisfaction (Moore, Stambrook, & Peters, 1993; Moore, Stambrook, Peters, & Lubusko, 1991; Peters et al., 1990; Peters et al., 1992; Wood, Liossi, & Wood, 2005) using correlational design. However, these studies have reported contradictory findings for the impact of factors such as injury severity, age, gender and ethnicity on outcome. While there is some agreement that neurobehavioural characteristics of the injured spouse are associated with marital strain and breakdown, there is variation in which behaviours spouses experience as particularly problematic (Wood et al., 2005).

These findings suggest that it is not only the objective characteristics of the situation that are important but also spouses' perceptions of that situation. Support for this idea comes from studies which have shown that family schemas (specifically those relating to manageability and meaningfulness) are linked to family adaptation (Kosciulek, 1997) and positive reappraisal is linked to marital satisfaction and partner adjustment (Blais & Boisvert, 2007) following brain injury.

Of particular interest to the present study is research indicating that spouses' perceptions of their relationship are associated with marital and life satisfaction post-ABI. In the recent stroke literature, perceived reciprocity, measured using the Caregiver Reciprocity Scale II (Carruth, Holland, & Larsen, 2000) comprising four domains of reciprocity (warmth and regard, intrinsic rewards of caregiving, love and affection, and balance within caregiving), was reported to be positively correlated with partners' ratings of relationship satisfaction and positive aspects of their caregiving role (McPherson, Wilson, Chyurlia, & Leclerc, 2011). In addition, partners who reported less perceived equity in their relationship (an imbalance of give and take) reported greater negative responses to their caregiving role. In one of the few longitudinal studies, Ostwald and colleagues (Ostwald, Godwin, & Cron, 2009) reported that of several physical and psychosocial variables measured, only mutuality (measured at 12 months post-stroke, using a 15-item scale which assesses whether the relationship is characterised by love, shared pleasurable activities, common values and reciprocity; Archbold, Stewart, Greenlick, & Harvath, 1990) was predictive of life satisfaction in both stroke survivors and their spouses at 24 months post-stroke.

Another strand of the research on the role of perceptions of one's relationship in partner adjustment to brain damage, which has been developing within the recent dementia literature, relates to the concept of relationship continuity-discontinuity (Riley et al., 2013; Walters, Oyebode, & Riley, 2010). The concept refers to whether the spouse experiences the relationship as "a continuation of the premorbid relationship", or as "essentially changed and radically different". While all people and relationships undergo change following brain damage, it is whether that change is seen as essential and fundamental that distinguishes experiences of continuity from discontinuity (Riley et al., 2013, p. 264). Based on qualitative research, a quantitative questionnaire measure of relationship continuity was developed proposing five dimensions of relationship continuity: *relationship redefined* (whether the relationship is viewed as a continuation of the premorbid relationship or completely finished and redefined by caregiving); *same/different person* (whether the person is still seen as fundamentally the same despite dementia-related changes or as having changed in an essential way); *same/different feelings* (whether there is continuing love and affection or feelings have changed from love to protection and emotional detachment); *couplehood* (whether there is continued identity as part of a couple or the spouse views themselves in an individualistic way); *loss* (relating to the sense of loss for premorbid person and relationship experienced by those spouses experiencing discontinuity but not those experiencing continuity; Riley et al., 2013).

The qualitative dementia literature indicates that experiences of continuity-discontinuity have implications for spouses' response to caregiving and the quality of care they provide. While continuity is associated with a sense of positive meaning from caring and person-centred care, discontinuity is associated with resentment and more depersonalised and controlling care (Riley et al., 2013; Walters et al., 2010).

The concept of continuity-discontinuity appears to be highly relevant in the context of ABI, having appeared in various guises in the ABI literature for several decades, particularly in relation to perceived discontinuity of *person* following ABI. Early work by Lezak (1978) emphasised the impact on spouses of "characterological" changes in individuals with traumatic brain injury (TBI) and several researchers have reported that "personality" changes appear to present the greatest difficulty for families (Brooks & McKinlay, 1983; Florian, Katz, & Lahav, 1989; Kreutzer, Gervasio, & Camplair, 1994; Willer, Allen, Liss, & Zicht, 1991; Yeates, Gracey, & Collicutt Mcgrath, 2008). In a survey of family reactions to ABI, Mauss-Clum and Ryan (1981) reported that nearly half of the wives surveyed identified with the statement "I'm married but don't have a husband" and a third identified with the statement "I'm married to a stranger" (p. 168). Gosling and Oddy (1999) similarly reported that over half of partners of people with TBI endorsed the questionnaire item, “My partner has felt like a stranger to me since the injury” (p. 789). The concept of the injured spouse as a “stranger” is also common in anecdotal accounts of partner experiences following ABI (Wood, 2005, p. 138; Oddy, 1995, p. 173).

Furthermore, resonating with the findings on continuity-discontinuity in the dementia literature, Oddy (1995) proposed that relatives’ perception of personality change following TBI varies according to not only “objective” change in the person but also the extent to which relatives focus on change rather than aspects of the person that remain familiar. He suggested that if those characteristics for which the relative had the most affection are preserved, the perception of change is likely to be less (p. 173). Oddy (1995) further suggested that the extent to which relatives emphasise continuities or discontinuities in personality is likely to affect their coping. While highlighting the clinical relevance of the concept of continuity-discontinuity in an ABI context, Oddy’s (1995) account is based on clinical experience, rather than empirical evidence.

It is not only the concept of continuity of *person* but continuity of *relationship* that appears relevant in an ABI context. In a survey study of spouses of people with TBI who remained in the marital relationship a minimum of two years post-injury, the authors reported that couples who stayed together tended to focus on continuing aspects of their relationship together including longevity of their relationship; longstanding friendship and affection; and alliance against a mutual problem (Anderson-Parenté, DeCesare, & Parenté, 1990). In their mixed methods study of partners of people with TBI, Gosling and Oddy (1999) reported qualitative data which suggested that approximately half of the participants reported their relationship to be defined by a parent role; a quarter reported relational change including loss of an equal and sharing relationship and loss of companionship; while half reported continuing commitment, friendship, and mutual affection. Although not explicitly drawing on the concept of continuity-discontinuity, the themes discussed in these studies, as well as those studies cited previously which discuss reciprocity and mutuality (McPherson et al., 2011; Ostwald et al., 2009), overlap with the concept of relationship continuity, particularly with respect to the idea of the maintenance of love, warmth, and affection.

A small number of recent qualitative studies have conducted more detailed exploration of what happens to relationships following ABI, indicating the potential relevance of the concept of continuity-discontinuity. Gill and colleagues (Gill, Sander, Robins, Mazzei, & Struchen, 2011) reported that perception of the injured partner as a different person, and role changes were amongst the barriers to intimate relationships in partners of people with TBI. In contrast, unconditional acceptance of one’s partner; being there; commitment to staying together; and drawing on the pre-injury relationship foundation were experienced as relationship strengths. A second study (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011), which analysed data from two gender-specific focus groups, suggested that changes in relationship dynamics following TBI affect movement towards “pulling together” or “pulling apart” (p. 75). In particular, suggesting gender-specific responses, they reported that husbands described continued love in the present while wives described hope of the return of the pre-injury person; husbands accepted the present while wives expressed a sense of loss for the past; husbands described coping by sharing physical space while wives described getting away and coping alone. Husbands also expressed a less blaming approach to increased responsibilities following TBI compared to wives. Although these studies made no explicit reference to the concept of relationship continuity-discontinuity, the themes presented speak to this concept.

Unfortunately, both studies presented a large number of themes with little supporting data or analysis. Furthermore, Hammond et al. (2011) failed to clarify the links between perceptions of relationship dynamics and experiences of caregiving, while Gill et al. (2011) offered no exploration of the impact of perceptions of the relationship on the caregiving experience. Both studies employed a grounded theory approach which focuses on theory building, emphasising the similarities between participant experiences rather than drawing out individual differences.

While these studies indicate that the concept of continuity-discontinuity is likely to have application in ABI, as yet there is a lack of in-depth, well-conducted studies that systematically explore the relevance of continuity-discontinuity in understanding spousal relationships following ABI and spouses' responses to their caring role. Furthermore, none of the previous studies have used a methodology that supports sustained in-depth focus on individual accounts and detailed exploration of similarities and differences across accounts to explore spouses' experiences of their relationship and caregiving role following ABI. Given the potential clinical impact of experiences of continuity-discontinuity on adjustment to caregiving and the quality of care provided, further exploration of the application of the concept in an ABI context was considered clinically relevant.

The aims of the present study were therefore: 1) to explore how spouses of individuals with ABI experience, give meaning to and make sense of their relationships post-injury, with a view at the interpretative stage of considering the relevance and usefulness of the idea of relationship continuity in aiding understanding of these experiences. 2) to explore how spouses perceive and manage their caregiving role, with a view at the interpretative stage of considering any connections between their perceptions of what has happened to the relationship and their response to the caregiving role.

Interpretative phenomenological analysis (IPA; Smith, 1996) was considered a suitable approach for the current study for a number of reasons. IPA is phenomenological in that it is interested in exploring lived experiences of the participant and how they make sense of and give meaning to them (Smith, Flowers, & Larkin, 2009; Smith & Osborne, 2003), which was also the aim of the present study. At the same time, IPA recognises the interpretative role of the researcher such that the analytic account, always jointly produced by the participants and researcher, is not a description of the participants' lived experienced but an interpretation of it influenced by the research orientation the researcher. Smith (2004) described this as a "double hermeneutic" (p. 40) in which the researcher tries to make sense of the participant who is trying to make sense of their personal and social world. An approach which explicitly acknowledges the interpretative role of the researcher was considered necessary given the expressed aim of considering the usefulness of concept of continuity-discontinuity within the study. Finally, IPA's commitment to the ideographic, starting with the individual case moving to drawing out "convergence and divergence" between accounts, rather than theory-building (Smith & Osborne, 2003, p. 57), was also considered well-suited to the study aims.

Method

Ethical considerations. Ethical approval was obtained from the NHS National Research Ethics Service (NRES; See Appendix E). At least a week prior to taking part, participants were provided with written information about the study and discussed questions and concerns with the researcher in order to facilitate informed consent. Written consent was obtained from all participants prior to interviews (See Appendices F and G).

Participants were advised of the potentially distressing nature of discussing their relationship experiences and avenues for debrief were identified if appropriate/requested (this happened once when a participant was signposted to her GP for further support due to distress expressed in the interview). During the interviews the researcher monitored participant distress and took appropriate action (this happened once when a participant was given the option of terminating the interview due to distress, which she opted for).

Researcher. The researcher has not had personal experience of ABI. However, over the course of clinical training (the last three years) she has worked both clinically and academically in the area. She has developed a particular interest in psychosocial understandings of brain injury where outcomes of injury, for both the individual and family, are considered a result not only of neurological impairment, but of cognitive (sense-making) and contextual (particularly relational) processes. Her recent academic readings have centred on the concept of continuity-discontinuity within individual and family perceptions of brain damage. This context undoubtedly affected the research process and findings. However, alongside an acknowledged interpretative component, there was a desire to be true to the experiences of the participants. An effort was made at each stage of the research to maintain an awareness of the impact of the researcher’s own expectations; not to impose her concerns onto the process; and to remain open to participant experiences, as will be discussed within the remainder of the Method section.

Participants and recruitment. As appropriate for the study design, a purposive, broadly homogenous sample of participants who had experience of the phenomenon of interest was recruited (Smith et al. 2009; Smith & Osborne, 2003). Potential participants were identified through an NHS out-patient brain injury service and branches of Headway, a brain injury charity. Potential participants were approached on an opportunity basis and according to their suitability to the phenomena of interest (see inclusion/exclusion criteria below). They were initially approached by clinicians or Headway staff and provided with the written information leaflet. If they expressed an interest in participating, consent was obtained to pass their contact details to the researcher who contacted each of them directly by telephone. For recruitment of participants from Headway, the researcher also attended carer events, providing the written and verbal information about the study. Interested individuals passed their contact details to the researcher who contacted each of them directly by telephone. Of the ten potential participants approached, four declined to take part, two stating they thought it would be too distressing and the remainder not giving a reason.

Inclusion criteria comprised spouses of working age adults who had suffered a moderately severe ABI at least nine months but no more than ten years previously; cohabiting at the time of the injury and currently; and who had been in the pre-injury relationship for a minimum of ten years. The rationale for using a mixed ABI sample is based on research which indicates that psychosocial issues (such as those relating to what happens to relationships following injury) are similar across ABI subgroups, as outlined in the Introduction. This is in keeping with the IPA approach which prioritises meaning rather than medical-model influenced assumptions about diagnosis. The further inclusion criteria were applied to maintain homogeneity. In particular, life-stage was considered likely to influence experiences of ABI, with working age, a time of productivity and involvement in family life, considered uniquely vulnerable to the psychosocial impact of ABI. Time post-injury has been found to impact on experiences of family carers, with empirical research indicating that carer awareness of changes increases over the initial six-month to 12-year period (e.g. Brooks & McKinlay, 1983). A post-injury time-frame of nine months to ten years was considered to balance sufficient time for developing awareness of relational impact while ensuring the pre-injury relationship was still in recent memory.

Exclusion criteria included a current diagnosis of a severe mental health disorder or a learning disability in the caregiving spouse or individual with ABI that predates the injury, as well as being unable to speak English. These restrictions were an attempt to ensure that all participants could reflect meaningfully on their experience of ABI.

Six participants were recruited and interviewed in total. However, one set of interviews was removed due to the participant opting to terminate the second interview before completion due to distress discussing her post-injury relationship. Although the participant gave consent for the remainder of her data to be used, there was not sufficient data regarding her post-injury relationship to undertake meaningful analysis, so the full data set was removed. Of the remaining five participants (four females, one male; age range 51-66; all white Caucasian), four were recruited via the out-patient service and the fifth via Headway. Small samples are advised for the idiographic approach taken by IPA to allow for detailed, in-depth case-by-case analysis which draws out subtleties in the data (Smith et al., 2009; Smith & Osborn, 2003). Given that each participant was interviewed on two occasions, with rich data generated in each interview, it was considered that ten interviews would provide sufficient data for the emergence of convergence and divergence within the data (Smith et al., 2009; Smith & Osborne, 2003). Characteristics of the participants and their spouse with ABI, along with allocated pseudonyms can be found in Table 5. All individuals with ABI were still receiving services for their brain injury a minimum of nine months post-injury, indicative of a moderate-severe ABI.

Table 5

Participant Characteristics

Participants		Spouses with ABI			Relationship	
Pseudonym	Age	Pseudonym	Age	Cause of brain injury	Length of pre-injury relationship	Time post-injury
Frank	66	Wilma	52	TBI – fall	25 years	9 months
Janet	52	Jeff	52	TBI – motorbike accident	34 years	9 months
Joan	55	Matthew	62	Stroke	20 years	10 years
Maureen	51	David	50	TBI – motorbike accident	28 years	3 years
Claire	54	Nick	57	TBI – cycling accident	25 years	2 years

Semi-structured interviews. Each participant was interviewed on two separate occasions approximately a week apart in a place negotiated with them that was private and quiet. Three participants opted to be interviewed in their home, with two participants interviewed at the University. The interviews ranged from 56 to 91 minutes in length (mean=75 minutes).

While an acknowledged aim of the research was to consider the relevance of relationship continuity at the interpretative stage, an effort was made not to impose the researcher's concerns on the interview schedule. The researcher avoided asking any direct questions regarding relationship continuity or the dimensions which are proposed to be part of the construct (outlined in the Introduction). Rather, the schedule explored more broadly participants' experiences of their relationship before and after the brain injury, comprising open questions about the couples' relationship history and aspects of daily and married life before and after the injury such as happy memories, time spent together and coping with difficult times. The first interview explored aspects of the pre-injury relationship, while the second interview focused on the post-injury relationship. On reflection, the researcher considered that splitting the interviews into *pre* and *post* could be interpreted as presupposing a difference in pre- and post-injury relationships, thus inviting participants to make sense of their experiences in this way. See Appendix H for the interview schedule.

Questions were open-ended and employed a narrative style (*Can you tell me about...?)* in order to allow the participant to tell their own story in their own words with minimum prompting in keeping with the participant-centred approach associated with phenomenological interviewing (Smith, Flowers, & Osborn, 1997). Questions and prompts were formulated to facilitate the grounding of responses in particular memories and instances (*Do any memories or incidents come to mind?)* in order to generate rich data on participants' experiences and the meanings attributed to them (Kvale, 1996). In an effort to support the participant to feel at ease and get used to talking, the first interview opened with a question about how the couple met and became a couple which was considered likely to be a well-rehearsed story.

In keeping with IPA, the schedule was a guide. It was used flexibly with the researcher frequently deviating or asking questions in a different order depending on the direction taken by the interview and the interests and concerns of the respondent. This democratic and flexible approach is considered central to IPA which is concerned with entering the psychological world of the participant (Smith, 1995). In keeping with this ethos, at the end of each interview, the researcher asked the participant if there was anything that had not been spoken about that they would like to discuss.

Interviews were audio-recorded and transcribed verbatim, using transcription conventions cited in Smith et al. (2009). The semantic content was transcribed including all words spoken as well as non-verbal utterances, such as pauses and laughter. To protect participant anonymity, all information that could lead to participant identification was removed or changed. After each interview, participants were asked if there was any part of the conversation that they did not want to be used in the study. One participant requested that two short sections were not used, with these sections not transcribed or analysed.

Analysis. The analytic procedures for IPA outlined by Smith and colleagues (Smith et al., 2009) were used as a guide. The interview transcripts for the first case were read several times and comments annotated on the text, starting with descriptive comments moving towards more abstract analytic comments. These were developed into a list of emerging themes by clustering and forming hierarchies so that some themes subsumed others. The researcher found that the use of post-it notes which could be physically moved supported her in developing connections between emerging themes as well as in noting divergence. The process resulted in the production of a master list of themes, with instances from the transcript noted using in vivo terms and line numbers. The researcher continually flipped between the emerging themes and the transcripts. Smith and Osborne (2003) suggest that this close interaction with the text allows the researcher to draw on her own interpretative resources while remaining grounded in the meanings of the participant.

The researcher then moved to the next set of transcripts and repeated this process, with a master list of themes produced for each set of transcripts. The next stage was to look for patterns of convergence and divergence across cases. Again the use of post-it notes and a large space allowed the researcher to physically move themes to form clusters and hierarchies. Themes were modified, re-clustered, and became more nuanced as the analysis proceeded. Throughout the analysis and write up, the researcher continually returned to the transcripts to ensure that the themes and the way they were presented matched the participants’ concerns and meanings. For a sample from an annotated transcript, see Appendix I.

Credibility of the interpretation was checked by discussing emergent themes and how they were derived with the research supervisor who also read all transcripts, with differences resolved during meetings. To aid reflexivity, central to IPA (Smith et al., 2009), the researcher also kept a journal throughout the interview and analysis process recording initial responses, ideas and interpretations. Given the researcher’s acknowledged interest in continuity-discontinuity, she found the reflective journal particularly useful for recording initial interpretations congruent with this concept, as a way of “bracketing” them off to avoid imposing them on the analysis. She also found it useful to record interpretations that were not congruent with the concept. In this way, the journal aided the researcher to suspend the interpretative process and remain engaged with and open to the participants’ concerns, meanings and sense making. The journal also provided a further “audit trail”, contributing to the transparency of the analysis process.

Findings

The themes discussed in this paper can be found in Table 6. The dynamic of continuity-discontinuity emerged as central across participant experiences of person, relationship, and caregiving role.

Table 6

List of Study Themes

Super-ordinate theme	Theme	Subtheme
Dynamics of person	(Dis)continuity of person Depersonalising narratives Loss and grief	
Dynamics of relationship	(Dis)continuity of relationship	Mutuality/reciprocity Togetherness Feelings
	Pre-injury relationship	
Dynamics of caregiving	Making sense of changes in the person Impact of caregiving	

Dynamics of person.

