VOLUME I

RESEARCH COMPONENT

Consequences of Traumatic Brain Injury for the Family: Family

Functioning and Partners' Experiences of Personality Changes

BY

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Overview

This thesis is submitted in partial fulfilment of the requirements for Doctorate of Clinical Psychology at the University of Birmingham. It consists of a research (Volume I) and a clinical (Volume II) component.

VOLUME I

This volume contains three chapters. The first chapter presents a systematic review of literature looking at the functioning of the family system after traumatic brain injury (TBI). It examines the status of family functioning in families where one member has had a TBI and reviews factors associated with poorer family functioning. Generally findings indicated higher levels of family dysfunction in TBI families than in the general population. Poorer family functioning was particularly associated with the presence of neurobehavioural disturbances in the injured person. Conceptual and methodological issues in the field are considered and the clinical implications of the findings are discussed.

The second chapter presents an empirical study exploring partners' experiences of personality changes in persons with TBI. Interpretative phenomenological analysis was used to explore the meanings personality changes had for participants' perceptions of the injured partner's identity and the couple relationship. Most participants were struggling to cope with negative changes in their partner. These changes had led them to feel that their partner was a different person since the TBI and had altered their perceptions and feelings towards the couple relationship. Feelings of loss and grief were associated with the perception of the person as different since the TBI.

Brain Injury and *Neuropsychological Rehabilitation* are nominated as suitable journals for submission of the literature review and empirical paper (see Appendices i & ii

for details of author instructions). The final chapter of this volume comprises an executive summary of the former literature review and empirical study, written with wider dissemination for non-academic audiences in mind.

VOLUME II

This volume comprises five clinical practice reports (CPRs) representing clinical work carried out across a range of clinical specialities and services.

The first CPR describes a case* of an older lady with a fear of falls and agoraphobic behaviour formulated from cognitive behavioural (CBT) and psychodynamic perspectives. A service evaluation of a memory assessment pathway for individuals with suspected dementia conducted in an older adult community mental health service is presented in CPR 2. CPR 3 describes a case study of a12 year old boy born with a chronic heart condition who was struggling with feelings of anger, being different and health fears. This piece of work was undertaken in a paediatric psychology service and adopted a CBT approach in formulation and intervention. A second case study is described in CPR 4. This presents the case of a 49 year old man with chronic depression and insomnia seen in an adult community mental health service and formulated within a CBT framework. A CBT intervention, incorporating ideas from compassion-focused therapy, is discussed and evaluated. The final CPR presents the abstract of an oral presentation that described and evaluated a single-case experiment undertaken in an inpatient neurorehabilitation setting. A single-case experimental design was used to evaluate the effectiveness of a visual scanning training intervention in addressing unilateral neglect in a 55 year old man who had suffered a right-sided stroke.

*All names have been changed to maintain confidentiality.

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Chapter I

Family Functioning after Traumatic Brain Injury: A Systematic Review

ABSTRACT

Background: Traumatic brain injury (TBI) can cause widespread disruption to the whole family. Early family outcome studies focused on the impact on individual family members, but an accumulating body of research has adopted a family systems approach. This paper aimed to summarise literature on the functioning of the family as a system after TBI.

Method: 31 papers using standardised assessments of family functioning to examine family outcome after TBI were identified from a search of four databases. These papers were critically reviewed to investigate the status of family functioning in TBI families and factors linked with family dysfunction.

Findings: Overall findings suggested higher rates of family dysfunction in TBI families than in the general population, though estimates varied across studies. Neurobehavioural problems in the person with TBI and low levels of social support were most consistently associated with poorer family functioning. There was also evidence that pre-existing family qualities may be important in understanding family adjustment following TBI.

Conclusion: There is a need to support families after TBI, particularly in managing neurobehavioural problems and in communication. Methodological and conceptual issues that need to be considered in the interpretation of findings and for future research are discussed.

INTRODUCTION

When one member of a family experiences a traumatic brain injury (TBI) the whole family is affected. For families it may mean loss of the person they knew and loved while having to get to know a person who now has physical, cognitive, behavioural and/or emotional difficulties, who is unable to perform old roles and who now has significant caring needs (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Knight, Devereux, & Godfrey, 1998). Widespread disruption to family functioning may result from the impaired role performance, dependency, financial strain and social isolation that frequently follows TBI (Brooks, 1991; Harris, Godfrey, Partridge, & Knight, 2001) and high rates of burden, anxiety and depression have been reported in family members (Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013; Linn, Allen, & Willer, 1994). Moreover the adverse effects of TBI on families are thought to be enduring, seen in families even 15 years post-injury (Thomsen, 1984) and many families do not survive, with high rates of separation and marital breakdown (Tate, Lulham, Broe, Strettles, & Pfaff, 1989; Wood & Yurdakul, 1997).