(Dis)continuity of person. This theme describes experiences of change in the known person post-injury. All participants identified post-injury changes in their spouse. However, while some participants experienced their spouse to be so fundamentally changed post-injury that they were considered to be a different person, others retained a sense of their spouse still being the same person despite change. Both a sense of *loss* of who the person was (whether that be the loss of defining pre-injury characteristics or a more general experience of absence of the person) and the *intrusion* of new negatively-perceived characteristics appeared to contribute to participants making sense of their spouse as a different person.

Frank described definitive, categorical change in Wilma post-injury ("I picked Wilma up from the hospital at four-thirty [...] and that was four-thirty and seven-thirty Wilma changed. Her personality changed. All within that three hours"). For Frank the experience of

Wilma being a “different wife” appeared to centre on the perceived loss of her sweet, caring and thoughtful nature which he felt defined her pre-injury (“When you go to the beginning of this tape, you’ll ask what- what- what she was? Well and I think I said, sweet. She’s not anymore”).

Joan similarly experienced Matthew as definitively changed/lost post-injury (“Matthew’s gone. He’s not there [CRYING]. He’s not my Matthew”). The loss of specific characteristics, central to how she experienced Matthew in their pre-injury relationship, contributed to her sense of him being a different person (“[H]e’s just not loving. He’s not exciting”). However, it was also the loss of an intangible but fundamental aspect of Matthew that appeared central to her experience of loss of person (“[H]e’s just lost something. He’s lost his mojo. If mojo’s a word like”). Echoing Joan’s description of Matthew as “gone”, for Maureen it was the sense of complete absence of person post-injury that contributed to her experience of David as “not the man [she] married” (“[T]here’s nothing [PAUSES] [...] His character- there is no character. [...] Empty, I suppose”). She experienced a distance or separation in David (“I call it Dave’s world”), stating, “That’s what makes him different to what he was before”.

For Frank and Joan particularly, their partner’s argumentative and aggressive behaviours post-injury contributed to their experience of them being a different person (“He’s- he’s aggressive, he’s childlike, he’s snarly. He was never a snarly person”, Joan). Joan’s repetition of the word “snarly” perhaps suggests that she experienced the intrusion of negative traits that have a less than human quality, as will be discussed further below.

Despite describing definitive change in person, the narratives of Frank and Joan indicated that they also experienced “glimmers” (Joan) of the old person to varying degrees. However, even within these glimmers, qualitative aspects of their partner’s behaviour appeared to signal change. For example, describing Wilma’s sense of humour, Frank said, “Err she’ll laugh her head off if somebody’s hurt themself. Mind you, she used to do that before anyway but it wasn’t with the same lack of thought that it is now for other people”. By making sense of Wilma’s behaviour with reference to her “lack of thought”, Frank indicated that, while on the surface Wilma’s behaviour may appear the same, he considered the underlying person to be very changed. Similarly, Joan described experiencing glimmers of the old Matthew particularly in the company of others. “[A]nd that’s when you see the old Matthew- when other people are around. He does perform for an audience”. However, her description of Matthew “performing” could suggest that, while reminiscent of the pre-injury person, these current glimmers were experienced as inauthentic: These instances are of particular interest because they suggest that glimmers of the old person are discounted, or cannot be integrated, in the face of what is experienced as fundamental change in the person.

For Maureen, the “traits” of the pre-injury person that she experienced tended to be associated with pre-injury negative characteristics (“[U]nfortunately I can see traits in David now [...] that were there twenty years ago [...] which was, I think, my most unhappiest time [...] where he was- he could be quite selfish [...] you know, spiteful”). However unlike Frank and Joan, she appeared able to integrate these negative traits into her memory of a person she knew and loved:

> I'm not saying I didn’t like him at that time, 'cause obviously I did [...] but, um [PAUSES] I didn’t much like him. [...] I loved him. [...] Um, I suppose it brings it back again [...] you know and I think, “Ooh”, you know, “I don’t like you today”

For the other participants, there was a sense that the identity of their partner remained fundamentally the same as their pre-injury identity. Changes were acknowledged but were assimilated within the old identity and did not threaten it. Claire described continuity of key characteristics in Nick (“Err, well, he's love- very loving [...] and caring and considerate [...] [PAUSES] err, thoughtful”). Even when describing change, Claire made sense of it in ways that allowed her to retain a sense of Nick as the same person. For example, rather than understanding changes as global, she described specific aspects of Nick that had been changed by the accident such as his cognitive functioning (“[H]e’s still got cognitive impairment”) and emotional responses (“but he does cry over things which he wouldn’t have cried about before. [...] So he’s quite an emotional person”). In addition, rather than complete change/absence of person, Claire’s account suggested the addition of new characteristics to Nick’s existing personality (“[O]h, and the other thing I've noticed with him, he’s- he’s become a lot more philosophical, like [...] and he’s more of a serious person now”). New negatively-perceived characteristics were not considered so extreme as to make Nick a different person (“[He’s] temperamental but, you know, not in a strong way”).

Janet in particular understood Jeff to be fundamentally the same person despite changes. She experienced Jeff as not only retaining many of his pre-injury qualities but also being “in essence” the same person as he was pre-injury:

> [B]ecause he is different in lots of ways but his core essence I think is still- but you see I know him extremely well so his- yeah I still think his essence is still the same to be quite honest. It’s just how he uses it. He’s still a very proud man. Um he’s still quite persistent in his views. Um [PAUSES] he still loves his family. He still- you know a lot of things haven’t changed. Um he probably- his emotions are probably more to the fore so he’s- he’s still very protective but all these things are enhanced and heightened.

In her account, Janet made sense of the inner person (Jeff’s “core essence”), as being separate from external aspects of the person (“how he uses it”), thus retaining a sense of Jeff as fundamentally the same person, despite change. Her description of Jeff’s opinions and emotions as “enhanced and heightened” suggests she experienced continuity of traits, changed only in their degree or intensity.

Rather than discounting instances of continuity, Claire and Janet appeared to be vigilant to instances that confirmed that their partner was the same person and described progress towards the pre-injury person (“So he- I think he's beginning to think along the lines of things that he used to do when he was- before his accident”, Claire). Within this context of perceived continuity of person, some changes can be accepted and at times even embraced (“You have to accept that things are going to change but those little things as well can be quite sweet. They’re not always bad”, Janet).

Depersonalising narratives. Appraisals of their partner as a different person tended to be associated with depersonalising discourses which denied the personhood of the individual. The objectifying language that Frank at times used to describe Wilma is an example of this: “’cause that what’s in there is not Wilma that I knew”. Although less negative in their characterisation, Joan’s description of Matthew as “gone” and Maureen’s description of David as “empty” also suggest difficulty preserving a sense of their partners’ post-injury personhood. As well as perceived absence of the person inside, in Frank and Joan’s narratives there was a sense of the intrusion of something less than human, as Frank described: “And sometimes she gets all this saliva in her mouth and yeah, it’s like a horror film really”.

In contrast, participants who experienced continuity of person seemed to retain a sense of their partner’s personhood as separate from their own, as captured in Janet’s account of Jeff’s strong post-injury opinions: “[T]hat’s what he thinks and it’s hard to dissuade him otherwise as well- which is quite right as well. He should have [HIS OWN OPINIONS], you know...”.

Loss and grief. Perhaps unsurprisingly, given that they experienced the known person to be fundamentally changed/lost post-injury, participants who experienced discontinuity of person also described a sense of loss and grief for the pre-injury person. Joan stated: “Because it’s such a- it’s- it’s a loss and for five years I grieved of Matthew- was not there- he’d gone”. Also expressing his grief, Frank said, “[T]his year I got a different wife and that breaks my heart”.

Participants who perceived their partner to be essentially the same person also experienced distress at the changes in person. For example, Claire stated: “[I]t does upset me to think, when I look at him and I think how he used to be [...] and how he is now. [...] It does upset me”. However, as described previously, Claire tended to seek comfort in experiences of continuity of person and progress towards the old self (“I think as time’s going by, he's gradually rehabilitating [...] from his accident”).

For Janet, although changes could be unsettling at times, rather than grief, she described feeling “glad to have [Jeff] here”:

> I mean it might be the first time you notice things and you think, “Ooh that’s, you know- that’s quite not you or, you know, that’s not quite you” but then you get over that [...] because it’s, you know [EXHALES]- it’s there and you can’t do, you know- I don’t want to change what he does because, you know- I’m just glad to have him here.

Furthermore, the narratives of Claire and Janet indicated a sense of loss *for* the person, rather than loss *of* the person (“I suppose my biggest thing is the- the loss for him not being able to ride his bike. It’s- it’s like um- it’s almost like an appendage [LAUGHS] the bike really to bikers. [...T]hat saddens me”, Janet).

Dynamics of relationship.

(Dis)continuity of relationship. A further theme that emerged from the interview data was change in the dynamics of the relationship post-injury. Relational change was experienced by all participants, with descriptions of a shift from couplehood towards caregiver-care-receiver/parent-child dynamics present across accounts. However, again, there was a continuum of experiences from the relationship as definitively changed/lost (such that it became defined only by caregiving), to the relationship as changed but fundamentally intact (with caregiving as just one part of it). Participants were positioned at different points along this continuum.

At one end of the continuum, when asked about her post-injury relationship, Joan stated, “What relationship? That’s where I would start really. Because there isn’t a relationship. I look after Matthew”. Frank also perceived definitive change in his relationship described in terms of a shift towards a parental rather than spousal role (“[U]nfortunately you feel more like a father than you feel like husband, lover or all of that”). Similarly Maureen described discontinuity in her relationship (“But it’s not the same relationship [...] and I do often feel like a carer [...] 'cause there's no- there's nothing else there, you know what I mean?”). However, for Maureen, the role of caring itself was perceived to be continuous with her pre-injury relationship role, as will be discussed further below.

For Claire, although her role had changed towards caregiving (“mothering”), there was also a sense of continuing couplehood (“Um, well, before, we were just- you know, we were a coup- a couple, a married couple, husband [...] and wife [...] which we still are, but now I feel more like a- a mother”).

At the other end of the continuum, Janet made sense of her relationship as fundamentally unchanged despite relational and role changes. This is captured in the metaphor she used to describe her post-injury relationship: “Um perhaps the goalposts have moved or the rules are different or, you know, we’re playing with one leg, rather than two but it- it’s still- in essence it’s still the same”. The implicit suggestion that she and Jeff are still playing the same game suggests that she experienced core continuity amid change.

A number of subthemes emerged relating to participant experiences of post-injury relational change: change in *mutuality/reciprocity*; change in *togetherness*; and change in *feelings*. These subthemes have been conceptualised as subthemes of *(dis)continuity of relationship*, as participants reported varying degrees of change in each of the areas which appeared to link to their experience of the relationship as continuous/discontinuous. For clarity, these subthemes will be discussed separately, although there is overlap between them.

Change in mutuality and reciprocity. As mentioned, all participants described a shift in the balance of their relationship towards caring for their partner. Some participants described global changes in mutuality and reciprocity such that their post-injury relationship had become defined solely by experiences of caregiving while feeling that they received little in return (practically and emotionally). For other participants, caregiving was experienced as just one part of the relationship. There was a continued sense of being “there for each other” (Claire) which was in part based on continued warmth, affection and enjoyment of time spent together.

For Joan, an imbalance in practical contribution defined her relationship both pre- and post-injury (“[B]ecause I did everything. I do everything in my house. I did everything then and I do everything now”). However, pre-injury, the warmth, affection and intimacy she experienced within the relationship appeared to mitigate the impact of this imbalance such that she described her relationship as mutually satisfying. (“It was a-a very loving relationship [...] and fulfilling being- I think we both gave each other what- what we wanted and what we needed at that time”. In contrast, post-injury, with the loss of warmth, affection and intimacy, the relationship was described in terms of unidirectional providing (“Matthew’s in the house. I feed him. I water him. [...] That’s- that’s the couple. [...] There is no loving, holding- [...] there is no loving, holding, sexual in any shape or form. That’s all gone”). The change in the balance of her relationship is captured in the metaphor she used to describe her relationship over time: having described her pre-injury relationship in terms of each being the other’s “rock”, she stated, “Well I’m a bloody boulder now”.

Maureen also experienced loss of affection and intimacy post-injury which appeared to contribute to her understanding of her relationship as being defined by caregiving (“And to be honest, I just feel like a carer. [...] There's- there's nothing else, you know, I’ll peck him on the cheek when I go to work-”). However, it was the loss of emotional support that seemed central to her understanding that her relationship had fundamentally changed. For example, Maureen’s account of her decision whether to take a new job highlighted the lack of recognition of her emotional world (feelings, needs, desires) and personhood (values, history) that she experienced which led her to conclude “there's nothing there”:

> [I]t’s not being able to have the full conversation with him. You know, I’ve been offered another job in [LOCAL TOWN] [...] and, err, I can’t talk to him about it. [...] 'Cause I start, “Oh yeah, I’ll be in [LOCAL TOWN]”- 'cause it’s only ten minutes up the road- “Yeah, take it, take it and come home at dinner time” and then that’s it. [...] There's no, “Oh well, you’ve really worked hard to get where you are. You know, you’ve done this. You’ve done that” [...]. But he doesn’t, there's- there's nothing there, you know [...]

The change in emotional reciprocity that Maureen experienced is captured in the way she described David’s feelings changing from “loyalty to me” to “I’m here for him” indicating a shift in the give and take of their emotional life: “Um, the loyalty now I would say is more [PAUSES]- what’s the word? [PAUSES]- he relies on me. [...] It’s not loyalty. [...] Not loyalty to me. [...] It is just, um, I’m here for him”.

Both Maureen and Joan described no longer feeling held in mind by their partners. In particular, they described the absence of small pre-injury acts (such as making dinner, buying gifts) and made sense of their absence as signalling that their partner no longer thought about them (“’Cause he doesn’t think about me”, Maureen; “‘I just wanted you to think about me’”, Joan).

However, alongside the changes she experienced, Maureen also described a tentative mutuality in her relationship with David. This seemed to be based on her experience of an on-going emotional connection between them (“[A]s I say to you, if you’ve got that chemistry, I don’t think it ever goes, does it?”).

Frank also experienced a fundamental change in his relationship such that it became defined by responsibility and duty:

> [S]omebody got to be here to give her her tablets. Somebody’s got to be here to make sure she doesn’t hurt herself or if she falls to- to do what you’ve got to do. Somebody has to be here and I just- I see that as in a sense a responsibility

As well as a loss of affection (“Err yeah Wilma was err quite lovey dovey. [...] But she’s not at all now. Not at all”), it was the absence of shared pleasure that seemed central to his experience of the loss of his pre-injury relationship. Before the injury he described a shared enjoyment of life (“And to be able to go as Wilma was before just like her and I to get on a bus or get anywhere doesn’t matter would have been really enjoyable”). In contrast post-injury, he experienced the relationship as defined by “Absolutely nothing- nothing positive, nothing pleasurable”.

While Claire and Janet also experienced changes in mutuality and reciprocity, their post-injury relationships were not purely defined by caregiving. For Claire, changes in reciprocity post-injury seemed to centre on Nick being unable to contribute fully to the household or offer practical support. For example, describing her mother's funeral, she said: "Nick was- he- he hugged me and [...] kissed me and [PAUSES] um, but deep down, I know I'm not- I- I'm dealing with- having to deal with everything [...] physical side, you know, emptying the house and dealing with everything". However, at the same time, Claire described experiences of continued mutual warmth and affection ("I feel- like we're always hugging each other now and he calls me 'My love' and I call him 'My love'"). There was a sense of being held in mind by Nick ("I just think he's very thoughtful and considerate. [...] It- it was our wedding anniversary last week and he bought me a ca- a lovely card and [...] and he also made me a pottery thing [...] And he- he did- he'd made all this for me"). She also described continuing enjoyment of each other and time spent together ("[W]e still do have a lot in common Yeah, so we had lots of interests that we both enjoyed and we enjoy- still do enjoy each- each other's company").

Janet described role changes such that she had become responsible for all aspects of the household ("Um and yeah so I suppose now that all that's changed and I have to make the decisions on- [...] and now I find that I'm having to do all that and that's- that has been quite difficult really"). However, she described on-going affection in the relationship and made sense of post-injury changes in their sexual relationship as shared natural progression: ("We're not young lovers so yeah. Um I don't think that's changed much at all. I mean we still have a cuddle and, you know, so"). In these ways, Claire and Janet perceived continuing mutuality and reciprocity in their relationships, rather than relationships defined by caregiving.

Change in togetherness. Across participant accounts, there were experiences of changes in togetherness following injury. Where pre-injury participants described a sense of connection; facing challenges together; and shared interests and goals, post-injury there seemed to be a shift towards separation to varying degrees.

For some participants this centred on a sense of disconnection and aloneness despite time spent together. For example, a central theme in Joan's narrative of her pre-injury relationship was what she described as the "magic [...] of being together". In contrast, the experience of separation she described post-injury was definitive: "But we're not together. [...] We're not together. We might sleep in the same bed, but we're not together". Maureen similarly described feeling separate within shared time and space ("[W]e sit there [...] in the two chairs, watching the television. [...] No conversation, nothing"). She also described a sense of aloneness in the absence of shared couple activities post-injury, captured in her description of going to buy a car: "[I] had to go and sit in the showroom on my own and buy a car [...] and you've got all these other couples, you know, 'Honey what colour?' and I'm thinking, 'Hmm…'".

In contrast, Claire described a continued sense of closeness and connection in time spent together ("and sometimes he- like last night, we were watching a bit of television and there was something on that was quite funny and we were both laughing at it. That, you know, those are the nice things and [...] being together"). For Janet, there was there was a strong sense of the continuation of an intimate shared life with Jeff ("[W]e still talk at night, you know, you know we do- although we're together we still- even if we're together for the day, we still reflect on it").

Another facet of change in togetherness post-injury related to experiences of coping alone, present in the narratives of Frank, Joan, Maureen and Claire. For example, Frank described a sense of togetherness pre-injury which centred not only on pleasure in their shared company but facing challenges together as a couple ("It's always been her and I."). His experienced loss of these facets of togetherness prompted Frank to question what remains of their relationship ("and you get through all that [CHALLENGES] but when you haven't got that..."). Claire's account spoke to the theme of coping alone. She talked about coping with life since the brain injury: "but you have to deal with it [...] and get on with it because if I don't do these things [REFERRING TO HOUSEHOLD TASKS], nobody else is going to do them". In contrast, Janet's account suggested that she was still able to draw on their strength as a couple to manage post-injury life:

> We'll- you know, we'll work it out. But I still think that is down to the fact that we are partners, you know, we've been together a long time and we are, you know, we are partners so I think that's got a lot to do with it.

A further facet of change in togetherness was the shift from shared pleasure, fulfilment and goals to doing things "for me". Participant accounts suggested an increased focus on their individual interests and time to themselves. For Frank, this was connected to his perception that he had nothing else of value in his life: "Okay, I- I like to achieve the things with my photography [...] err but apart from that, what else is there really? For me? Sad isn't it [SHORT LAUGH]?".

The need to focus on their own individuality also seemed to relate to participants' experiences that post-injury, there was less "room for me" (Janet). For example, Claire described:

> I feel like I do nothing for me. It's [...] either for work or for Nick [...] or for my mum's- doing stuff for my mum's house [...] but, um, not much for me [...] So I did actually do something for me.

Maureen described a similar experience:

> M: Because if I'm not at work, I'm here caring for David and I don’t seem to have any time for me.
>
> *I: Yeah, yeah.*
>
> M: You know.
>
> *I: What's that like for you then?*
>
> M: It’s horrible.

Janet also talked about wanting to do things “for me” which appeared to prompt her to consider the changed dynamics of her relationship and the shift in togetherness:

> I’d like to go back to work. I’d like to do certain things for me because that’s what I always di- no that’s the wrong way to put it because [PAUSES] it wasn’t really for me. I suppose now as well- it used- things used to be for us [...] and it seems as though that we’re not- we’re not- it’s not ‘me and him’ but it’s not quite ‘us’.