If the negative impact of TBI on the emotional well-being of family members was not sufficient justification to focus on the consequences of TBI for the family, family functioning has been shown to affect outcomes of the person with TBI themselves (Stejskal, 2012). Following brain injury, individuals may be dependent on others for their needs to be met, and this care often falls to families (Oddy & Herbert, 2003). The ability of the family to provide this support may depend on the emotional well-being of individual members as well as the quality of family relationships and the ability of the family to operate effectively as a unit. In support of this, patients with acquired brain injury from healthier family environments have been observed to make greater progress following rehabilitation than those from more dysfunctional families (Barclay, 2013; Sander,

Caroselli, High, Becker, & Neese, 2002). Similarly, patient outcomes at three years post-TBI have been found to be related to family cohesion (Kaplan, 1991).

In a critical review of the literature on psychosocial outcomes of families 15 years ago, Perlesz, Kinsella, and Crowe (1999) noted a strong tendency in the literature to view the impact of TBI on families in terms of stress and burden. Other reviews of family outcome after TBI have emphasised the emotional consequences for individual family members (e.g. Florian, Katz, & Lahav, 1989; Verhaeghe, Defloor, & Grypdonck, 2005). However, it has been argued that it is important to look at the family as a system whereby interactions amongst family members influence the family environment, which may then in turn affect psychosocial outcomes of both the injured person and their non-injured family members (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007). In support of this, persons with TBI from families who are highly critical have been found to be more distressed than those with less critical relatives (Weddell, 2010). Similarly, Hammond and colleagues (Hammond, Davis, Cook, Phulbrick, & Hirsch, 2012) have highlighted how family interactions can influence the occurrence and severity of behavioural problems. Furthermore, Harris and colleagues (2001) found that the impact of the injured person's behavioural and cognitive difficulties on primary caregivers' mood was mediated by adverse effects on the family.

In the last twenty years, a number of studies have taken a family systems approach to studying the impact of TBI on families, but a synthesis of this literature is currently lacking. To redress this, the current review targeted studies using standardised measures of general family functioning to evaluate family well-being after TBI. The assessment and understanding of family functioning in these studies has been influenced by ideas of how families function and by theories of family adaptation. These are briefly discussed here.

Theories of family adaptation

Family systems theory suggests that all family members are related in various ways, that the family system develops and evolves over time according to the family life cycle, and that change in one element of the system will change it all (Leaf, 1993; Maitz & Sachs, 1995; Miller, Ryan, Keitner, Bishop, & Epstein, 2000). Families need to negotiate life events and adapt if they are to maintain healthy and effective functioning (Leaf, 1993; Moore, Stambrook, & Peters, 1993).

A number of frameworks, first proposed to understand family adaptation to illness, have been applied to the TBI population including the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988), the Resiliency Model of Family Stress, Adjustment, and Adaptation (Kosciulek, McCubbin & McCubbin, 1993) and Hobfoll and Spielberger's (1992) Conservation of Resources Model. These models share many features being heavily influenced by Hill's (1949) ABCX model of family adaptation to stress and Lazarus and Folkman's (1984) intrapersonal stress-coping model. Space precludes a detailed review of these models, but some of the central elements are summarised here. According to these models, families respond to demands placed on it (stressors and strains) by drawing on its capabilities (resources and coping strategies) (Hobfoll & Spielberger, 1992; Kosciulek et al., 1993; Patterson, 1988). Stress may result when the nature or extent of demands reduces or exceeds the family's capabilities for any length of time, as is often the case when one member of a family experiences a brain injury (Kosciulek et al., 1993). The family's appraisal of both the demands and their capabilities is also argued to be important in how successful families are at adapting (Patterson, 1988). Families who view the demands associated with brain injury as manageable, for example, may adapt better than those who perceive the demands to be overwhelming (Kosciulek et al., 1993). According to these models, poorer adaptation might be expected in families

with a high number of demands, few resources and adaptive coping strategies and negative appraisals of their demands and capabilities.