Change in feelings. Another aspect of relational change which applied across participant accounts was change in feelings with the introduction of uncertainty, ambivalence and complexity into post-injury feelings. Joan described a shift from the certainty of her feelings of love for Matthew throughout their pre-injury lives (“I’ve never stopped loving Matthew through anything”) to present uncertainty about how she feels (“[B]ecause I do love him. I did love him. I do love him. Did love him. Don’t know where that sits at the minute”). Frank also seemed to experience doubt about his present feelings towards Wilma, as the following quotation indicates (“Mm well I think I- well I must still love her ‘cause if I didn’t I wouldn’t be here I don’t think”). He went on to describe his mixed emotions towards Wilma since the injury (“but love and pity. It’s hard just- feeling sorry for somebody and loving them”).

Although expressing greater certainty in the continuity of certain pre-injury feelings; the other participants' narratives similarly spoke to experiences of increased ambivalence and complexity in the way they felt towards their partner. For example, although sure of her love and loyalty to David, Maureen described how post-injury she also felt "resentment" and "bitterness" ("Don't get me wrong, I'm very loyal to him and I love him. There's a lot of resentment [...]. I do feel [PAUSES] bitter"). For Janet, there seemed to be a shift from feelings being "quite easy" to confusing and difficult:

> [T]his is where I get a bit confused because [EXHALES] I still love Jeff, don't get me wrong, um but I think my feelings have- have changed they've- not in [PAUSES]- and I think it's because of the role that I play. So [SIGHS] I don't know. It's hard. It is difficult um but I st- when Je- when my Jeff is there [...] it's quite easy. But when- I mean sometimes he can throw a fit because he doesn't want to do something [...] I do find that is [PAUSES]- I think your feelings change then.

Alongside these experiences of uncertain, conflicted and confusing emotions, participants described a shift from love and passion towards caring, protection, and for some participants, duty and responsibility. Frank described the change in the way he feels: "'cause it's turning into responsibility, rather than just, you know, loving and caring". For Claire and Janet, the shift was less definitive. While Claire also described feelings of protection and duty, these feelings were experienced in the context of continued love for Nick ("I, I love him so much and got to look after him"). For Janet, there was an oscillation in her feelings which she found confusing:

> Some days I'm, you know, his partner Janet or- or I can get a mixture of lots of different ones [FEELINGS TOWARDS JEFF] in a day. So that can be- at first it was

> like, “Oh”, you know. It- it was quite upsetting. But now, like I say, it- it [SHORT LAUGH]- and confusing. It was quite confusing as well.

Pre-injury relationship. As already touched upon within the preceding themes, the dynamics of their pre-injury relationship seemed to contribute to participants’ experiences of continuity-discontinuity of relationship (and person) and may provide a context for understanding why some relationships were able to assimilate changes associated with brain injury while others were completely redefined by it.

For Frank, his pre-injury relationship with Wilma was based in part on her fitting in with him and his lifestyle (“[T]here’s always been this boss and that’s always been me”). Describing Wilma he said “[S]he’s I think always put me before her” and referred to her as “everybody’s sweetie”. Given these are the qualities that Frank appeared to particularly value in his pre-injury relationship, it is perhaps unsurprising that he described being less able to cope with some of the changes in Wilma’s behaviour than others:

> No it- I can cope with the childness. That’s alright in a sense. It’s- it’s- that is what it is and I can cope with that. Um and if that continues up until I die, I- I don’t have a problem with that at all [...] but the uncertainty of knowing when she’s gonna go off on one of these [REFERRING TO HER AGGRESSIVE BEHAVIOURS], that’s the problem.

Frank described how Wilma’s “childish” behaviour post-injury fitted with how he experienced her pre-injury: “[W]hen she woke up she was very childish. [...] With her loving nature and all the rest of it that all went together quite well”. In contrast, Wilma’s argumentative and aggressive behaviours are more difficult for Frank to integrate, perhaps because they go against some of the defining aspects of their pre-injury relationship.

For Joan, intimacy and affection, passion and excitement were central to her pre-injury relationship: “[I]t was magical. [...] and good times like that that were um exciting and- and loving times, you know. Um he can just sneak up on you and- and grab you like. That- that’s- that was lovely”. She described that “magic” getting her through the stressful times she experienced in her pre-injury relationship:

> Err but all my friends were, you know, “Why are you with him?”, you know. “He’s no good for you and he’s leaving you in the lurch” [...] Because you cannot stop- and I don’t know what that magic is- I’m hoping my kids have the magic [...] that we’ve had of being together.

For Joan then, the experienced change in Matthew’s loving behaviour post-injury (“Can’t even throw an arm across you. Nothing. Nothing”) is likely to be perceived as a threat to the relationship as a whole.

Maureen also described affection (“[I]f we ever went out we always held hands and things like that”) as well as emotional support (“um he sort of boosted me up and reassured me”) as central to her pre-injury relationship, the absence of which seemed to contribute to her experience of a different relationship, as described in previous sections. However, Maureen described another side to her pre-injury relationship. Although contributing to the home, she described David as putting himself and his needs first at times. Discussing the birth of their child she said, “He still went out, did exact- you know did exactly what he wanted. Had what he wanted”. In turn, she described herself as having patience with him (“I’ve always been patient with him. [...] I really don’t know why, I’ve always been the same with him”) and caring for him (“I'm a nurturer”). These aspects of the pre-injury relationship dynamic may contribute to making sense of why, although the circumstances of providing care have changed, Maureen expressed feeling comfortable in her current role ("And you know, I'm quite happy caring for Dave").

For Claire, a division of roles, with Nick taking responsibility for decision-making and administrative aspects of their life, characterised their pre-injury relationship, with Claire describing a balance in their pre-injury relationship:

> Um, yeah, so we- we just worked really well together, 'cause, I mean, I like housework and cleaning, so [...] I did all that and he did all the cooking [...] and he looked after all the bills and the, um, financial and admin side of things, you know. And I thought, "Great", you know.

Post-injury, it was the loss of this practical support that seem to contribute to experiences of relationship change ("[N]ow I'm having to do everything- so I'm, I suppose I'm the, you know, the, the head of the household now [...] and having to deal with everything". However, another key component of their relationship and part of the initial attraction was Claire's experience of Nick as "very caring [...] and considerate [...] and thoughtful", qualities which she still experienced post-injury and which contributed to her experiences of continuity.

In Janet's account of her pre-injury relationship, challenges, difficult times and arguments were accepted as being part of the fabric of their relationship:

> I mean we have had some rough times don't get me wrong. I don't think over nearly what thirty- do you know I can't even remember how long- thirty-four years [...] there's bound to be some rough times [...] err but nothing that we couldn't resolve.

This was underscored by a strong sense of underlying commitment ("Yeah and we just always made up. There was- you know. Neither of us were going anywhere so, you know, you've got to get on and you've got to get along"). It is perhaps this ethos of acceptance and ability to cope with life's ups and downs, central to the story of their relationship, which contributed to the relationship being able to assimilate the challenge of the brain injury, as Janet described talking about daily challenges after the injury, “Days are like that. They’re not perfect days. They weren’t perfect before and they’re not going to be perfect now”.

Dynamics of caregiving.

Making sense of changes in the person. This theme focuses on the ways spouses made sense of and responded to post-injury changes in the person. Some participants tended to draw on medical models for making sense of post-injury changes and to look externally for ways of managing. Other participants appeared to draw on their pre-injury knowledge and understanding of the person to understand and cope with post-injury changes, expressing empathy for their spouse.

Frank and Joan drew predominantly on medical models to make sense of post-injury changes in their spouse attributing changes directly to the brain injury, with little reference to the pre-injury person or their current circumstances. For example, discussing Wilma’s aggressive behaviour post-injury, Frank stated, “Err... once again and according to what I’ve read that’s all to do with the parts of the brain that- that err have been damaged”. He later went onto describe:

> I think I understand why Wilma’s the way she is and, why I say that is that, comes back to what I’ve read and what I’ve been told about what happens to people that have brain damage [...] err back to that chart I’ve got- everything comes back to that brain damage.

Similarly Joan made sense of post-injury changes in Matthew as having a direct relationship to the damage to his brain (“This is somebody whose brain has been buggered up- I think Matthew has lost- is it thirty per cent of the right side of his brain?”).

Both Frank and Joan described the need for external support to manage the challenges of brain injury. For example, Frank said, “I’ve done what I can do and I now need somebody or groups of somebody to say, ‘You might try this’”. For Joan, having made sense of changes in Matthew as a direct result of his brain injury, there was a sense that the “switching on” of the damaged part of Matthew’s brain was the responsibility of external professionals (“They have put on the lights for his walking, his talking. [...] So where have you switched on Matthew’s other part of the brain to be loving?”). Their own approaches to managing challenges did not always come across as person-centred. For example, talking about Matthew’s argumentative behaviour, Joan said, “You tell him to- ‘Oh shut up’ and I ignore him and he don’t like that. You know, ‘Oh for god’s sake, Matthew just calm down for god’s sake’, you know”.

In contrast to the accounts of Joan and Frank, Janet’s narrative indicated that she drew on her pre-injury knowledge and understanding of Jeff to make sense of and manage post-injury changes. An example of this can be seen in the way she made sense of Jeff’s argumentative behaviour post-injury with consideration of his pre-injury qualities and the external circumstances he found himself in:

> [W]hen Jeff was at home a lot it happened more [...] and I think it’s because of his- his nature and his intelligence. He’s not used to staying with one person every day. [...] He’s just not. He’s a very social person, you know, in his job and in his gym [REFERRING TO JEFF GOING TO THE GYM PRE-INJURY], day-to-day life.

In trying to support and motivate Jeff, again Janet used what she knew about his personality. For example, she described encouraging his “competitive side” when he was learning how to walk again:

> [I] used to say [SHORT LAUGH], "I wonder if you or [GRANDDAUGHTER] will walk first?" do you know and things like that because it would- that- oh he's competitive as well. Sorry I didn't say that did I? He's very competitive [...] so um the competition side of it was like- even though it was against a little baby, it was still there [LAUGHS] so we used that to our advantage

While valuing external support, Janet described a sense of self-efficacy in coping with challenges post-injury ("And people can help but, I don't know- I don't know. Maybe I'm stubborn as well in the fact that I think I can cope and- and do things"). Rather than looking for solutions externally, Janet described finding answers within her own knowledge and understanding of Jeff ("I don't look on the internet about this, that and the other [...] we take it each day as it comes and we, you know- I try to stick to a format that Jeff understands").

Claire's account suggested a very empathic approach to understanding post-injury challenges. For example, she described an incident when Nick got upset on realising that he'd been out with his shirt on back to front and none of his friends had told him. Although stating "it was a trivial thing really" and describing that since the injury "he builds things a little bit out of proportion", Claire did not dismiss Nick's emotional experience:

> and that upset me a little bit, to think that none of them had, you know, had a quiet word with him and told him that his shirt was on inside out. So things like that, you know, I feel a little bit hurt and it's obviously hurting his feelings as well

Claire's account indicates that rather than understanding Nick's response solely with reference to changes brought about by his brain injury (e.g. emotional lability), she made an effort to enter his emotional world. Like Janet, Claire also drew on her pre-injury knowledge of Nick to understand certain post-injury changes. For example, she described Nick as "a little bit more in his own little world now" but went onto understand this by remembering that pre-injury he also tended to get absorbed in the activities he was doing:

> [A]rt's always been a big part of his life and now that he's getting back into it, he gets absorbed [...] by what he's doing. So he's- he- he gets absorbed by doing art and by reading

Maureen also appeared to draw on her knowledge of David and his history, and the dynamics of their relationship to make sense of post-injury changes, although she tended to draw on her knowledge of the more negative aspects of his personality and their relationship. For example, describing David's refusal to attend Headway she said:

> Because David never did anything he didn't want to do. [...] He was very strong-willed. [...] And so people making him do these things, going there, having carers, he didn't like it, [...] because it wasn't his say. [...] but because decisions were taken away from him- see that was another big part of our relationship before [...] although we made decisions together [...] he sort of had the last say. [...] And he always had his own way. He was very spoilt as a child. [...] So I- I think after the accident when people were making the decisions, [...] he didn't like it, you know.

Broadly, Frank and Joan, the participants who experienced greater discontinuity between the pre- and post-injury person and relationship, tended to draw on medical models for making sense of post-injury behaviours and to look externally for ways of managing. In contrast, Janet and Claire, the participants who retained greater sense of their partner and relationship as continuous, appeared to make sense of post-injury changes with reference to their pre-injury knowledge and understanding of their spouse and their relationship. They drew on this information to cope with their changes, resulting in person-centred, empathic approaches to caregiving. Their narratives indicated a sense of self-efficacy in managing difficult moments and challenges. For Maureen, there was a sense of divergence from this pattern as although she appeared to perceive David and the relationship as broadly discontinuous, her response was person-centred. This perhaps relates to her experienced continuity of certain traits relating to David and the relationship, which particularly centred on her "patience" and caring role pre- and post-injury.

Impact of caregiving. While across participant accounts the experience of caring for a partner with a brain injury was described as a significant challenge, for some participants it seemed to present a particularly insurmountable challenge while for others it was described to be more manageable.

For Frank and Joan, there was the sense that the challenge of caring for their partner was at times more than they could cope with. As Joan expressed, "so you think, 'How much more can I cope with this?'". Maureen, on the other hand, described the situation as "tolerable". Claire, although feeling overwhelmed at times with her present roles and responsibilities, expressed feeling she was coping well ("I feel like, um, I am coping with it quite well"). Similarly, Janet described feeling able to cope with the challenge of the situation:

> and I don't find that things are unbearably different. Let's put it that way. They're not- you know, they're quite cope- they're manageable and they're cope- you know [...] coping with them. It is different [...] but it's not- I mean I might eat me words in six months' time [LAUGHS] but it- it's manageable, you know.

The experience of caring for a partner with a brain injury appeared to present a particularly difficult challenge for those participants who experienced discontinuity (Frank and Joan) compared to those who experienced continuity (Janet and Claire). Again there was some divergence in Maureen’s account, which may be explained by her expressed identification with the role of “nurturer” both pre- and post-injury.

Discussion

Summary of findings. The themes *dynamics of person, dynamics of relationship,* and *dynamics of caregiving* show the convergences and divergences across participant accounts with regards to participants' experiences of their spouse, their relationship and their caregiving role post-injury. It is useful to pull these themes together and offer an interpretation of how they are interconnected, drawing on the concept of continuity-discontinuity.

It is proposed that Frank and Joan appeared to experience discontinuity with the past across their perception of the person and the relationship. Maureen also experienced discontinuity but was perhaps slightly closer towards the centre of the continuum between continuity and discontinuity. Claire and particularly Janet appeared to experience greater continuity.

With regards to experiences of continuity-discontinuity of person, participant accounts indicated that where there was continuity, there were changes but these were incorporated into the continuing identity of the person (e.g. "his essence is still the same", Janet). However, where there was discontinuity, changes became the defining characteristics of the person and there was nothing beyond this (e.g. David is otherwise "empty", Maureen). It is understandable then that experiences of discontinuity became associated with a depersonalised view of the person and with experiences of loss and grief for the person who has "gone" (Joan), rather than feeling glad that the person was "here" (Janet).

With regards to participants' experiences of their relationship, the analysis suggested that there were a number of facets to post-injury relational experiences: changes in *mutuality/reciprocity, togetherness,* and *feelings* which can be drawn together under the umbrella of continuity-discontinuity. In relation to *mutuality/reciprocity*, it is proposed that for those participants who experienced discontinuity, the relationship was now defined in terms of provision of care (“[T]here isn’t a relationship. I look after Matthew”; Joan). By contrast, for those participants who maintained a sense of continuity, caring was one aspect of a broader relationship that was still characterised in a richer and more varied way (“[W]e enjoy- still do enjoy each- each other’s company”; Claire).

In relation to *togetherness*, it is proposed that those participants experiencing discontinuity expressed the strongest change in togetherness in terms of sense of connection; facing challenges together; and shared interests and goals (“We’re not together. We might sleep in the same bed, but we’re not together”; Joan). In contrast, those participants experiencing continuity appeared to still experience togetherness at times (“[T]hose are the nice things [SHARED TIME AND ENJOYMENT] and [...] being together”; Claire). In relation to *feelings*, those participants experiencing discontinuity expressed greater uncertainty in their feelings of love towards their spouse and a greater shift towards feelings of responsibility, compared to those participants experiencing continuity. However, a shift in experiences of togetherness towards an individual focus (“[It’s not ‘me and him’ but it’s not quite ‘us’”; Janet) and a shift in feelings towards their spouse (with increased uncertainty and ambivalence) was present, to varying degrees, across all participant accounts.

It is proposed that experiences of continuity-discontinuity may relate to spouses’ pre-injury relationships in idiosyncratic ways. In particular, if those aspects of the person and relationship which were particularly valued or central to the pre-injury relationship are changed following injury, this may result in greater perceived discontinuity.

Participant experiences of continuity-discontinuity of person and relationship appeared to link to their experiences of caregiving in a number of ways. It is proposed that the re-definition of the person solely in terms of problematic changes or absence, and the relationship in terms of nothing but caring, has important consequences for spouses' emotional and behavioural response. For example, if the person is perceived to be "gone" or "empty", the spouse then comes to understand them in terms of what they have been told about people with brain injury, such that the person becomes defined by brain injury, as is evident in the accounts of Frank and Joan ("everything comes back to that brain damage"; Frank). Furthermore, defining the relationship solely in terms of the provision of care seems to bring with it a sense of an exchange of services – with the services all going in one direction (all give and no take), and inevitable resentment at the unfairness of the exchange.

Continuity-discontinuity literature. The findings of the present study resonate with the findings within dementia research addressing the concept of relationship continuity. In particular, there were clear linkages between the themes presented and the five dimensions of continuity-discontinuity proposed by Riley et al. (2013) in their measure of relationship continuity based on qualitative research (*relationship redefined, same/different person, same/different feelings, couplehood, loss*).

The theme *(dis)continuity of relationship* links with the dimension *relationship redefined* in that there is a continuum of experiences from the relationship as a continuation of the pre-injury relationship to completely finished and redefined by caregiving. In the present study, the concept of *reciprocity/mutuality* seemed particularly important for making sense of these experiences, such that it was the lack of practical and emotional give and take (including feeling held in mind by their spouse) that contributed to participants' sense of the relationship as redefined by caregiving. This finding resonates with quantitative findings in the stroke literature that indicate that reciprocity and mutuality are predictive of life and relationship satisfaction following stroke and a positive response to the caregiving role (McPherson et al., 2011; Ostwald et al., 2009).

The theme *(dis)continuity of person* links with the dimension *same/different person,* in that there is a continuum of experiences from the person as fundamentally the same to changed in an essential way. While echoing the findings within the dementia literature that spouses who perceive continuity actively seek signs of this (Riley et al., 2013), the present study further suggested that those spouses also tend to look for signs of progress. This finding is perhaps more applicable to an ABI than dementia context as, unlike dementia, ABI is associated with the potential for rehabilitation. The present study also indicated the presence of "glimmers" of the old person even in the context of discontinuity, a finding not highlighted within the dementia research but perhaps of clinical relevance as these glimmers could present a building block for strengthening continuity post-injury.

The theme *feelings* links to the dimension *same/different feelings*, such that there is a shift from love to protection which is greater in those couples who perceive discontinuity. However, the present study further suggested that there is a change from relative certainty of pre-injury feelings to ambivalence and complexity post-injury across participant accounts.

The theme *togetherness* links to the dimension *couplehood* such that there is a shift from identity as part of a couple to viewing oneself in an individualistic way. In particular, the present study spoke to the idea of doing things "for me" post-injury related to experiences that there was less "room for me" (Janet). Another facet of togetherness perhaps less emphasised in the dementia literature is the concept of feeling alone in shared time and space post-injury. This is perhaps a clinically important finding as it suggests that support could be offered to couples to strengthen a sense of shared identity both at the macro level (e.g. planning shared activities) and at the micro level (e.g. seating arrangements in the home; touch; eye-contact).

The theme *loss/grief* in the present study clearly links to the dimension *loss.* However, while in the present study, it was conceptualised as a greater sense of loss of the person for those spouses perceiving discontinuity of person, the dementia literature highlights that as well as loss of the person, it is a sense of loss of the relationship that contributes to sense of loss.

An aim of the present study was to consider whether continuity-discontinuity is a useful and relevant concept to aid understanding of relationship and caregiving experiences following ABI. Its usefulness and relevance was apparent in that the concept of continuity-discontinuity corresponded to the themes that emerged from the data and provided an effective framework for conceptualising those themes. Continuity-discontinuity also offered a way of understanding how spouses respond emotionally and behaviourally to the situation, further indicating its usefulness and relevance in the present context.

Methodological considerations. The present study hopes to make a detailed, idiographic contribution to the existing literature on relationship and caregiving experiences post-ABI. In line with an IPA approach, the study findings are based on the expressed experiences and meanings of a particular sample and the researcher’s interpretation of those. Therefore the findings cannot be broadly generalised beyond the participants and researcher. The present study may not have captured the full range of experiences relating to the identity of the person and the relationship. In particular, it is possible that individuals for whom the experiences of their relationship are particularly ambivalent chose not to participate in the research. Some indication of this comes from the participant who withdrew from the study, stating that it was too distressing to reflect on the challenges of her post-injury relationship in the context of also trying to restore that relationship. Furthermore, of course the present study did not capture the experiences of those individuals separated or divorced from their partner post-injury. This limitation notwithstanding, the resonance of the present findings with accounts based on clinical experience (e.g. Oddy, 1995) and with findings within the dementia literature (Riley et al., 2013; Walters et al., 2010) indicates their potential applicability to clinical work and potential value of further research.

A further possible limitation of the present study is the relative heterogeneity with regards to the recruitment of a mixed ABI sample. However, this was considered justifiable as the literature indicates that experiences of personality and relationship change apply across ABI groups, with some research groups committed to using mixed ABI samples to parallel the clinical populations that services serve (G. Yeates, personal communication, February 8, 2013). Furthermore, the additional inclusion criteria ensured the homogeneity of the sample with regards to factors such as age at time of injury and length of pre-injury relationship, factors arguably more likely to contribute to participant experiences and meanings. Indeed, although Joan was the only participant whose spouse had suffered a stroke rather than TBI, the themes that emerged from interviews with her were consistent with those of the other participants. Joan herself expressed that, given the young age at which Matthew had the stroke, she did not identify her experiences with those of a typical stroke population:

> You know, they put me in touch- or I got myself in touch with the Stroke Association. [...] Oh Jesus Christ what a place to go. Err we went- I went to a meeting with them and I sat in this room. Everybody must have been what felt like seventy plus. Um I'm forty here. I've got kids. How can you possibly relate to my life?

While an effort was made to ensure homogeneity in terms of length of time post-injury, there was some heterogeneity with regards to this criterion in the final sample, reflecting the challenge of recruiting a homogenous sample. Convergences and divergences in participant accounts did not appear to vary based on time post-injury. However, further investigation of changes in relational and caregiving experiences over several years is needed as, to date, the longitudinal literature tends to focus on the impact of caregiving over the first year post-injury only (e.g. Brooks & McKinlay, 1983; Rosenbaum & Najenson, 1976).

A further limitation relates to the fact that the type and extent of neurobehavioural disturbance in the injured spouse was not assessed. It is possible that more “challenging” changes in the injured spouse were more difficult for spouses to assimilate and were more likely to result in experiences of discontinuity, but the design of the current study did not allow exploration of this hypothesis. Although by no means disregarding the impact of neurobehavioural changes on experiences of relationship and caregiving, there is evidence to suggest that spousal perceptions also play a role, as summarised in the Introduction. Further exploration of the factors impacting on spouses’ perceptions (including factors such as their pre-injury relationship) is likely to contribute to our understanding of why some spouses appear to experience less distress in the face of stressors.

A further methodological consideration relates to the use of the concept of continuity-discontinuity to provide a framework for the emerging themes. An expressed aim of the present study was to consider the usefulness and relevance of the concept of relationship continuity in the present context; at the same time the researcher made an effort to ensure that the concept was not imposed on the findings and that the experiences and meanings of the participants was central. In particular, as described, interview questions and prompts were broad and open and did not ask about (dis)continuity. Furthermore, while the emergence of themes relating to continuity-discontinuity was admittedly an interpretation on the part of the researcher, she tried to evidence the presence of these themes through the liberal use of quotations. The researcher also tried to establish the credibility of the interpretation through sharing of interview transcripts and discussion of emerging themes with the research supervisor, as well as use of the reflective journal.

Future research and wider implications. The present study indicates the potential utility of the concept of continuity-discontinuity to understanding spouses' experiences of their relationship and caregiving following brain injury, and more generally the value of examining relational factors that may contribute to spousal adaptation post-injury. While there are pockets of research which have examined individual factors relating to the uninjured spouse (e.g. coping style) that may moderate adaptation to neurobehavioural change (e.g. Blais & Boisvert, 2007), fewer studies have examined relational factors that moderate adaptation within an ABI context (e.g. McPherson et al., 2011; Ostwald et al., 2009). Future research, both qualitative and quantitative, is needed to further explore the applicability of the concept of continuity-discontinuity to a wider population of spouses. In particular, future research is needed to further investigate why some spouses perceive continuity and others discontinuity (considering factors such as the pre-morbid relationship, the injury profile and the intersect between the two), as well as the impact of these perceptions on the spouse's response to the situation (both in terms of their own coping and the quality of care they provide).

With regards to implications for rehabilitation, the concept of continuity may be useful for understanding the post-injury experiences of spouses. Arguably this line of research which focuses on spouses' perceptions and experiences of their relationship is particularly useful to inform the development of interventions as these factors may be more amenable to change than the ABI survivor's neurobehavioural disturbance (Hanks, Rapport, & Vangel, 2007).

In particular, it was proposed that experiences of continuity-discontinuity may impact both on the caregiving experiences of the uninjured spouse and on the care they provide. Spouses who perceived greater continuity were proposed to use their knowledge of the person to understand why their spouse was behaving and responding to things in the way they did, which arguably provides a more solid foundation both for coping emotionally and for providing person-centred, empathic support. In contrast, those participants who experienced discontinuity were left perplexed by their spouses' behaviours and responses, and reliant on professional support to guide them. Therapeutic work to strengthen connectivity and continuity with the past may then benefit both members of the couple. This could include family work that supports couples to identify the particular contexts and meanings in which discontinuity of person or relationship are experienced and to identify strategies to support reconstruction of connectivity and continuity at those times. These strategies may include assisting the partner to cognitively reappraise in a more positive way the specific situations that give rise to the experience of discontinuity. Other more general strategies to promote experiences of continuity may include reminiscence on shared lives, building in shared time into current routines, and supporting intimacy through use of touch and eye contact.

Pulling together findings from the empirical paper and the literature review, the literature review indicated that preserving a sense of their identity as continuous despite change was important to survivors' maintaining a positive sense of self coherent with their pre-injury self. Given that the construction of identity is a social process, it is likely that spousal responses can impact on this process, with a positive sense of identity perhaps more likely if the spouse is engaged in a similar process of maintenance of continuity. At any rate, the ways in which spouses perceive the person with a brain injury are arguably likely to impact on survivors' own identity experiences. Perhaps for those survivors who remain in an intimate relationship post-injury, any intervention to support positive identity reconstruction could be most effectively delivered by working with the couple as a partnership.

References

Anderson, M. I., Parmenter, T. R., & Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: Path model analysis. *Brain Injury, 16*, 743-757. doi:10.1080/02699050210128906

Anderson-Parenté, J. K., DeCesare, A., & Parenté, R. (1990). Spouses who stayed. *Cognitive Rehabilitation, 8,* 22-25.

Arango-Lasprilla, J. C., Ketchum, J. M., Dezfulian, T., Kreutzer, J. S., O'Neil-Pirozzi, T. M., Hammond, F., & Jha, A. (2008). Predictors of marital stability 2 years following traumatic brain injury. *Brain Injury, 22,* 565-574. doi:10.1080/02699050802172004

Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. A. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 12,* 375–384. doi:10.1002/nur.4770130605

Blais, C. M., & Boisvert, J. M. (2005). Psychological and marital adjustment in couples following a traumatic brain injury (TBI): A critical review. *Brain Injury*, *19*, 1223-1235. doi:10.1080/02699050500309387

Blais, M. C., & Boisvert, J. M. (2007). Psychological adjustment and marital satisfaction following head injury. Which critical personal characteristics should both partners develop? *Brain Injury*, *21,* 357-372. doi:10.1080/02699050701311075

Brooks, N., Campsie, L., Symington, C., & Beattie, A. (1987). The effects of severe head injury on patient and relative within seven years of injury. *Journal of Head Trauma Rehabilitation*, *2,* 1-13. doi:10.1097/00001199-198709000-00003

Brooks, D. N., & McKinlay, W. (1983). Personality and behavioural change after severe blunt head injury-a relative's view. *Journal of Neurology, Neurosurgery & Psychiatry, 46,* 336-344. doi:10.1136/jnnp.46.4.336

Burridge, A. C., Williams, W. H., Yates, P. J., Harris, A., & Ward, C. (2007). Spousal relationship satisfaction following acquired brain injury: The role of insight and socio-emotional skill. *Neuropsychological Rehabilitation, 17,* 95-105. doi:10.1080/09602010500505070

Carruth, A. K., Holland, C., & Larsen, L. (2000). Development and psychometric evaluation of the Caregiver Reciprocity Scale II. *Journal of Nursing Measurement*, *8*(2), 179-191.

Clark, M. S., & Smith, D. S. (1999). Psychological correlates of outcome following rehabilitation from stroke. *Clinical Rehabilitation, 13,* 129-140. doi:10.1191/026921599673399613

Epstein-Lubow, G. P., Beevers, C. G., Bishop, D. S., & Miller, I. W. (2009). Family functioning is associated with depressive symptoms in caregivers of acute stroke survivors. *Archives of Physical Medicine and Rehabilitation*, *90*, 947-955. doi:10.1016/j.apmr.2008.12.014

Eriksson, G., Tham, K., & Fugl-Meyer, A. R. (2005). Couples' happiness and its relationship to functioning in everyday life after brain injury. *Scandinavian Journal of Occupational Therapy, 12*, 40-48. doi:10.1080/11038120510027630

Evans, R. L., Bishop, D. S., Matlock, A. L., Stranahan, S., Halar, E. M., & Noonan, W. C. (1987). Prestroke family interaction as a predictor of stroke outcome. *Archives of Physical Medicine & Rehabilitation, 68,* 508-12.

Florian, V., Katz, S., & Lahav, V. (1989). Impact of traumatic brain damage on family dynamics and functioning: A review. *Brain Injury, 3*, 219-233. doi:10.3109/02699058909029637

Forsberg-Wärleby, G., Möller, A., & Blomstrand, C. (2004). Life satisfaction in spouses of patients with stroke during the first year after stroke. *Journal of Rehabilitation Medicine, 36,* 4-11. doi:10.1080/16501970310015191

Gan, C., Campbell, K. A., Gemeinhardt, M., & McFadden, G. T. (2006). Predictors of family system functioning after brain injury. *Brain Injury, 20*, 587-600. doi:10.1080/02699050600743725

Gan, C., & Schuller, R. (2002). Family system outcome following acquired brain injury: clinical and research perspectives. *Brain Injury, 16,* 311-322. doi:10.1080/02699050110104426

Gill, C. J., Sander, A. M., Robins, N., Mazzei, D., & Struchen, M. A. (2011). Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners. *Journal of Head Trauma Rehabilitation*, *26*, 56-68. doi:10.1097/HTR.0b013e3182048ee9

Gillen, R., Tennen, H., Affleck, G., & Steinpreis, R. (1998). Distress, depressive symptoms, and depressive disorder among caregivers of patients with brain injury. *Journal of Head Trauma Rehabilitation*, *13*, 31-43. doi:10.1097/00001199-199806000-00004

Godwin, E. E., Kreutzer, J. S., Arango-Lasprilla, J. C., & Lehan, T. J. (2011). Marriage after brain injury: Review, analysis, and research recommendations. *Journal of Head Trauma Rehabilitation*, *26*, 43-55. doi:10.1097/HTR.0b013e3182048f54

Gosling, J., & Oddy, M. (1999). Rearranged marriages: Marital relationships after head injury. *Brain Injury*, *13*, 785-796. doi:10.1080/026990599121179

Hammond, F. M., Davis, C. S., Whiteside, O. Y., Philbrick, P., & Hirsch, M. A. (2011). Marital adjustment and stability following traumatic brain injury: A pilot qualitative analysis of spouse perspectives. *Journal of Head Trauma Rehabilitation*, *26*, 69-78. doi:10.1097/HTR.0b013e318205174d

Hanks, R. A., Rapport, L. J., & Vangel, S. (2007). Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation*, *22*, 43-52.

Kendall, E., & Terry, D. (2009). Predicting emotional well-being following traumatic brain injury: A test of mediated and moderated models. *Social Science & Medicine, 69,* 947-954. doi:10.1016/j.socscimed.2009.06.021

Kosciulek, J. F. (1997). Relationship of family schema to family adaptation to brain injury. *Brain Injury*, *11*, 821-830. doi:10.1080/026990597123034

Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury*, *8*, 211-230. doi:10.3109/02699059409150974

Kreutzer, J. S., Marwitz, J. H., Hsu, N., Williams, K., & Riddick, A. (2007). Marital stability after brain injury: An investigation and analysis. *NeuroRehabilitation*, *22*, 53-59.

Kreutzer, J. S., Rapport, L. J., Marwitz, J. H., Harrison-Felix, C., Hart, T., Glenn, M., & Hammond, F. (2009). Caregivers' well-being after traumatic brain injury: A multicenter prospective investigation. *Archives of Physical Medicine and Rehabilitation*, *90*, 939-946. doi:10.1016/j.apmr.2009.01.010

Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing.* London: SAGE Publications.

Lezak, M. D. (1978). Living with the characterologically altered brain injured patient. *The Journal of Clinical Psychiatry*, *39*, 592.

Mauss-Clum, N., & Ryan, M. (1981). Brain injury and the family. *Journal of Neuroscience Nursing*, *13*, 165-169. doi:10.1097/01376517-198108000-00002

McPherson, C. J., Wilson, K. G., Chyurlia, L., & Leclerc, C. (2011). The caregiving relationship and quality of life among partners of stroke survivors: A cross-sectional study. *Health and Quality of Life Outcomes*, *9*, 29-39. doi:10.1186/1477-7525-9-29

Moore, A., Stambrook, M., & Peters, L. (1993). Centripetal and centrifugal family life cycle factors in long-term outcome following traumatic brain injury. *Brain Injury*,*7*, 247-255. doi:10.3109/02699059309029677

Moore, A. D., Stambrook, M., Peters, L. C., & Lubusko, A. (1991). Family coping and marital adjustment after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *6*, 83-89. doi:10.1097/00001199-199103000-00013

Oddy, M. (1995). He’s no longer the same person: How families adjust to personality change after head injury. In M. A. Chamberlain, V. Neumann & A. Tennant (Eds.), *Traumatic brain injury rehabilitation: Services, treatments and outcomes* (pp. 167-179). London: Chapman & Hall.

Ostwald, S. K. (2008). Predictors of life satisfaction among stroke survivors and spousal caregivers: A narrative review. *Aging Health*, *4*, 241-252. doi:10.2217/1745509X.4.3.241

Ostwald, S. K., Godwin, K. M., & Cron, S. G. (2009). Predictors of life satisfaction in stroke survivors and spousal caregivers after inpatient rehabilitation. *Rehabilitation Nursing*, *34*, 160-174.

Palmer, S., & Glass, T. A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology, 48,* 255-265. doi:10.1037/0090-5550.48.4.255

Peters, L. C., Stambrook, M., Moore, A. D., & Esses, L. (1990). Psychosocial sequelae of closed head injury: Effects on the marital relationship. *Brain Injury*, *4*, 39-47. doi:10.3109/02699059009026147

Peters, L. C., Stambrook, M., Moore, A. D., Zubek, E., Dubo, H., & Blumenschein, S. (1992). Differential effects of spinal cord injury and head injury on marital adjustment. *Brain Injury*, *6,* 461-467. doi.org/10.3109/02699059209008141

Ponsford, J. (2003). Sexual changes associated with traumatic brain injury. *Neuropsychological Rehabilitation*, *13*, 275-289. doi:10.1080/09602010244000363

Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke*, *4*, 285-292. doi:10.1111/j.1747-4949.2009.00289.x

Riley, G. A., Fisher, G., Hagger, B. F., Elliott, A., Le Serve, H., & Oyebode, J. R. (2013). The Birmingham Relationship Continuity Measure: The development and evaluation of a measure of the perceived continuity of spousal relationships in dementia. *International Psychogeriatrics*, *25*, 263-274. doi:10.1017/S1041610212001743

Rivera, P., Elliott, T. R., Berry, J. W., Grant, J. S., & Oswald, K. (2007). Predictors of caregiver depression among community-residing families living with traumatic brain injury. *NeuroRehabilitation*, *22*, 3-8.

Rosenbaum, M., & Najenson, T. (1976). Changes in life patterns and symptoms of low mood as reported by wives of severely brain-injured soldiers. *Journal of Consulting and Clinical Psychology*, *44*, 881-888. doi:10.1037/0022-006X.44.6.881

Sander, A. M., Carosell, J. S., High, W. M., Becker, C., Neese, L., & Scheibel, R. (2002). Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Injury, 16,* 649-657. doi:10.1080/02699050210128889

Schönberger, M., Ponsford, J., Olver, J., & Ponsford, M. (2010). A longitudinal study of family functioning after TBI and relatives' emotional status. *Neuropsychological Rehabilitation*, *20*, 813-829. doi:10.1080/09602011003620077

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harré, & L. van Lagenhove (Eds.), *Rethinking methods in psychology* (pp. 9-26). London: SAGE Publications.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*, 261-271. doi:10.1080/08870449608400256

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and it contribution to qualitative research in Psychology. *Qualitative Research in Psychology, 1,* 39-54.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: SAGE Publications.

Smith, J.A., Flowers, P., & Osborn, N. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material discourses of health and illness* (pp.68-91). London: Routledge.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London: SAGE Publications.

Tate, R. L., Lulham, J. M., Broe, G. A., Strettles, B., & Pfaff, A. (1989). Psychosocial outcome for the survivors of severe blunt head injury: The results from a consecutive series of 100 patients. *Journal of Neurology, Neurosurgery & Psychiatry, 52*, 1128-1134. doi:10.1136/jnnp.52.10.1128

Thomsen, I.V. (1974). The patient with severe head injury and his family. *Scandinavian Journal of Rehabilitation Medicine, 6,* 180-183.

Walters, A. H., Oyebode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia*, *9,* 169-189. doi:10.1177/1471301209354027

Willer, B. S., Allen, K. M., Liss, M., & Zicht, M. S. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. *Archives of Physical Medicine and Rehabilitation*, *72*, 460-464.

Wood, R. L. (2005). Waking up next to a stranger. *The Psychologist*, *18*, 138-140.

Wood, R. L., Liossi, C., & Wood, L. (2005). The impact of head injury neurobehavioural sequelae on personal relationships: Preliminary findings. *Brain Injury*, *19*, 845-851. doi:10.1080/02699050500058778

Wood, R. L., & Yurdakul, L. K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury, 11,* 491-501. doi:10.1080/bij.11.7.491.501

Yeates, G. N., Gracey, F., & Collicutt Mcgrath, J. C. (2008). A biopsychosocial deconstruction of ‘personality change’ following acquired brain injury. *Neuropsychological Rehabilitation, 18*, 566-589. doi:10.1080/09602010802151532

Chapter Three

Public Domain Briefing Document

This document provides an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. This document summarises a literature review and an empirical paper both written in preparation for submission to peer-reviewed journals.