Frameworks used to describe family functioning

The models described above attempt to explain or describe the process by which families adjust to traumatic events like brain injury. Other frameworks have been used to describe the current state of a family's functioning based on theoretical ideas of how families function. The McMaster Model of Family Functioning (Epstein, Baldwin, & Bishop, 1983) describes families according to their structural and organisational features, including their communication patterns, the rules guiding family transactions and behaviours, role allocation and performance, and the emotional investment family members have in each other. Its development was influenced by dimensions considered important in working with (psychiatric) families presenting clinically (Miller et al., 2000). A second model, the Circumplex Model of Marital and Family Systems (Olson, Russell, & Sprenkle, 1993), arose largely out of observations of families presenting for family therapy, and considers two dimensions thought important to explaining variations in how effectively families function: Cohesion and Adaptability. Cohesion relates to the emotional attachment family members have for each other, while adaptability refers to the capacity of the family to adjust flexibly in response to situational and developmental demands. These models have underpinned the development of assessments tools to measure family functioning.

Assessing functioning of the family system

Early studies of family outcome following TBI focused on the impact on individual family members and/or relied on descriptive accounts or idiosyncratic assessment tools

with unknown psychometric properties (Brooks, 1991; Kreutzer, Marwitz, & Kepler, 1992). More recently, studies of family outcome after TBI have made use of measures of family functioning developed in non-TBI populations. These measures consider how family members interact, relate to each other and operate together as a unit (Bishop & Miller, 1988; Epstein et al., 1983). A summary of the measures of family functioning used in the studies to be reviewed in the current paper are described in Table 1. Two of the most commonly used measures are the Family Assessment Device (FAD; Epstein et al., 1983), and the Family Adaptability and Cohesion Scales (FACES; Olson, Bell, & Portner, 1982; Olson, Portner, & Lavee, 1985).

The FAD is based on The McMaster Model of Family Functioning (Epstein et al., 1983) and classifies families as healthy or unhealthy according to normative cut-off scores. The FACES developed out of the Circumplex Model of Marital and Family Systems (Olson et al., 1993) and has been modified a number of times since it was first developed, with several versions in use (Table 1). Early papers using FACES II and FACES III assumed cohesion and adaptability to have a curvilinear relationship, with families moderate on both dimensions being the healthiest functioning (Kouneski, 2000; Olson et al., 1983). Such families are described as balanced and have been contrasted with families scoring at the poles of the dimensions (extreme) in numerous studies of family functioning (Kouneski, 2000). The curvilinear nature of the dimensions on FACES II and FACES III has since been questioned and a linear relationship is now more commonly accepted, with higher scores being healthier (Bishop & Miller, 1988). Failure of the FACES II and III to tap into the extremes of each dimension has been proposed to explain the absence of support for the curvilinear assumption of the Circumplex Model (Olson, 2011). Significant revisions to address this issue have led to the return of cohesion and

adaptability being measured in a curvilinear manner in the latest version (FACES IV; Olson, 2010).

Aims of current review

The main aims of this review were to summarise findings on the state of family functioning after TBI and to examine factors associated with poor family functioning. Broader aims were to consider methodological and conceptual issues in this area, to think about the clinical implications and to suggest directions for future research.

Although poor family functioning has also been reported in families with a child or adolescent with a brain injury (e.g. Max et al., 1998), this review focuses on families where the TBI was experienced in adulthood.

Table 1
Description of Family Functioning Measures used by Included Studies.

<u>**Family Assessment Device (Epstein et al. 1983)**</u> 60-item self-report questionnaire designed as a screening measure of family functioning based on the McMaster Model of Family Functioning (MMFF). The measure has six subscales : *Problem Solving* (FAD-PS; the family's capacity to work out problems in a way that maintains effective family functioning); *Communication* (FAD-Com; the extent to which verbal messages are expressed directly and clearly); *Roles* (FAD-Roles; how effectively family functions are organised and distributed and whether necessary tasks are carried out reliably by family members); *Affective Responsiveness* (FAD-AR; the degree to which individual family members display appropriate affect); *Affective Involvement* (FAD-AI; the degree to which family members show interest in and value each other's concerns); *Behavior Control* (FAD-BC; how the family maintains rules and standards of behaviour in the family). *General Functioning* (FAD-GF; assessing the overall functioning of the family). Family members rate how well each item describes their family on a four-point scale from strongly agree to strongly disagree. Scale scores range from 1.0 (best functioning) to 4.0 (worst functioning). Cut-off scores are used to classify families as showing healthy or unhealthy functioning in the different domains. A 12-item general functioning scale (FAD-GF) is often used in place of the full version.