Literature review: Experiences of Identity Change and Reconstruction after Traumatic Brain Injury: A Metasynthesis of Qualitative Research

Background. Evidence suggests that traumatic brain injury has a profound impact on survivors' sense of self or who they are as a person. This is often referred to as "identity change" (e.g. Biderman, Daniels-Zide, Reyes, & Marks, 2006; Coetzer, 2008; Gracey & Ownsworth, 2008; Segal, 2010). Reconstructing a positive sense of self after injury is thought to be important to successful rehabilitation (Biderman et al., 2006; Coetzer, 2008; Heller, Levin, Mukherjee, & Reis, 2006; Morris, 2004; Ylvisaker, McPherson, Kayes, & Pellett, 2008).

Several qualitative studies (mostly using interviews) have examined how survivors come to make judgements that their identity has changed and also how they reconstruct their sense of self after injury. They have looked at the psychological and social processes involved. As yet, these findings have not been brought together.

Aim. This literature review aimed to systematically review and integrate findings from qualitative studies which shed light on the psychological and social processes which contribute to experiences of identity change and reconstruction after TBI.

Method. A systematic literature search identified published qualitative studies which looked at the processes contributing to experiences of identity change and reconstruction in individuals with a traumatic brain injury. The findings of these studies were integrated using guidelines for metasynthesis outlined by Thomas and Harden (2008).

Findings. The review produced nine over-arching themes which summarised the processes contributing experiences of identity change and reconstruction following traumatic brain injury. These were: 1) loss of self-knowledge; 2) experiences of personal and social discrepancy; 3) discrepancies between self-experiences and the discourses and practices of others; 4) lack of legitimate social roles; 5) discourses and practices that deny personhood; 6) recovering self; 7) continuity amid change; 8) acceptance; 9) personal growth and meaning-making. Table 7 below provides a brief summary of the main features of each theme.

Table 7

List of Study Themes for Literature Review

Overarching Theme	Theme	Description
Processes contributing to appraisals of identity change or loss post-injury	Loss of self-knowledge	Gaps in their autobiographical memory and loss of knowledge about their skills and capabilities contributed to participants' judgements that they had changed after the injury.
	Experiences of personal and social discrepancy	Participants noticed changes in aspects of their cognition, functioning, emotional experience, and social roles after the injury. These changes prompted them to reflect on their identity and make judgements of identity change and loss.
	Discrepancies between self-experiences and the discourses/practices of others	The responses of family, friends, and employers towards them, and authoritative medical discourses, often contradicted how participants saw themselves. In particular, discourses of change, damage and deficit threatened participants' experience of a stable and intact inner self.

Overarching Theme	Theme	Description
Processes contributing to negative reconstruction of identity post-injury	Lack of legitimate social roles and unmet milestones	Participants found it difficult to take part in social roles, meet social milestones (like getting married), and compared themselves negatively with other people after the injury. This led to them making negative reconstructions of their identity as inferior or lacking self-worth.
	Discourses and practices that deny personhood	Discourses, including medical discourses, which denied the full personhood of the individual (as a unique, independent individual) contributed to participants' negative reconstruction of themselves as a member of a homogenous, low status, dependent group after the injury.
Processes contributing to adaptive and coherent reconstruction of identity post-injury	Recovering self	Being able to take part in meaningful social roles (like working) was important to reconstructing a positive sense of identity after the injury. But trying to get back to the exact person they were before the injury seemed to be linked to denial of change and was thought to hinder the development of a positive identity in the long-term.
	Continuity amid change	Recognising the aspects of themselves that had remained unchanged from before the injury (although lots of things had changed) was thought to support the development of a coherent identity after the injury.
	Acceptance and letting go	Letting go of the old self and accepting change and loss was considered to be important in order to move forward and reconstruct a positive sense of identity in the present.
	Personal growth and meaning-making	Some participants discussed that although they had lost a great deal, the injury had led to positive change in them as a person. They discussed learning about what was really important in life and growing as a person.

Conclusions. The review highlighted that it is not just the brain injury itself that leads to experiences that the survivor has changed as a person. A number of psychological and social processes contribute to survivors' judgements that they have changed. Understanding these processes may help rehabilitation services guide survivors more effectively through experiences of identity change and loss, avoiding undue distress to achieve more positive outcomes.

Empirical Paper: Experiences of Couplehood and Continuity after Acquired Brain Injury: An Interpretative Phenomenological Analysis

Background. Partners and spouses become a primary source of support after an acquired brain injury and relationships have been found to be extremely important for the well-being (Kendall & Terry, 2009; Palmer & Glass, 2003) and rehabilitation outcomes (Clark & Smith, 1999; Evans et al., 1987; Sander et al., 2002) of individuals following brain injury. A positive relationship is also important for the well-being of the spouse who has not been injured (Anderson, Parmenter, & Mok, 2002; Epstein-Lubow, Beevers, Bishop, & Miller, 2009). At the same time, there is lots of research saying that marital relationships are placed under significant strain after brain injury (Blais & Boisvert, 2005; Burridge, Williams, Yates, Harris, & Ward, 2007; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; Gosling & Oddy, 1999; Peters, Stambrook, Moore, & Esses, 1990; Peters et al., 1992; Ponsford, 2003).

Research shows that it is not just the changes in the injured spouse but also the way that the uninjured spouse *perceives* those changes that can impact on adjustment to brain injury. In dementia research, it has been suggested that spouses differ in terms of whether they see their relationship as continuous with the premorbid relationship or radically different. The research suggests that perceptions of continuity may be associated with more positive response to caregiving and more person-centred care (Riley et al., 2013; Walters, Oyebode, &

Riley, 2010). As yet, there is no detailed study looking at the idea of continuity in the context of acquired brain injury.

Aims. The aim of this study was to explore spouses' experiences of their relationship and caregiving after acquired brain injury. It also set out to see if the idea of continuity was useful for understanding how spouses of people with acquired brain injury understand their relationship and caregiving experiences.

Method. A qualitative approach was used which involved interviewing a small number of participants and analysing the interviews in detail.

Six spouses of people with acquired brain injury were recruited from an NHS out-patient brain injury service and branches of Headway, a brain injury charity. Each participant gave their informed consent to participate in the study. The participants each took part in two interviews about their experiences of their relationship and of caregiving before and after the injury. These interviews were all audio-recorded and transcribed word-for-word. To protect participant anonymity, all information (like names and places) that could lead to participant identification was removed or changed.

The transcripts of the interviews were analysed in detail using an approach called interpretative phenomenological analysis (IPA; Smith, 1996). The aim was to understand individual experiences. Each transcript was carefully read several times and a list of themes was developed for each participant. Finally the themes for all participants were looked at together and a final list of themes was developed. The researcher's interest in continuity of relationships after brain injury also contributed to this process.

Findings. Three overarching themes emerged from the interview data which showed that the idea of continuity-discontinuity was useful in understanding participants' experiences of their spouse, their relationship, and their caregiving role after the injury. Table 8 below lists the main features of each theme.

Table 8

List of Study Themes for Empirical Paper

Overarching theme	Theme	Description
Dynamics of person	(Dis)continuity of person	Following brain injury, some participants experienced their spouse to be fundamentally the same person, with changes incorporated into their continuing identity. Other participants experienced their spouse to be a completely different person
	Depersonalising narratives	Experiences of the person as completely different tended to be associated with a depersonalised view of the person.
	Loss and grief	Experiences of the person as completely different tended to be associated with experiences of grief and loss
Dynamics of relationship	(Dis)continuity of relationship	Following brain injury, some participants experienced their relationship to be completely finished and defined only by caregiving. Other participants experienced their relationship to be fundamentally intact although changed. All participants described changes in mutuality or reciprocity, togetherness, and their feelings towards their spouse which contributed to their experiences that their relationship had changed. Participants who experienced discontinuity described greater changes in these areas.
	Pre-injury relationship	It is proposed that experiences of continuity-discontinuity may relate to spouses' pre-injury relationships in idiosyncratic ways. In particular, if those aspects of the person and relationship which were particularly valued or central to the pre-injury relationship are changed following injury, this may result in greater perceived discontinuity.
Dynamics of caregiving	Making sense of changes in the person	It is proposed that those participants who experienced greater continuity with the past, were more likely to draw on their knowledge and understanding of the pre-injury person to make sense of and respond to post-injury changes in the person. Those participants who experienced discontinuity were more likely to require external support for understanding and managing changes.
	Impact of caregiving	It is proposed that experiences of continuity are associated with a better sense of adjustment to the caregiving role.

Conclusions. Broadly, experiences of relationship continuity were associated with a better sense of adjustment and more person-centred approaches to caregiving.

References

Anderson, M. I.,Parmenter, T. R., &Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: Path model analysis. *Brain Injury, 16*, 743-757. doi:10.1080/02699050210128906

Biderman, D., Daniels-Zide, E., Reyes, A., & Marks, B. (2006). Ego-identity: Can it be reconstituted after a brain injury? *International Journal of Psychology, 41*, 355-361. doi:10.1080/00207590500345963

Blais, C. M., & Boisvert, J. M. (2005). Psychological and marital adjustment in couples following a traumatic brain injury (TBI): A critical review. *Brain Injury*, *19*(14), 1223-1235. doi:10.1080/02699050500309387

Burridge, A. C., Williams, W. H., Yates, P. J., Harris, A., & Ward, C. (2007). Spousal relationship satisfaction following acquired brain injury: The role of insight and socio-emotional skill. *Neuropsychological Rehabilitation, 17,* 95-105. doi:10.1080/09602010500505070

Clark, M. S., & Smith, D. S. (1999). Psychological correlates of outcome following rehabilitation from stroke. *Clinical Rehabilitation, 13,* 129-140. doi:10.1191/026921599673399613

Coetzer, R. (2008). Holistic neuro-rehabilitation in the community: Is identity a key issue? *Neuropsychological Rehabilitation*, *18*, 766-783. doi:10.1080/09602010701860266

Epstein-Lubow, G. P., Beevers, C. G., Bishop, D. S., & Miller, I. W. (2009). Family functioning is associated with depressive symptoms in caregivers of acute stroke survivors. *Archives of Physical Medicine and Rehabilitation*, *90,* 947-955. doi:10.1016/j.apmr.2008.12.014

Evans, R. L., Bishop, D. S., Matlock, A. L., Stranahan, S., Halar, E. M., & Noonan, W. C. (1987). Prestroke family interaction as a predictor of stroke outcome. *Archives of Physical Medicine & Rehabilitation, 68,* 508-12.

Godwin, E. E., Kreutzer, J. S., Arango-Lasprilla, J. C., & Lehan, T. J. (2011). Marriage after brain injury: Review, analysis, and research recommendations. *Journal of Head Trauma Rehabilitation*, *26*, 43-55. doi:10.1097/HTR.0b013e3182048f54

Gosling, J., & Oddy, M. (1999). Rearranged marriages: Marital relationships after head injury. *Brain Injury*, *13,* 785-796. doi:10.1080/026990599121179

Gracey, F., & Ownsworth, T. (2008). Editorial. *Neuropsychological Rehabilitation*, *18,* 522-526. doi:10.1080/09602010802141509

Heller, W., Levin, R. L., Mukherjee, D., & Reis, J. P. (2006). Characters in contexts: Identity and personality processes that influence individual and family adjustment to brain injury. *The Journal of Rehabilitation, 72,* 44-49.

Kendall, E., & Terry, D. (2009). Predicting emotional well-being following traumatic brain injury: A test of mediated and moderated models. *Social Science & Medicine, 69,* 947-954. doi:10.1016/j.socscimed.2009.06.021

Morris, S. (2004). Rebuilding identity through narrative following traumatic brain injury. *Journal of Cognitive Rehabilitation, 22,* 15-21.

Palmer, S, & Glass, T. A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology, 48,* 255-265. doi:10.1037/0090-5550.48.4.255

Peters, L. C., Stambrook, M., Moore, A. D., & Esses, L. (1990). Psychosocial sequelae of closed head injury: Effects on the marital relationship. *Brain Injury, 4*, 39-47. doi:10.3109/02699059009026147

Peters, L. C., Stambrook, M., Moore, A. D., Zubek, E., Dubo, H., & Blumenschein, S. (1992). Differential effects of spinal cord injury and head injury on marital adjustment. *Brain Injury*, *6*, 461-467. doi.org/10.3109/02699059209008141

Ponsford, J. (2003). Sexual changes associated with traumatic brain injury. *Neuropsychological Rehabilitation*, *13*, 275-289. doi:10.1080/09602010244000363

Riley, G. A., Fisher, G., Hagger, B. F., Elliott, A., Le Serve, H., & Oyebode, J. R. (2013). The Birmingham Relationship Continuity Measure: The development and evaluation of a measure of the perceived continuity of spousal relationships in dementia. *International Psychogeriatrics*, *25*, 263-274. doi:10.1017/S1041610212001743

Sander, A. M., Carosell, J. S., High, W. M., Becker, C., Neese, L., & Scheibel, R. (2002). Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Injury*, *16*, 649-657. doi:10.1080/02699050210128889

Segal, D. (2010). Exploring the importance of identity following acquired brain injury: A review of the literature. *International Journal of Child, Youth and Family Studies*, *1*, 293-314.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11,* 261-271. doi:10.1080/08870449608400256

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8,* 45. doi:10.1186/1471-2288-8-45

Walters, A. H., Oyebode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia*, *9*, 169-189. doi:10.1177/1471301209354027

Ylvisaker, M., McPherson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping: Facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychological Rehabilitation*, *18*, 713-741. doi:10.1080/09602010802201832

Appendix C: Critical Appraisal Skills Programme (CASP) Tool

Critical Appraisal Skills Programme (2010). *Critical Appraisal Skills Programme: making sense of evidence about clinical effectiveness: 11 questions to help you make sense of a trial*. Retrieved from http://www.casp-uk.net/wp-content/uploads/2011/11/CASP_RCT_Appraisal_Checklist_14oct10.pdf

Appendix C: Critical Appraisal Skills Programme (CASP) Tool

	Screening questions	
1	Was there a clear statement of the aims of the research? *Consider:* *– what the goal of the research was* *– why it is important* *– its relevance*	
2	Is a qualitative methodology appropriate? *Consider:* *– if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*	
	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?)*	Write comments here
	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)*	Write comments here
	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*	Write comments here

	explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use 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	
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*	Write comments here
	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*	Write comments here
	Data Analysis	
8	Was the data analysis sufficiently rigorous?	Write comments here

	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*	Write comments here
	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*	Write comments here

Appendix D: Table A1. Table of Themes for Metasynthesis

Theme	Contributing studies	Key quotations
Processes contributing to appraisals of identity change, loss, and diminishment:		
Loss of self-knowledge	Conneeley, 2012	“I had no idea what I could do any more” (p. 78).
	Jumisko, Lexell, & Söderberg, 2005	“I don't remember anything about my life before the accident... [W]hen I woke up, I couldn't identify my mother, my brothers, and sisters, I couldn't identify anything. ...I didn't know I was an almost 18-year-old girl. ...I didn’t know what one should do as a human being” (p. 44).
	Krefting, 1989	“I lost it all – all of it. I lost my professional career, my education, even what I knew and felt about myself. I lost my goddam personality. There is nothing left, and at times I feel like a baby having to learn [about] me and the world all over again” (p. 75).
		“I don't remember myself in my later years with this amnesia. I remember myself most clearly at 17 years old. [...] I am now only just getting to know this person in the mirror. I don't even look anything like I remembered. I don't feel, somehow, like I am anything like I was.” (p. 76)
	Muenchenberger, Kendall, & Neal, 2008	“[my accident] had a big impact and that’s the date that I was re-born if you like” (p. 983).
		“’cause you’re brought up with the ‘self’ you know, you dealt with everything and it doesn’t matter how old you are, the history you’ve had gets you to the point that you’re at now and then to become something totally different.” (p. 985).
		“I wasn’t the way I used to [be] . . . 35 years builds you up dealing with everything to get to that point, then one day this happens, you wake up with a totally different everything.” (p.985).
		“I live my life without a certainty I must admit, of most things without a certainty of making the right decisions or thinking the right way or doing the right thing . . .” (p. 985-986).
	Nochi, 1997; Nochi, 1998a	“It’s like a void, or a black hole. It’s like, my memory is like a chalkboard, where some parts are erased” (p. 539).
	Nochi, 1998a	“I struggle daily to do my job and be the person I used to be. I still, after two years, am trying to redefine myself. I don't know this person any more. She is not reliable and cannot be trusted as my best friend” (p. 872).
	O’Callaghan, Powell, & Oyebode, 2006	“I was almost living like this little dream that I’m actually not here, and I felt that for a long, long time . . . I’m like a ghost that’s trying to still live a life, but who’s actually died” (p. 586).
	Padilla, 2003	“You would think that after 20 years my body wouldn’t keep playing tricks on me” (p. 418).
	Roundhill, Williams, & Hughes, 2007	“I had to be reborn, learn everything again” (p. 247).
		“It was like an ending to my life. It ended and began again. It felt like my life that I was living up until the head injury had ended. And that a different life had begun. I felt as though I didn’t even know that I had a personality to start with. I felt really sort of empty” (p. 247).

Theme	Contributing studies	Key quotations
Experiences of personal and social discrepancy	Chamberlain, 2006	“I used to be proud of my job and I earned a good wage. I’ll never be able to work in that [executive] job again. Now I have a fraction of that money to live on. I have dropped from $25 per hour to less than $6. I have lost my identity, who will respect me now? No respect, no income; and that which I value so much – my mind – it doesn’t work like it used to. I don’t think it will ever be the same” (p. 411).
	Conneeley, 2012	“I don’t feel like I did about myself when I didn’t have this incapacity. I don’t feel like I used to be, I feel, if you like, like a lesser person than I used to be because I used to be an assistant general manager . . . so now things are different” (p. 80).
	Crisp, 1993	“I'm bloody slower . . . I work slower . . . I hate saying that . . . I'm very evasive to admitting to that . . . It frustrates me knowing what my abilities used to be . . . We know what we were like before the accident and that's the worst bloody thing . . . Hardly a day goes by that I don't think about it . . .” (p. 398). “I hate the person I am now . . . I don't like the person I am. ‘Hate’ is too strong . . . There is a little bit I don't like about myself. It’s an ever moving scale” (p. 398)
	Gelech & Desjardins, 2011	“As soon as you have ‘doctor’ in front of your name, people look at you differently, you know what I mean? You know, if you don’t have a title in front of your name, that takes away a lot from you” (p. 66). “I’m no longer Miss M. the teacher. I’m Barb the resident at [long-term care facility]” (p. 66).
	Gutman & Napier-Klemic, 1996	“I feel like a less-than-competent male. I feel less than the man I know myself to be....I've been on the outskirts of society for 18 years because when you have a head injury, your whole being, your whole person, is put into another life-style and existence” (p. 538). “I worked for an import-export company. I was a landing agent. It used to take two guys to do my job when I wasn't on that night. I would definitely have been in an executive-level position in that company if I hadn’t had a head injury” (p. 540). “I know I would have been in an executive level position at work by now [...] It just feels like part of my life was not fulfilled” (p. 540-541).
	Hoogerdijk, Runge, & Haugboelle, 2011	“I’m not normal: it will never be like I was before. I think differently and I feel different” (p. 125). “Actually, I couldn’t perform my job properly any more. I pretended I could, but I couldn’t” (p. 125).
	Howes, Benton, & Edwards, 2005	“I just feel different somehow and I don’t know why or how I’m different but I just know I am” (p. 132). “Concentration is also a big one; I have trouble reading a book. I can read a book but only a chapter at a time, and then I have to have a break because my brain gets too tired” (p. 132). “I don’t have as much energy as I used to. I get tired far more easily, when I say tired I don’t really mean tired I mean exhausted” (p. 133). “Before I used to be the main wage earner [...]” (134).