The Family Adaptability and Cohesion Scale (FACES II; Olson, Bell, & Portner, 1982)

30-item self-report questionnaire based on the Circumplex Model of Functioning (Olson, Sprenkle, & Russell, 1979) describing families along two dimensions: *adaptability* and *cohesion*. Items are rated on a 5-point scale from almost never to almost always. Families can be classed as balanced (healthiest), midrange and extreme (most dysfunctional) based on their scores on both dimensions. Both family and couple versions of FACES-II exist. Can be used to assess both the respondent's actual perception of the family and their ideal family state, with the gap between the two used as a measure of family satisfaction.

The Family Adaptability and Cohesion Scale (FACES III; Olson, Portner, & Lavee, 1985)

20-item version of FACES II.

The Family Adaptability and Cohesion Scale (FACES IV; Olson (2010)

42-item self-report measure assessing cohesion and flexibility. Items are rated on a 5-point scale from strongly disagree to strongly agree. Contains two balanced scales for family *cohesion* and *adaptabilit*y and four unbalanced scales tapping the extremes of cohesion (enmeshed/disengaged) and adaptability (rigid/chaotic). Families can be classed as balanced, midrange or unbalanced. A cohesion/ adaptability ratio can also be calculated to describe the level of balance/unbalance in the system.

The Family Environment Scale (FES; Moos & Moos (1994)

90-item self-report measure of an individual's perception of their family environment. Items are scored as true/false, with 10 subscales across three domains:
Relationship dimensions – Cohesion, Expressiveness, Conflict subscales
Personal Growth – Independence, Achievement Orientation, Intellectual Cultural Orientation, Active Recreational Orientation, More Religious Emphasis subscales
System Maintenance –Organization, Control subscales

Family Satisfaction Scale (FSS; Olson & Wilson, 1982)

14-item self-report scale assessing the extent to which respondents are satisfied with family behaviours relating to family cohesion and adaptability. Respondents are asked to rate how satisfied they are with each aspect of family functioning on a 5-point scale from very dissatisfied to extremely satisfied.

Family Satisfaction Scale (FSS; Olson, 2010)

10-item version of FSS measuring the extent to which family members are satisfied with family closeness, flexibility and communication.

The Family Adaptation, Partnership, Growth, Affection, and Resolve (APGAR) Scale (Smilkstein, Ashworth, & Montano, 1982)

5-item self-report measure of 5 dimensions of family functioning (Adaptation, Partnership, Growth, Affection and Resolve). Respondents rate whether each item describes their family according to hardly ever, sometimes and almost always

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Note. The above measures of family satisfaction contain similar items, and have been observed to be strongly related, to other family functioning measures (Douglas & Spellacy, 1996; Lehan, Arango-Lasprilla, de los Reyes, & Quijano., 2012; Zarski, DePompei, & Zook, 1988) and therefore studies using these were retained in the review.

METHODOLOGY

Conduct of the review was informed by guidance on undertaking systematic reviews developed by the Centre for Review and Dissemination (CRD) based at the University of York (2009) and the Evidence for Policy and Practice Information and Co-ordination Centre (EPPI-Centre, 2010).

Identification of studies

Relevant articles were identified through a multi-stage process. Figure 1 shows the number of articles identified and excluded at each stage. The first stage involved searching relevant electronic literature databases. Four databases were searched to ensure coverage across the psychological, health and scientific literature. These were PsycINFO, MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. Relevant articles were located using keyword searches and Boolean operators *or* and *and* to combine terms. Table 2 lists the search terms used. The only limits applied at this stage were to restrict the search to peer-reviewed journal articles published in the English language. No limit was placed on the years of publication.

References were downloaded into bibliographic software, where duplicate articles were identified and excluded. Abstracts and titles of articles were screened against a set of inclusion criteria (see Table 3). Where it was not clear if the article met these criteria from the title and abstract, the full paper was screened.

In the next stage, both cited and citing references of studies fitting the inclusion criteria were searched for any additional papers. Finally, references of relevant review papers were screened for any final papers. This resulted in 31 studies being identified.

Data extraction

Data were extracted from articles into an Excel spreadsheet with a number of headings including the aim of the study, setting, sample size, sample description and characteristics, measure of family functioning used and findings.

Quality assessment

No paper was excluded on the basis of quality, but study quality was examined to assess the general status of research on family functioning following TBI and to identify specific methodological difficulties in the field. A quality checklist was purposively created to make it more relevant to the research question and the descriptive nature of the studies included in the review. This was based on criteria described in a number of existing quality assessment tools, including the Critical Appraisal Skills Programme (CASP) checklists, Downs and Black (1998), Durant (1994), Sale and Brazil (2004), Vickers (1995), von Elm et al. (2007) and Young and Solomon (2009), and is displayed in full in Appendix iii.