Theme	Contributing studies	Key quotations
	Jones & Curtin, 2011	"Before the accident I might have done probably 10% of the housework and now I probably do 90% of it; the wife's at work and that's how I fill in the day, just doing that. [. . .] Housework is virtually all I can do at the moment, which is getting on my nerves. [. . .] I help out as much as I can at home [but] it gets to you after a while, not being able to go out and do things. I wish it was reversed and the wife was home and I went out to work" (p. 1575). "I was always brought up that 'if you start a job you finish it' and that's what I can't do at the moment" (p. 1575). "I am so used to being able to work lots of hours in a day, every day, cause I am a big lad and for 13 years I worked 20-hour days. Now it frustrates me that I can only do 4 hours and still want to do more, but I can't" (p. 1575-1756).
	Klinger, 2005	"The way your body functions has changed, the way your habits has changed… the way you approach things has changed, the way you relate to people has changed. So that kind of [is] how you have to become a new person" (p. 12). "since I can't be… that physically active, I can't be into sports…. So my life used to be entirely engaged in activity – but since this happened to me… I feel like I'm useless" (p. 12). "things were tough, because I was different… I couldn't do everything I normally could have" (p. 12). "could-a been; should-a been; but wasn't" (p. 12).
	Kovarsky, Shaw, & Adingono-Smith, 2007	"No. School teacher's days they tell me are over now. [...] I'm still kind of upset that I can't go back to teaching" (p. 61).
	Krefting, 1989	"I had everything the American dream [describes] - there was nothing that could get in my way, [yet] I lost it all – all of it. I lost my professional career, my education, even what I knew and felt about myself. I lost my goddam personality. There is nothing left, and at times I feel like a baby having to learn [about] me and the world all over again" (p. 75). "I am not who I was" (p. 76). Gail said she did nothing 'major' because she was no longer a 'major' person as she was before the accident: "When they ask me what I do, for the last couple of years I have said 'nothing'. After that 75% of people don't want to talk to you. But if you are working, then you are one of the guys. If not, who knows what you are" (p. 77).
	Muenchenberger, Kendall, & Neal, 2008	"my whole life changed . . . I realized that a lot of the skills were gone, and I wasn't accepted socially as much . . . I knew there was something different" (p. 985).
	Nochi, 1998a	"After the accident... my son was three years old, and I knew he was my son. But the feeling like we were connected was gone. He was a total stand-alone person. (...) I'd always felt like we were somehow, like there was a magic cord from me to him. It was gone right after the accident" (p. 873). "It has been an extremely emotional roller coaster for me in realizing that the direction that I wanted to pursue has been snatched away" (p. 873).

Theme	Contributing studies	Key quotations
	O'Callaghan, Powell, & Oyebode, 2006	"I feel I was a very strong figure for my children and my husband, but now our roles have changed, I'm the child" (p. 586).
		". . . . Why am I still here? . . . Everything I can do has been taken away from me. What use am I?" (p. 586).
	Padilla, 2003	"I was exuberant, a complete extrovert. [...] I loved to be spontaneous. [...] I would still be that way, I think, if life hadn't changed. Now I don't do much spontaneously, and everything takes a lot of planning" (p. 417).
		"I felt fulfilled. I would have continued to work on my causes and made a difference to the world. Now, I am not sure of what difference I make. (p. 417).
		"I remember my life before my head injury as full, active, fun. [...] and the best way I can describe it is as though I woke up on one side of a ravine looking over at the other side where that full life of mine had taken place and where I saw everybody else's life taking place. I didn't know how I had ended up on this side, but I wanted to get back to the other side. [...]" (p. 419).
	Parsons & Stanley, 2008	"... even the f ... way I talk – it's so slow and I sound like I'm drunk or angry, it just makes me feel so small ... Before my crash I used to have a lot of friends – but now I've hardly got any ... I have lost things, my friends, normal way of everyday life, all these things that I can't do which are so easy and basic for other people to do" (p. 233).
	Price-Lackey & Cashman, 1996	"I do keep a journal, but...it is very frustrating. It's a constant reminder. It's like having been a dancer, and now being crippled and not being able to go up on one leg again. In trying to define myself in the world without some of the ways that] defined myself before, I asked myself, 'If I'm not a writer, if I'm not a doer, who can do things for other people because] no longer have the capacity. If I'm not any of those things, then who am I as a person?'" (p. 311).
	Soeker, 2011	"It is a little difficult to think, but what I realised was that my concentration was definitely weaker. It was really difficult for me to concentrate on something that was complicated" (p. 84).
		"I want to do something, like he is moving all his girlfriend's furniture now. Normally I would do it but they've taken over that role, which eventually would have happened if I were a 65 year old, old man, but I am a 65 year old young man. I did everything. It was always me, the main man" (p. 84).
		"I've lost a lot of it. I mean it was a lifetime, it took away a lifetime from me. It's a lot" (p. 85).
	Strandberg, 2009	"And suddenly after the injury I was forced to take help, myself, despite you are an adult, that is also – that takes naturally on the subconscious, somehow. That you can't do things by yourself, as you used to do earlier. . . . Later, you need to beg for help almost for everything you have to do, then people help you, of course, but it takes naturally on the *self-esteem*, that you can't do what you might have done earlier" (p. 286).
		"Yes according to my opinion, *identity crisis* is quite a good word, because when you are pulled from your own safety surroundings – if I say surroundings – I mean your established environment at home and work, leisure or whatever, then I have realized that at least I have need of security..." (p. 288)

Theme	Contributing studies	Key quotations
Lack of legitimate social roles and unmet milestones	Crisp, 1993	"I'm an idiot, I'm unmarried . . . I'm the only failure in the family . . . I don't feel like a brother. They [brother and sister] have made it, I have not. They have spouses, children, money . . . [my] self-esteem goes down and down . . . I feel useless" (p.397).
	Glover, 2003	"I felt absolutely useless because you're a survivor if you like but you're not . . . you feel worthless, you aren't profitable you just feel a spare part sitting there doing nothing, watching everyone else do it round you" (p. 753).
	Gutman & Napier-Klemic, 1996	"There's so much of my life that didn't go the way it should have... I'm a man who has been battling to prove myself a man for the last 18 years because of this head injury. I should have already fallen in love and gotten married, had a family, gone down that route. I know I would have been in an executive level position at work by now... I'd like to be able to show that I'm not the kind of man who is professionally and financially kept. You know, being a member of a community somewhere. [And my father could say,] 'Oh yeah, that's where [Jonny] lives'. You know, a normal community residence somewhere. It just feels like a part of my life was not fulfilled" (p. 540 - 541). "I should have achieved all that [marriage, family, career] by now. I imagine all of the guys [old friends] eventually hooked up with one woman and had the family and all that. All but [Jonny] here. [Jonny's] here with the head injury career" (p. 541). "I'm the oldest of four brothers. They're all married and have families. I feel like, when's it gonna be me?" (p. 541).
	Muenchenberger, Kendall, & Neal, 2008	"If I can do the same things as everybody else then that's all that matters" (p. 986). "everyone's got to have a girl . . . you feel really inferior without a partner . . . not good about yourself, frustrated, annoyed, I'd see the other blokes with lovely ladies marching off somewhere" (p. 986).
	Soeker, 2011	"Upset, I think about it all the time. I just think I'll never get a job where I can get decent money. So I just live day to day. Not like my brother who . . . they can do what they want you know, like my twin brother he just spends money left, right and centre" (p. 87).
Discrepancies between self-experiences and the discourses/ practices of others	Conneeley, 2002	"How I get on with people I don't think has particularly changed but I think people must obviously have a different view of me because they're assessing, you know, does he really understand this, this sort of thing" (p. 360).

Theme	Contributing studies	Key quotations
	Gelech & Desjardins, 2011	“Yeah, like I think, I think I’m okay. But yet I have tests, I have cognitive tests and they all prove that, no, you’re not what you used to be. I had tests done, you know, and he said, ‘Well according to what we have on your information, your standards and stuff, you’re down considerably’. But I don’t consider myself a dimwit really” (p. 67). “I don’t feel brain injured as far as how my brain works or how I experience reality. I was in a coma for so long and I couldn’t walk or talk for a year. They say that’s more evidence that I have a brain injury. But I don’t feel brain injured, so it’s like, just a story to me. I don’t feel anything wrong with my brain, [but] they insist that I’m brain injured. Well, wouldn’t they know?” (p. 67-68) “My dad was just crazy. He kept saying that he couldn’t believe that I wasn’t the same boy that I was. That’s the big thing” (p.68). “Oh yeah – other people see me as having changed. That’s why they’re not my friends anymore. That’s why I had to learn new friends and stuff” (p. 68). “Yeah. I think my family sees me as different. Well first of all, they see the wheelchair. And I have my sister that is condescending to me, because I’m in a wheelchair” (p. 68). “They [my family] feel I have changed because other people have told them it was going to be that way. They were counseled by people who told them that the person would have a complete personality change, like a split personality, like that” (p. 68).
	Howes, Benton, & Edwards, 2005	“I personally thought it went really well. but then work suspended me on grounds of not being able to do the job, so there was my perception and their perception and they were completely different . . .” (p. 135). “Now it’s got to the point where I am sick of people saying to me ‘oh no you don’t look very well’. And I look at myself and I think well to me I look ok and then I think maybe I’m not seeing myself properly” (p. 135).
	Muenchenberger, Kendall, & Neal, 2008	“[another challenge] is when you actually get over certain things but people around you are still thinking that you’re still the person that’s got the injury and that injury will always be with you because doctors or support workers or whoever, have told the people around you that this is how they will react, they’ll be like this forever, they’ll be this way, they can’t they’re just thinking that they can” (p. 988).
	Padilla, 2003	“I have a sense of total aloneness and isolation I started to feel during my rehabilitation and that has never left me … I couldn’t talk, I couldn’t move. I could understand perfectly what was going on around me, but I’d get frustrated because I couldn’t tell them how wrong they were when they’d tell my sister or father that I would only function at a ‘reflex level’ the rest of my life – that I probably didn’t have much of a mind left. Inside of me I was screaming! I felt marooned, [...] . I couldn’t bear the pity in my father’s eyes, the constant tearfulness of my sisters. I think everyone still just sees a twisted body and assumes I have a twisted mind to match” (p. 418).
	Soeker, 2011	“I could see the guys will no longer rely on me . . . They are no longer the same to me. They underestimate me” (p. 85).

Theme	Contributing studies	Key quotations
Discourses and practices that deny personhood	Chamberlain, 2006	“I haven’t recovered. I can’t even do my own hair. No sense of control…I don’t even choose what I wear” (p.413).
	Cloute, Mitchell, & Yates, 2008	“yeah but it is it is very peculiar to see one’s wife (.) whose head’s shaved totally inert (.) being you had physio every day when you were in coma (.) and then suddenly you’d be put on the tilt bed (. . .) er (.) it was quite surrealistic you know (.) it wasn’t you it was you were viewing somebody else” (p. 660).
	Conneeley, 2002; Conneeley, 2012	“Because I’ve been classed as this head-injured patient, other people approach me and talk to me and I can tell they’re making assumptions about what I can take and what I can’t take, or coming to conclusions. And sometimes they’re right and sometimes they’re not and I feel like shouting back, ‘Hang on a minute, I’m a normal human being too!’” (p. 360, p. 80).
	Conneeley, 2012	“In the early stages I had no problem with the hospital calling the shots. They said what I should do and where, and all the rest of it and I think that was entirely appropriate. . . . There’s me, I’d nearly been killed in a road accident, badly damaged as a result and not able to think for myself. I needed other people to take responsibility and I was given close direction at all stages, but then through the different stages of therapy, growing, not only in your ability to do things, but also in confidence and self-awareness, at what point do you then start to reclaim some sort of responsibility for your own? And I need the opportunity to do so” (p. 81) “I need a lot of help, I used to be able to go out on my own, do what I wanted, and now I can’t do that and when you’re used to doing a thing and them you can’t do it, it makes you feel very down. I’m finding it very hard to cope with, I just feel like I’ve lost my freedom” (p. 82).
	Gelech & Desjardins, 2011	“I’m no longer Miss M. the teacher. I’m Barb the resident at [long-term care facility].” (p. 66). “I am dependent on others now, like almost totally. I was pretty independent before. That’s been a change in my identity” (p. 66). “Umm . . . people in public, they just look at me and stare. Or they’re condescending to me, because of the wheelchair. . . . To the staff we are all the same, one body is just like the next” (p. 69). “There was an employee there [at a supported living home] who was an asshole from Assholeville. He didn’t care. ‘You fricken mentals, go suck rocks or watch TV, or whatever you want’” (p. 69). “Now that I have diabetes they’re really watching out for me. Which is a good thing for my own health, but I don’t feel like I am in control of my own body, of my own self” (p. 70).
	Gutman & Napier-Klemic, 1996	“I can recall once or twice being this close to suicide. I was in this program and that program, and after you get done with another program you say to yourself, ‘Well [Jon], when is this going to be, or that going to be?’ And nothing happens. When is my life going to be my own and not [that of] a client. If you're a client, you're not a person. You're looked at in a very clinical way” (p. 541). “We're dependent on staff members to be together. Either someone has to take me to my boyfriend or, if he comes over, someone has to rake him home. He can't stay over in my room [in the community group home] and I'm not allowed to spend nights at his apartment” (p. 541).

Theme	Contributing studies	Key quotations
	Kovarsky, Shaw, & Adingono-Smith, 2007	"so you all had a head injury that's why you're in this group" (p. 60).
	Lawson, Delamere, & Hutchinson, 2008	"I feel that I am losing my identity to a system which saved my life and thus seems to assume that it has a right to my soul; a system made up of well-meaning people who, through their professional arrogance, feel that they can control the path of their client's strengths and weaknesses from their few hours of professional evaluation, and that with their professional status and control of the purse strings they can impose their values and dictate the life course of their client who becomes a passive patient even if no longer hooked up to the fancy lifesaving equipment of the intensive care unit" (p. 242). "It is humiliating to be victim to the judgements of young professionals who are secure that they knowhow another should live, should work, what tires them, what is difficult, what is dangerous. I feel that I am rendered totally impotent. Decisions are made by others - I am incidental" (p. 243).
	Muenchenberger, Kendall, & Neal, 2008	"Getting out of the sick role [was a challenge] and I think I knew it wasn't me. It was never me. But I was told it was" (p. 985). "Initially, mum wanted to take me to the head injury society . . . I said 'what, I'm not like them' . . . I didn't want to be a part of a group that had a disability . . . and my disability was quite invisible to look at, and [being part of a society] kind of put me in the same category as people who had wheelchairs, and canes, and I didn't want that . . . because of that need for normality, to be so offended by your own disability and then to be thrown in a group [of people] with disabilities" (p. 987).
	Nochi, 1997	"I think they [medical staff] took that upon themselves to move me whether I liked it or not, because I needed other places besides this town" (p. 543). "I'm not able to do [make new friends] because, when you get into a new work place, you go in there as a head-injured person, and you go in there with a job coach. That makes them think differently of you because I have a job coach and I am head-injured. They might not really treat me the same as another person, ordinary person" (p. 545). "I don't, I don' t like the word 'disability' . I, I just, you know, that' s just society' s way of saying, you know. They [people with TBI] are more unique" (p. 547).
	Nochi, 1998a	"I don't like the term 'TBI' because it just puts another stigma. It puts things on people. It's just a title. (...) [Suppose I say] 'I have TBI", and that's going to stop people from getting to know me" (p. 873). "They're not like people who are retarded or mentally ill. They are perceived like that all in society" (p. 874).
	Nochi, 1998b	"I guess one of the fears now is this. If I say, 'Oh, I had a head trauma', then people are going to think that I'm, you know, beyond whole person. You know, then I'm going to be, you know, wacko, or 'Oh no! She can't', you know, 'She may not be dependable, she might be', you know, 'have a behavior problem!' or whatever" (p. 670). "They [parents] were worried about me too much. They always threatened me, 'If you go out, then you can't make it on your own!'" (p. 671).

Theme	Contributing studies	Key quotations
	Roscigno & Van Liew, 2008	"I feel that because of the head injury other people, mostly relatives and those who don't know me or just met me, treat me like a small child. I feel that some of my older relatives think of me as "little Kevin." … I notice people who work with the elderly or small children will raise the pitch in their voice. I notice people who do not know me very well will talk to me with a high pitch. … Those same people will explain to me what I need to do as if I am a 3-year-old" (p. 215).
		"Presently, due to my disability, I feel like girls that I show the slightest bit of interest in will still not even get a chance to know me" (p. 217).
		Describes an occasion when he broke his wrist: "The new childcare director wanted to call my mom, who didn't even live in the same area of the state. He wanted her to come and take me to the emergency room. I said, 'No!' The director insisted that my mom come and take me to the ER" (p. 217).
	Sabat, Moodley, & Kathard, 2006	"The trick is leaning how to deal with prejudices. It's not easy. Sometimes I get really angry like when I go to the till to pay and my fiancé is with me and they ask her for the money. It is as though I don't exist! [...] I wish they would see me and treat me like they would anyone else. I know that my body has been injured but my brain is still happening!" (p. 22).
		"I see that I fit in perfectly into society. But society, I feel, has a problem with me. I am a person! I think that people need to give us a chance" (p. 22).
	Soeker, 2011	"I can't live like this for the rest of my life [...] I'm not used to it. I like to be independent and not to depend on other people" (p. 86)
	Strandberg, 2009	"And suddenly after the injury I was forced to take help, myself, despite you are an adult, that is also – that takes naturally on the subconscious, somehow. That you can't do things by yourself, as you used to do earlier. . . . Later, you need to beg for help almost for everything you have to do, then people help you, of course, but it takes naturally on the *self-esteem*, that you can't do what you might have done earlier" (p. 286).
		"Yes, it has been clear for me that the view I had on disability, before the accident, that is quite common. [...]Yes, disabled people, they couldn't manage anything and need help with everything and you are 'clapped on your head' and so on. [...]" (p. 287).
Processes contributing to adaptive reconstruction of identity:		
Recovering self	Chamberlain, 2006	"I'll keep improving, with hard work of course, for the next… 10 years, or 20 years, no matter what. It's going to be difficult… never being 100% again. But I think I'm going to be close, eventually" (p. 413).
	Douglas, 2013	"I keep fit—gym, bike riding, yoga, karate . . . so I'm really doing stuff" (p. 66).
		"I got my licence back—very happy with that achievement" (p. 66).
	Gelech & Desjardins, 2011	"Well, the best aspect is it gave you an identity back. That a person's back in the workforce. Then you can feel proud; say, 'Yeah, I work at London Drugs'. People think, 'Good, he's a part of—a productive member again', you know? It's good" (p. 67)
		"My neuropsychologist tells me I'll never work competitively again, but I've been an entrepreneur in the past and I assume I'll get some sort of business going at some time" (p. 67).
	Glover, 2003	"You never accept disability, you never come to terms with it because you are always trying to be how you were before" (p. 754).

Theme	Contributing studies	Key quotations
	Gutman & Napier-Klemic, 1996	“I know that if I could have the opportunity to prove myself the man I know myself to be... to be the married man, the family man, to be the workaholic I was before my head injury, I know I could be the man I know myself to truly be” (p. 538).
	Hoogerdijk, Runge, & Haugboelle, 2011	“When I succeeded in doing something, it made me stronger, and the next day I tried it on my own” (p. 126). “My body and mind aren't 100% yet. I'm still working on it. Who knows?” (p. 127). “I’m not the old one [old self] yet” (p. 127)
	Jumisko, Lexell, & Söderberg, 2005	“I should understand that I've got this injury and that I will never be normal again, but on the other hand it’s difficult for me to think in that way; it is like giving up” (p. 46)
	Lawson, Delamere, & Hutchinson, 2008	“Seven months have now passed since the accident. Seven long months, seven short months – an eternity and no time at all. I cannot accept my disabilities. I feel that if I work hard enough, then I shall overcome them” (p. 244)
	Muenchenberger, Kendall, & Neal, 2008	“. . . all you want to go and do is be the person you can . . . cause you’re brought up with the ‘self’ you know, you dealt with everything and it doesn’t matter how old you are, the history you’ve had gets you to the point that you’re at now and then to become something totally different” (p. 985). “A major challenge would have been just trying to emulate the person that I was and the way I thought beforehand” (p. 985). “If I can do the same things as everybody else then that’s all that matters” (p. 986). “trying to keep up with them was noticeable . . . before, I could do everything they could” (p. 986). “I was in so much denial over my injuries and consequences, I just wanted to be normal, so I tried to partake in normal activities and sometimes it wasn’t so good” (p. 986). “[I was] learning a different way, the way of how to go about life and how to fit into the ‘norms’ of society. What society might class as ‘normal’ is what I was trying to fit into in the last 2 years to make sure I was being a part of society and behaving the right way and also seeing where I could correct my ways in order to keep the friends that I already have and to make new friendships” (p. 986). “the marriage didn’t last very long, but the reason that it was there, it achieved that . . . I suppose this [chapter] describes someone who was lost, who was trying to show the world that he wasn’t lost by doing things like getting married” (p. 986). “I think it was about the fact that I found something that I liked, I got excited about and someone else acknowledged it and that . . . confirmed that what I was doing was on the right track and that made me more excited about it and to take it to the next level and that’s what I feel now. I’m deciding for ‘me’ now . . . it wasn’t about the job itself it was about getting it. It was about the acknowledgement that I could do something . . . someone said I could do it” (p. 987).

Theme	Contributing studies	Key quotations
	Nochi, 1997	“I started to ride my bicycle again, uhm, gradually, a year after the accident. About six months after the accident, the first week or so, I managed to walk to stores to get a few supplies and came back (. . .) Then my life was expanding quite a bit. It was a gradual process” (p. 542).
	Nochi, 1998a; Nochi, 2000	“I'm still working on it [recovery]. I'll keep probably working on it for ten years, twenty years, no matter what, you know. I'm not looking forward to... never being 100% again. But I think I'm going to be very close to be 100%, you know”. (p. 873; p. 1799).
	O’Callaghan, Powell, & Oyebode, 2006	“For many months after the accident I completely denied there was anything wrong apart from the very physical injuries . . . I just thought if people would let me get back to work, let me get back to my house, let me get on with my life then it’d be ok” (p. 586).
	Padilla, 2003	“I tried, I really tried hard all those years – I tried to do everything people told me would be good for me, but didn’t realize that it wasn’t important what I did or even how I did it. What was important wasn’t ‘‘doing” at all. It was that through doing I could realize I could be myself, and be someone who, like others, continues to live and change and grow” (p. 419).
	Petrella, McColl, Krupa, & Johnston, 2005	“Up until that point I figured I could do this – which is one thing that they’ve been telling me is my biggest problem from the start of this – my perception of what I can do and my knowledge of what I can do. There is always a constant war between the two of them. I think I can do much better than I actually can and then I try to achieve that and I don’t make it” (p. 650). “I was at that point in my life trying very hard not to be a known brain injured person” (p. 650).
	Roscigno & Van Liew, 2008	“I always kept myself ultra busy. … I took all kinds of different therapies in order for me to overcome this disability” (p. 216).
	Roundhill, Williams, & Hughes, 2007	“However bad things are with people around me, I do know now I will improve. I know that I am going to make more of a recovery to be able to relate to that person much better than I was” (p. 248).
	Shotton, Simpson, & Smith, 2007	“I’ve sort of become more determined as well, since the accident to, I don’t know (pause). It makes me strive to be . . . you know to be something. It seems, it seems I want to get back to how I was before but I know that’s not possible but it still, that still hasn’t stopped me being . . . more determined” (p863). “I just wanted to get as far as I could before it stopped because I suppose I was realistic enough to know that it would stop eventually, but everyday that was going by things were improving and I could sense there was an (pause). I just wanted to get as far I could before it stopped . . . Even now, last weekend I proved I can still manage to be out at a function and I really enjoyed it. It’s the first time in a long time that I’ve really enjoyed that, that, that situation. I got a real buzz out of it . . . which in a way is good because you’re still striving [...]” (p. 864).
Continuity amid change and the essence of self	Conneeley, 2012	“It’s a process of, this was the case before the accident, put it in easier terms, growing up, I think the accident has speeded it up a little bit. To realise you’re married, with 2 kids, you just can’t do, go out. People at work, some of them are married too so I think I was on that way anyway” (p. 79).
	Crisp, 1993	“I haven't undergone extreme personality change . . . I feel the same as I've always been” (p. 399).

Theme	Contributing studies	Key quotations
	Gelech & Desjardins, 2011	“I have changed in other people’s eyes for sure, ’cause every time my mom sees me she cries. Yeah. But I still feel like the same person. It makes me sad, uh, makes me angry” (p. 68-69).
	Howes, Benton, & Edwards, 2005	“You are not completely different, you are still human” (p. 136).
	Jones & Curtin, 2011	“The jewellery course I’m doing [is] an extension of my trade as a Fitter and Turner; I’m working with metal still. So it’s great” (p.1573).
		“I am on my own now and doing heaps, doing a lot of community work on Tidy Towns [committee], the Community Drug and Alcohol team, on the Rates Committee and I am also President of the Country Music Muster Association [. . .] I have a bit of a profile in [names town] and I am a respected person. [. . .] I have always been a community person, but since my marriage break-up I have become a community person big time” (p. 1574).
	Nochi, 1998b	“I have to be who I am. That's normal to me. Sure. OK, I had a head injury. OK, I don't have a leg. I wake up in the middle of the night. I don't just get up and go to the bathroom. That's normal for me. But people and society don't see that as me. They are normal to them. Maybe I don't think they are. Normal is what you believe. I believe I'm normal” (p. 673).
		“Everybody falls down and bumps their heads. They have a head injury. They had a head injury in their life. What, what extent was it? Who knows? Give me that same chance. I have a head injury. I had a little more hurt, head injury than you have when you fell down and injured. But still have a head injury, the same as you” (p. 673).
		“I just have problems. It's better than saying he's got head injury or has disability or he's not right in the head, or whatever.... Everybody in the world has problems, so” (p. 673)
	O’Callaghan, Powell, & Oyebode, 2006	“To me it wasn’t a problem, it was just something that I always did. Of course it wasn’t!” (p. 587).
		“The first few days I was quite down and then after that I felt better really, like a weight was taken off me. It was like I didn’t have to kid myself anymore” (p. 587).
	Padilla, 2003	“I … spend … a … lot … of … time … looking … for … special … friends … from … the … past …or … keeping … track … of … them … I … don’t … know … what … I … would … do … if … I … couldn’t … do … this. It … helps … me … feel … like … I … still … belong … to … them … and … to … the … life … we … shared … back … then…” (p. 418).
	Parsons & Stanley, 2008	“just another chapter” (p. 234).

Theme	Contributing studies	Key quotations
	Price-Lackey & Cashman, 1996	“There are times of standing outside and looking at myself in the process of recovery] and appreciating my own determination [and] say ‘Well, at least I've got that.’ And I discovered that...who I was as a core person wasn't lost and wasn't damaged. And that was really an amazing discovery to come too So then I would look at moments like that and say, ‘I couldn't have achieved this level of discovery without having lost everything that was a part of my self-definition’” (p. 311)
		“Being able to write again had to do with how what I lost freed me. This summer [1994], I was trying to explore what it means to be a writer if you can't write. What is being a writer? Is it a mind set rather than a product? Then if it's a mind set and you can never do the product, then I'm stil1 a writer. [...] That even if I could never write another word ... 1 was still a writer” (p. 312).
	Roscigno & Van Liew, 2008	“One thing that I did not lose when I received the head injury is my extraordinarily vivid memory and my sense of humor. If I had lost my sense of humor, having to go through these traumatic experiences probably would have been impossible” (p. 215).
	Roundhill, Williams, & Hughes, 2007	“My drive and determination is, I believe, limitless. I get something in my brain and I am sure that I am damn well going to do it. It is my drive that does it for me. That is very much part of the old me” (p. 249)
Acceptance and letting go	Chamberlain, 2006	“I think recovery is a state of mind. Once I stopped focusing on what happened, I was very angry for a while, and once I started to get over the anger, everything fell into place” (p. 413).
	Conneeley, 2002; Conneeley, 2012	“I don’t see it simply a question of getting back, of reintegrating, just getting back to where I was before. The future’s going to be different anyway. It’s just a case of saying, in what way is the future going to be different from the past” (p. 361, p. 81)).
	Crisp, 1993	“I'm happy . . . I don't feel bitter. I know it's impossible to get back to the way I was. I often dream about it. I'm trying to. Then again, the world has opened up more to me. Things I know now I didn't then. I'm more independent (p. 398).
	Glover, 2003	“It takes you about 7 years or more to come to terms with the fact that yes, this is the way things are. This is the life, so we have to make the most of what we’ve got basically” (p. 754)
	Hoogerdijk, Runge, & Haugboelle, 2011	“not everything needs to change back” (p. 126).
		“I have read a story of a woman with brain injury who said that you have to stop trying to be who you were. It’s exactly like that” (p. 126).
		“Things just aren’t the same and I am trying to accept that, more and more” (p. 126).
	Howes, Benton, & Edwards, 2005	“It’s recognizing that you can do some things, which is good. As oppose to trying to be like you were before” (p. 136).
	Jumisko, Lexell, & Söderberg, 2005	“It's now almost 5 years actually. I should understand that I've got this injury and that I will never be normal again, but on the other hand it's difficult for me to think in that way; it is like giving up” (p. 46)

Theme	Contributing studies	Key quotations
	Klinger, 2005	"And I guess the real key was trying to deal with the fact that okay that old self was, I don't know, almost put it to rest and leave it behind, and you have to start a whole new person. So that doesn't happen overnight that's for sure, that takes some time… And you're struggling to get a new identity or at least retain what's left of the old one. And kind of adapt it" (p. 12). "There is a big step of acknowledgment that has to happen… you have to acknowledge that you need to find new things. So if I was content in spending the rest of my life assuming that I was going to be back in computer sciences, then I would never venture out to learn any strategies, or if I was going to assume that I was going to be back playing soccer or whatever, I would never have taken up Tai Chi… But it's hard to lay all those things to rest because that is what you've been doing your whole life. But you have to lay those things to rest, before you get started on the new things" (p. 12).
	Muenchenberger, Kendall, & Neal, 2008	"I didn't want to go back to [the early chapters], so I was able to get going again, you know sort of like 'no, I don't want to go back there'. Keep going, and it's hard and I say this to myself all the time, it's hard but you've got to keep going because somewhere something will happen and that will help you, but if you don't keep going, you know, you won't get anywhere" (p. 986).
	Nochi, 1997	"Gradually you can put that accident in perspective. It takes us, takes us a while, about a year. Then say, uhm, 'OK, it' s not the most important thing'. Then, I was focusing on what you can do with strength that you got" (p. 542-543).
	Nochi, 2000	"Every day I live for today. I do everything for today because, to me, the past never comes back. . . If I look at life from that respect, it gives me respect. It gives me hope. That's [how] I can make today, like, better than yesterday, and I don't worry about tomorrow" (p. 1799).
	O'Callaghan, Powell, & Oyebode, 2006	"This is how I feel, . . . I don't want to be unnatural . . . people have got to deal with me as I am now" (p. 588). "I don't completely accept it, but this is the way I am, this is what it will always be like" (p. 588).
	Padilla, 2003	"I have to abandon the past. It's gone – that's it" (p. 418). "I am no longer trying to crawl back to my old life and pick up where I left off. I am just trying now to find who I really am and what my life is about… Another sense in which I think of abandonment has to do with what I must do and redo every day in order to cross that ravine: I have to abandon my expectations of myself, the past, and others in order to live as fully as possible. I have to let go of everything I think holds me back so that I can actually wonder at what is …" (p. 419). "abandon yourself to this new day – abandon yourself to what might be new for you today – abandon yourself to what may come, and let go of what you wish were true. Keeping your hand clenched on the past doesn't let you accept anything new – abandon yourself and open your hand to see what new might come" (p. 419) "Maybe I needed this time to go by so I could finally be ready to let go" (p. 419).

Theme	Contributing studies	Key quotations
	Parsons & Stanley, 2008	"I just have to accept it that I have got that brain damage. It's not going to go away – it's there. I have to live with it. I either have to accept that I've got brain injury or kill myself. Two possibilities, I don't want to die so I've got to live with this" (p. 234). "Not very nice for me thinking – considering the past trying so hard to move on and forget about the bad things. Being repeating self to so many people ... like wearing the same old shoes for about 15 years, shoes too small for you and nearly worn out. Wants to get to new shoes, but everyone asks you questions about old shoes. After 10 years talking about same shoes ... had enough ... being fed up, sick of saying things. I have to repeat myself over and over again when I didn't want this brain injury. Want to forget about it and on the other hand people keep asking" (p. 235).
	Petrella, McColl, Krupa, & Johnston, 2005	"I was beginning to understand that there is this limitation thing that may be more pronounced than I thought it was, or maybe the limits are bigger than I thought they were (laughs). That's when I started having to accept that there are some things that have changed, and there is nothing I can do about it. Up until that point, I had actually contemplated the idea that I could eventually some day return to work. That was a realization process, I guess for me to sort of say, well maybe this is not going to happen. And I guess there is an acceptance – a period of time when you start accepting the way things are and although you've learned whatever coping strategies and or ways of dealing with things, it's time to say, well this is the way it is, it's not going to change. Not that that may be a bad thing. You know, it's that – well, is the glass half empty or half full thing. But admitting that it's not full any longer, I think is a big step" (p. 650).
	Price-Lackey & Cashman, 1996	"[...] what I lost freed me. [...] I started thinking about my creative process as being like a husband who died and ... if I was ever going to move on with my life ... I had to be open to new relationships... I could grieve and let go and accept a new relationship. And that allowed me to begin to write in a new way with a new process. ... The most positive thing to learn from the accident is ... that things will never be the same again. The only way for a major trauma to end up positive is to allow for the entire falling apart and restructuring. Life is about change. [...] [I]f I had only been focused on getting my writing skills back, I would have met with a great deal of constant failure. It would have placed too much emphasis on whether I could do those exact skills again.... [T]he experience that I've had exploring other things [tells me] I wouldn't necessarily have to be a writer. I could do something else. You always have to leave the door open to who you're becoming, not just who you were, bur to the possibility that you might discover, through this, that you can approach life entirely differently" (p. 312). "The process of healing and redefinition has also been a profound experience, providing new depth and richness to my life. The fact that my life has changed is no longer a source of grief to me, but something I embrace. [...] Life is, after all, an eternal process of being and becoming" (p. 312).
	Roscigno & Van Liew, 2008	"The children do not have a lot of preconceived notions about the way that I am. I find that the children are just more accepting of me the way that I am than most adults are" (p. 216).

Theme	Contributing studies	Key quotations
	Roundhill, Williams, & Hughes, 2007	“Well I don’t [think about losses] less. Because I’ve accepted it. Not happy about it but I can’t change it. So I think ‘Oh well, just get on with it’” (p. 246).
		“It used to make me upset. But now I sort of take it in regardless like. . . life goes on. That was life – it stopped. It’s moving but slowly. . .I feel I’m dealing with it. I never dealt – have never dealt with it, till I die” (p. 246).
		“Whatever happened to me happened to me. Nothing I can do about that now is there? But there’s something I can do about what I’ve got left. So I’ve got on with it" (p. 247).
		“You’ve got to accept what’s happened. You can either give up or try and approach things from a different angle” (p. 247).
	Sabat, Moodley, & Kathard, 2006	“I can either be happy and accept what is happening and look forward to the future, or be sad and regret what is done” (p. 22).
	Soeker, 2011	“I mean, I did sit and wonder. You know, how lucky I am, I can’t deny that, and obviously thinking about dying and near death experiences” (p. 86).
Personal growth and meaning-making	Chamberlain, 2006	“I need to have hope and respect. I get up in the morning and the sun is shining and I live for today, I do everything for today. That way, I can have hope in my life and the difficulty of coping is less. I am moving on” (p.413).
	Conneeley, 2012	“The accident has made me re look at everything, all that I’m concerned about now is my husband and my son and my sister and that we have a valuable life ahead of us and a long life ahead of us, and as for work, not really important, let’s do the things that are important” (p. 80-81).
		“Mentally very good, because in comparison, well, everything compares with dying, so, you know, everything’s great now. It’s incredible that it take something so hideous to make you appreciate life so much” (p. 82).
	Crisp, 1993	“Being in my position you tend not to follow the crowd . . . being alone gives me a chance to see really what is real” (p. 397).
		“Having the accident ruined my life . . . but I sort of feel that's life on earth . . . this has been sent to make me for some reason which I don't understand . . . I don't believe death is the end of everything . . . So I believe this part of my life is a bit horrible but maybe there's a reason . . . my religion is good support . . . I feel very secure with the affection of my family and friends and other people . . . ” (p. 399).
	Douglas, 2013	“I’m glad I had my accident because it’s made me into a better person. It’s made me help people. If I see a lady across the road with shopping I will run over and help her” (p. 68).
	Gelech & Desjardins, 2011	“Retards. That’s how I used to see the disabled. People, now I see them as people” (p. 70).
		“A person’s world maybe revolves too much around financial and having. That can happen too. And, you know, it’s easy to get involved in that” (p. 70)
	Glover, 2003	“I had the accident when I was 47 and it saved me from becoming staid in the job as I got older. I got up at four in the morning, how long could I keep working like that? It was God’s way of saying for Christ’s sake John slow down!” (p. 755).
		“[The accident] did me a favour [...] I was the most important thing on this planet, I wasn’t a very nice person. Some people say I’m better now, less aggressive, more laid back and they find me easier to talk to” (p. 755).

Theme	Contributing studies	Key quotations
	Howes, Benton, & Edwards, 2005	“I value life more. I don’t take it for granted. Every time I go out I think . . . you learn to live for the moment . . . I think you appreciate things more” (p. 136).
	Jones & Curtin, 2011	“The motor bike accident fitted in well with me trying to put my life back together because there was a big wake up [. . .] I could have died like that [clicks fingers], I went ‘I really should do something a bit more positive with my days on the planet [. . .]” (p.1573). “I believe that I am ‘chosen’; to find alcoholics anonymous, chosen to be living the life I am living now” (p. 1574). “I don’t earn much money but I own all this and this is all I have ever wanted, never wanted to be rich but comfortable and that is what I am. It is a bit harder now, cause there is Rick and her children, but they light up my life in a different way. Like I give them pleasure as much as they give me pleasure, I hope. They do their netball and football and dancing; they do whatever they want cause I want to help them do that. So that makes me happy and rich” (p. 1576). “I realise now that you don’t know when the end’s coming, it could be tomorrow; I went to work one night, fit and healthy, and woke up a month later laying in hospital. [. . .] It is a miracle how different am I from where I was before. [. . .] It wasn’t just a life changing experience for me; it was a life changing experience for a lot of people” (p. 1576).
	Jumisko, Lexell, & Söderberg, 2005	“I think I've developed a lot because of my suffering. I've got more from it I think. ...so, there is more good than bad” (p. 47).
	Klinger, 2005	“I think in a lot of ways, I’m a better person now than I was before the accident… I always had blinders on… I was kinda carefree and things happened in the world but they weren’t going to happen to me… Like before when I used to see someone walking down the street, they were retarded or something… I couldn’t care, get lost. Now when I see someone walking down the street, I don’t necessarily think they’re retarded, I have a lot more tolerance and a lot more appreciation for somebody that might look a little different; what they might have been through” (p. 12)
	Lawson, Delamere, & Hutchinson, 2008	“Our challenge, Dear doktor, Is to discover How to use, My near death, My fractured vision, My splintered brain For benefit In this, our world. Dead orchid – to garbage; Live woman – to living!” (p. 242).

Theme	Contributing studies	Key quotations
	Muenchenberger, Kendall, & Neal, 2008	“. . . a very dark period [but] I didn’t choose black for the reason that there has been a lot of good that has come out of my accident. Although probably when I was in that period I would have said black, now that I have perspective, it was grey” (p. 983). “I question everything because I feel that the ‘born again’ day made me a different person” (p. 986) “I think after having the accident you know, it’s like if I died right now, I’ve got to know that everything I do is good. Because you never know. I never knew that the accident was going to happen so I see that I’m still alive and I must be here for a reason, so, got to keep going” (p. 986). “. . . to actually accept that I had problems I had to fix was a challenge. And when you go through something like that you realize that the emphasis people put on certain things aren’t really that important. It’s not that important to show people that you are good . . . there are a lot more important things in life than what other people think” (p. 987).
	Nochi, 1998a	“My alcohol use mixed up quite a bit of my life. So I just... when I had my accident, it kind of was a balancing because it stopped my drug use and alcohol” (p. 873). “I, I don't know, there're no similarities to, of who I am and who I was. I don't know who I was. I don't care I don't know who I was. I tell you, if you live twice, the second time is the best”. (p. 873).
	Nochi, 2000	“My alcohol use mixed up quite a bit of my life. So I just... when I had my accident, it kind of was a balancing because it stopped my drug use and alcohol use for a while” (p. 1798). “If she [motorist who hit him] didn't do what she did, I probably would be dead by now if I lived the same way I was” (p. 1798). “I don't want to forget how bad I was because – I feel that I've worked so hard and trying to be better that – why should I forget it? I deserve a pat on the back for it. . . I like the idea of being – a guy that has been through something this bad. And I'm strong enough, mentally and physically, to conquer it. I like that feeling” (p. 1798). “I think it [the TBI experience] has really expanded my appreciation of other people and problems” (p. 1798).
	O’Callaghan, Powell, & Oyebode, 2006	Participants described having: “learned from their mistakes”; feeling “stronger”; and “valuing life more” (p. 588).
	Padilla, 2003	“Maybe this disability can give me the opportunity to relate to life more meaningfully. Maybe there is something I can share with others after all” (p. 419)
	Price-Lackey & Cashman, 1996	“I found I was turning 40 without a home ... without assets ...without a profession ...without a job, and without a man in my life. At different times in your life, when you turn a certain age, you have expectations that go along with it. Forty is an age [of] being settled professionally and physically.... [And I wasn't]. [Yet] at the same time, [turning 40] meant that I had entered this next segment of my life without preconceived ideas of what I was going to do with it. Once I... looked at how free I was [of] everything, then my choices were totally open. I could [...] evaluate where I was with things, what was important to me” (p. 311).

Theme	Contributing studies	Key quotations
	Roundhill, Williams, & Hughes, 2007	“This head injury stopped me going down the road I was. . .it made me reflect on my life before, saying ‘Don’t go down that road again’. I was a complete nutter. I thought to myself ‘You weren’t actually going anywhere. And the friends you did were a load of nut-cases, with no life and no prospects’” (p. 249). “I’m completely different, because in my younger days I was a bit of a tearaway. I’ve quietened down. It’s definitely positive, because I would have probably ended up in prison, for a long time, or dead” (p. 249). “I’m actually more compassionate and caring than before. I’ve become a very good husband. . .And compassionate toward other handicapped people” (p. 250) “It’s one good thing with the head injury that I do actually care about other people now. And know they exist!. . .I’m more patient as well. More patient with people who’ve got disabilities” (p. 250) “The most important things in life, things that really matter, I think the head injury has made me realise what they actually are. And they should be worked on. The other stuff shouldn’t be bothered with” (p. 250)
	Sabat, Moodley, & Kathard, 2006	“I used to be very naive and carefree. But the accident has transformed my life, the way I see things. I feel more grounded. I'm able to see the lighter side of things. I used to be a very negative guy” (p. 22-23). “The one and only thing I can remember from my coma is saying God please don't let me go. I was literally begging God to let me live, especially for my mother. Since then religion has become so important to me. It's brought my life into perspective. It has made me realise what is really important to me” (p. 23). “I believe that God is supreme. He is in charge of absolutely everything. And if he wanted this to happen, there had to be a Way. It had to be His Will. If God is willing who am I to question that? [...] My gift from Him is to help people by sharing my experiences with them and trying to put back into society what I've taken out. To search within myself and make a difference to others’ lives” (p. 23).
	Shotton, Simpson, & Smith, 2007	“The time I’ve spent with (my daughter) is a real bonus, there’s no way I would have spent that time with her before the injury . . . (p. 864). “So in an odd way, yeah it was a serious injury, on the one hand. But on the other hand, maybe it's done me bloody good. It's woken me up. It's brought me out of being stuck in this rut to getting out in the real big world” (p. 864).

Appendix F: Participant Information Sheet

UNIVERSITY OF BIRMINGHAM

Participant Information Sheet

Study title: Exploring close relationships after Traumatic Brain Injury

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

One of our team will go through this information sheet with you and answer any questions you have. This should take about 20 minutes. Ask us if there is anything that is not clear.

Talk to others about the study if you wish.

What is the purpose of the study?
I am a Trainee Clinical Psychologist at the University of Birmingham, supervised by Dr. Gerard Riley. This research study is being carried out as part of a Clinical Psychology Doctorate course. The study is exploring experiences of partners and spouses of people who have suffered a traumatic brain injury (i.e. damage to the brain caused by external forces such as a blow to the head).

Previous research has shown that relationships with partners or spouses are vitally important for the well-being and rehabilitation of people who have suffered a traumatic brain injury, as well for the well-being of the uninjured partner or spouse. We also know that these relationships can be placed under strain after a traumatic brain injury. Therefore it is important to look at what happens to relationships with partners and spouses after traumatic brain injury. Findings from this research may be helpful in developing family interventions after traumatic brain injury.

The main aims of our research are:

- To explore what happens to close relationships after traumatic brain injury.
- To explore how partners' and spouses' experience of their relationship impacts on the emotional aspects of caregiving.

Why have I been invited to take part?
You have been invited to take part because your partner or spouse has suffered a moderate or severe traumatic brain injury in the last five years, still experiences difficulties in daily life because of this. We will be recruiting a maximum of eight people to take part in this study.

Do I have to take part?
It is up to you to decide whether to take part in the study. We will describe the study and go through this information sheet with you. If you agree to take part, we will ask you to sign a consent form. You will be free to leave at any time and without having to give a reason. This would not affect yours or your partner's NHS care.

What will I have to do during the study?
If you decide to take part, then I will meet with you **three** times. On the first occasion I will go through this information sheet with you and answer any questions you have about taking part in the research. If you decide to go ahead with the research, I will meet with you on two further occasions.

On each of these two further meetings, you will take part in a face-to-face interview with me. We will discuss your experiences of intimacy and closeness as well as difficult times in the relationship before and after the brain injury. We will also discuss how these experiences have affected your coping. Personal questions will be asked about past and present but you are free to decline to answer any question or stop the interview at any time.

Directly before the first interview, I will ask you to sign a consent form saying that you agree to take part. I will give you a copy of the consent form to keep for your records.

All interviews will be audio-recorded. After the interviews, the recordings will be typed up word-for-word into a typed record so that the researchers can analyse them at a later date.

Where will the research take place?
The research will take place at your home, local clinic or another suitable location of your choice.

How long will my participation in the study take?
If you decide to take part, I will meet with you for two interviews which will take place on two separate occasions. These will be about a week apart at times that are convenient for you. Each interview will last about 60 to 90 minutes.

How long will the research last?
The research is taking place between January 2012 and December 2013.

Expenses
We will reimburse you for any travel costs you incur as a result of taking part in the research. This will include petrol costs (at 40p per mile) and/or public transport costs (please retain tickets) for the return journey from your home to the interview location.

What are the possible disadvantages and risks of taking part?
It is the nature of the research to discuss your experience of your relationship in the context of a traumatic brain injury. Some of the discussion may involve talking about sensitive issues and you may find this distressing.

You will be offered breaks during the interviews and the option of rescheduling the interview if it becomes distressing. If you become very distressed during the interview, I will request your consent to speak to my academic supervisor, Dr Gerard Riley, at the University of Birmingham or Dr Louise Lorenc, consultant clinical neuropsychologist at Moor Green out-patient brain injury service, about any concerns and to signpost you to appropriate avenues of support.

What are the possible benefits of taking part?
We do not expect that you will experience any direct benefits from taking part in this research study. However, we do hope that our findings may help to improve our understanding of what happens to close relationships after traumatic brain injury. Such research may help to improve family interventions following traumatic brain injury.

What will happen if I don't want to carry on with the study?
Even after you have given consent, you are free to leave the study. You are free to stop and leave the interviews at any time without giving a reason. You do not have to answer a question if you do not wish to.

At the end of each interview, you will have an opportunity to identify any sections of the interview that you would prefer not to be used in the research study. These sections will not appear in the typed record and will not be used in the analysis.

Even after participation in the interviews, you can withdraw from the study. You will have **one week** after your final interview to inform the research team that you want to withdraw from the study. We will destroy any data collected including audio-recordings and typed record. After this time it will **not** be possible to destroy your data.

Your decision to leave the study will not affect yours or your partner's NHS care in any way.

What if there's a problem?
If you have a concern about any aspect of this study, you can speak to the researchers, Darrelle Villa or Dr Gerard Riley or the local collaborator for the project, Dr Louise Lorenc.

If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from your local Patient Advice and Liaison Service (PALS).

You can also make a complaint to the Head of the School of Psychology at the University of Birmingham, Prof Chris Miall.

Contact details are provided in the section '**Further information and contact details**' below.

Will my taking part be kept confidential?
Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

Your name and other identifying information will be changed to protect your anonymity. All your interview data, including audio recordings and typed record of your interviews will be identified using a pseudonym. Your personal details will be kept separately from the information collected so that it will only be possible to connect your interview data to you via a special code. Only members of the research team will have access to your identity, personal details, full interview recording and typed record of your interview.

Direct quotations from the interviews will be used in the write up of the project for doctoral thesis and in academic papers and presentations to academic conferences. Your name and other identifying information will be changed to protect your anonymity. There will be no way to identify who said the quotations.

Directly after each interview, you will be given the opportunity to identify parts of your interview that you would prefer not to be used in the analysis. These sections will not appear in the typed record and will not be analysed.

In the unlikely event that you said something in the interview that indicated that you or someone else may be at risk of harm, I would have a duty to disclose this. I would discuss this with my supervisor, Dr. Gerard Riley, to decide what action needs to be taken. This may include making a referral to social services. If you said something of this type, I would indicate this to you in the interview and we would discuss what the next steps would be.

Where will my personal information be stored?
All information will be kept at the University of Birmingham. Data stored on computers will be in password protected files. The computer will also be password protected and will be in a private locked office. Non-electronic sources of information such as consent forms and audio-recordings of your interviews will be locked in a cabinet in a locked office, where access is limited to the research team.

What will happen to my personal information afterwards?
According to University regulations, after the study is finished your data and personal information will be kept for 10 years after which it will be disposed of. Audio tapes will be kept until the researcher's degree is awarded. At that time, they will be erased and disposed of.

What will happen to the results of the study?
The findings of the research study will be written-up as part of a doctoral thesis. This thesis will be held in the University of Birmingham library and in the University of Birmingham e-Theses Repository.

The findings may also be published in academic journals and presented at academic conferences.

What will happen after I have participated?
After you have taken part, you will be sent a summary of the general findings of the study. This summary will not contain any identifying information or direct quotations.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Northampton Research Ethics Committee.

Further information and contact details

General information about research

For general information about taking part in research, please see the document: *Health Research and You* available at The Association of Research Ethics Committees website at: http://www.arec.org.uk/health/

Specific information about this research study

If you would like any further information about this study, please contact the researchers Darrelle Villa (Chief Investigator for the study) or Dr Gerard Riley (academic supervisor for the study).

Advice on participation

If you would like advice on whether to participate, please contact Darrelle Villa (Chief Investigator for the study) or Dr Louise Lorenc (local collaborator for the study).

For general advice about taking part in research you can also contact your local Patient Advice and Liaison Service (PALS).

Concerns and complaints

If you have a concern about any aspect of this study, please contact the researchers Darrelle Villa or Dr Gerard Riley. You can also contact the local collaborator for the project, Dr Louise Lorenc.

If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from your local Patient Advice and Liaison Service (PALS).

You can also make a complaint to the Head of the School of Psychology at the University of Birmingham, Prof Chris Miall.

Sources of support

If taking part in this study raises anything distressing for you, the following sources of support are available: Carers' Support Team at Moseley Hall Hospital, your local Patient Advice and Liaison Service (PALS), your local Headway brain injury charity branch.

If you are very distressed by the issues raised in this research study, please contact your GP.

Appendix G: Consent Form

Consent Form

Study title: Exploring close relationships after Traumatic Brain Injury

Name of researcher: Darrelle Villa

Thank you for considering taking part in this research. If you have any questions please ask a member of the research team before you decide whether to take part. You will be given a copy of this consent form to keep and refer to at any time.

Please tick

- I confirm that I have read and understood the information sheet dated 6 March 2012 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
- I understand that my participation is voluntary and that even after I have given consent, I am free to withdraw at any time without giving any reason. I understand that this will not affect any services that I or my partner/spouse receives from the NHS. ☐
- I understand I will have up to **one week** after my final interview to inform the research team that I want to withdraw from the study. Any data collected up to that point, including my audio-recordings and transcripts, will be destroyed. I understand that after that time, it will **not** be possible to destroy my data. ☐
- I understand that all information collected during the study will be confidential. Only members of the research team at the University of Birmingham will know if I have participated in the study and my name will not be held with any of my data or published in any reports. My name and contact details will be held in a password protected file on a password protected computer in a private locked office at the University of Birmingham separate from my data. ☐
- I understand that as part of the above study, interviews with me will be audio-recorded and that this recording will be used to produce a word-for-word typed record of the interview. ☐

- I understand that the audio-recordings will be kept in a locked cabinet at the University of Birmingham that only members of the research team will have access to. ☐

- I understand that quotations of things I have said in the interviews may be used in the study write up, academic publications and presentations at academic conferences. However, my name will not be used and there will be no way to identify who said the quotations. ☐

- I understand that I will be given the opportunity directly after each interview to identify parts of the interview that I would prefer not to be used in the analysis and that these sections will not appear in the typed record and will not be analysed. ☐

- I understand that in the event that I said something in the interview that indicated that myself or someone else may be at risk of harm, the researcher would have a duty to disclose this. This would be discussed with the research team to decide what action needs to be taken including making a referral to social services. ☐

- I agree to take part in the above study. ☐

- I agree for my GP to be informed of my participation in the above study ☐

Name of Participant (please print) ---

Signed -- Date ---

Name of Researcher taking consent (please print) -----------------------------------

Signed -- Date ---

Appendix H: Interview Schedule

Interview 1

Thank you for agreeing to share your personal experiences for this research. I would like to start by getting a sense of you and your relationship.

1. Can you tell me about how you met and became a couple? [Prompt: What was it about him/her that attracted you to him/her?]
2. Can you tell me about the early days of your relationship and memorable moments from that time?
3. Can you tell me about your (happy) memories that stand out over time from your lives together before the injury? [Prompt: How do you remember your feelings towards him/her?]
4. Can you tell me about time spent together as a couple before the injury? [Prompt: Did you do a lot together as a couple or have separate interests?]
5. Can you tell me about difficult or stressful times in your relationship before the injury and how you dealt with them as a couple?
6. Please can you pick out five words to describe him/her before the injury. I know this may take a bit of time so think for a minute, then I'd like to ask you why you chose them. I'll write each of them down as you give them to me.

   You described him/her as______ (each word in turn). Do any memories or incidents come to mind?
7. Please pick out five words to describe your relationship before the injury. Then I'd like to ask you why you chose them. I'll write each of them down as you give them to me.

   You described your relationship as______ (each word in turn). Do any memories or incidents come to mind?

8. If you feel comfortable, can you tell me about what happened when he/she was injured and how it has affected him/her.

Interview 2

1. Can you tell me your experiences of your relationship from the time of the accident?
2. Can you tell me about your time spent together as a couple now?
3. Can you tell me about what's good about your lives together at the moment?
4. Is there anything you find difficult about lives together at the moment? [Prompt: How does that feel? How do you manage/cope with that?]
5. How do you manage difficult/stressful times as a couple now?
6. What are your feelings towards him/her now?
7. Can you pick out five words to describe him/her now.
8. Can you pick out five words to describe the relationship now?
9. Do you think much about what life was like before?
10. How do you feel about the situation you find yourself in now?
11. What do you hope and fear for your relationship over the next few years? What do you expect will happen in reality?

Appendix I: Sample of Coded Transcript

I: So first of all really, I'd like to get a sense of you [and

J: Right [LAUGHS]]

I: your relationship. So can you tell me how you met and became a couple?

J: Um well we met- do you know I think the first time we met, I'd a been about fifteen something like that, um yeah. But we were- we knew each other and we said, "hello" and there was big crowd of us that used to hang round and um some of us would go camping away on weekends and then, you know, certain- there was just a big crowd of people that just hung round together

longevity of relationship

Sociable – part of wide social circle

remembering/telling me

– part of 'big crowd'

– camping, weekends away

I: Yeah.

J: um and then I- I think it was when Jeff broke his leg- Jeff had a bike accident years and years ago

Bikes + accident = part of relationship history

– injury + bike accident – part of story of their relationship

I: Right.

J: and broke his leg and we got chatting more then because I used to go to work on the bus and he used to- used to sit on the bus and we got chatting and so- that's how that happened really [[LAUGHS]

– Get together through talking – ?get to know each other deeply

I: [LAUGHS] Oh right]. And that's when you were fifteen?

J: No, no. Oh God I'd be- I was over eighteen I think. I think I was about eighteen then and then we just started to see each other as you do and then one thing led to another and I moved in and [BOTH LAUGH] so yeah, yeah.

emphasises normality

Serious from start?/ misses details

I: And what was it about him in those early days that you...?

J: Well I suppose um he was intelligent, he was chatty, he seemed to know a lot about things, he'd um- he'd got a motorbike which, you know- excellent fun um and we just used to have a good time together, you know.

?Difficult to define intelligent, chatty

Motorbike = part of pre-injury relationship – fun times

– Motorbike = part of early lives together → fun, good time

I: Yeah.

J: Yeah [so, so

I: Can] you tell me about those early days and any kind of memorable moments from that time?

fun/funny

J: Oh yeah, we used to go away to err- oh the first [LAUGHS]- the first um long bike ride we did together-

Memories about activities related to motor bike + fun.

I: Yeah.

J: the first- err we went to [PLACE]

I: Oh wow.

J: In November [BOTH LAUGH]. Yeah and there was a group of us that went. Um we just decided that we- we'd all go and I- I think there was about I don't know, fifteen, twenty of us, something like that and err camping [BOTH LAUGH] and I think it was a bit of a test. It was like [BOTH LAUGH], "If she survives this [LAUGHS] then alright for me kind of thing" I don't know [LAUGHS] and I did yeah and I did and it was excellent fun and I made it to about three miles outside of where- where we were going and I just had to get in a car then. I was freezing [BOTH LAUGH] so- so yeah and we had a good weekend there. That's- that's- there are so many memorable memories

Their relationship is set in context of ride group

She has to fit in c̄ biking lifestyle + ethos?

? Bike ethos → Accept / embrace as part of lives together.

Repeats 'fun'

– Relationship based on many happy memories, fun times

I: Yeah.

J: that are just like things that we done over the years and places we've been and-

longevity of relationship

– years together, activities, places.

I: Could you think of any other ones?

J: Well that was the- that was probably the first one that sticks in my mind. Um we've been to so many places on- on the bike. We've toured France, Spain. Um we go over to France regularly- well we're hoping to still go as well.

Hope.

– Hope to continue lifestyle in future.

I: Yeah.

J: Um to err a friend's place in um- a little, tiny, tiny place called [PLACE NAME]

I: Oh right.