Data synthesis

A narrative approach to data synthesis was judged to be most appropriate given the diversity of the included studies. This included a synthesis of study characteristics and findings, exploration of commonalities and discrepancies in findings and evaluation of methodological issues.

Table 2

Keyword Searches

Search number	Construct	Keyword terms (variations)
1	Traumatic brain injury	Traumatic brain injur* (traumatic brain injury/ies)
		Head injur* (head injury/ies)
		TBI
		Combined with *or*
2	Family functioning	Family relations* (family relations/family relationships)
		Family adjustment
		Family adaptation
		Family coping
		Family cohesion
		Family functioning
		Famil* role* (familial role/s/family role/s)
		Family satisfaction
		Family system* (family system/s)
		Family environment
		Family outcome* (family outcome/s)
		Family communication
		Family dynamic* (family dynamic/s)
		Combined with *or*
3	Searches 1 and 2 were combined with *and*	

Note. "Acquired Brain Injury" was not included as a search term in order to reduce the articles retrieved to a manageable number given that the majority of papers referencing ABI used samples of individuals with brain injuries of other aetiology, typically stroke.

Table 3

Selection Criteria for Inclusion in Review

Inclusion Criteria

1) Published in a peer-reviewed journal in the English language before the end of June 2013 (with no lower limit on the year published)
2) Participants were family members of a person who experienced a traumatic brain injury in adulthood (> 18 years old)
3) Contains empirical research with primary quantitative data
4) Includes an established standardised measure of family functioning. This included measures of family satisfaction, found to be strongly related to family functioning (Douglas & Spellacy, 1996; Lehan et al., 2012; Zarski et al., 1988)[1]
5) Reports data on the state of family functioning following TBI and/or examines factors associated with family functioning following TBI

Exclusion Criteria

1) > 80% of the injured relatives experienced a non-traumatic brain injury or experienced the traumatic brain injury in childhood/adolescence (< 18 years old)
2) Reports only the person with TBI's perception of family functioning
3) Review papers, case studies or qualitative research
4) Used purpose designed questionnaires
5) Validation studies
6) Assesses marital adjustment or quality (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011) or the impact on individual family members (psychological distress, burden; Verhaehge et al., 2005)
7) Intervention studies or studies where family functioning was only reported as a predictor of patient outcome
8) Estimates family functioning pre-injury only

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[1] The content of Items on the Family Satisfaction Scale (Olson & Wilson, 1982) overlaps with that of family functioning measures such as the FACES (Olson et al., 1985); the main difference is in response. In the former, participants are asked to rate satisfaction with a specific aspect of family functioning whereas in the latter case they are required to rate the extent to which the item describes the functioning of their family.

| Total number of articles identified by search of databases *n*=846 | → | Duplicates *n*=343 |

| Titles and abstracts screened *n*=503 | → | **Excluded** *n=472* **Reason for exclusion** |

Excluded
n=472
Reason for exclusion
- Not TBI (*n=53*)
- Not adults (*n=168)*
- Not primary quantitative data (*n=127)*
- No assessment of family functioning using established measure (*n=101)*
- Respondent not family member (*n=3*)
- < 80% of sample TBI (*n=8*)
- Intervention study (*n=6*)
- Family member and survivor's responses analysed together (*n=1*)
- Studies assessing pre-injury family functioning (*n=2*)
- Family functioning a predictor of patient outcome (*n=3)*

| Full paper screened *n*=90 |

| Number of articles included from search *n*=31 |

| Total number of studies included *n*=31 | ← | Number of studies identified through screening citing and cited references *n*=0 |

Figure 1. Number of papers identified by the search and excluded at each stage

FINDINGS

Characteristics of studies

 The studies identified (see Table 4) were published between 1988 and 2013, with all but three conducted in North America and Australia. A number of studies came from the same research groups (indicated in Table 4).

Table 4

Characteristics of Included Studies

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Anderson et al. (2002)	Tested model of the relationship between neurobehavioural problems, family functioning and spouse distress	Australia Spouses of individuals discharged from six rehabilitation programmes	64 spouses (47 female; M=45 years, 22-74 years) Primary caregivers; Living with injured person	64 persons with severe TBI (47 male; M=46 years, 27-75 years); 5-184 months post-injury (M=43 months)	FAD – General Functioning Scale
Anderson et al. (2009)	Extension of Anderson et al. (2002). Tested if relationship between neurobehavioural problems, family functioning and distress was the same for parents	Australia Parents/Spouses of individuals discharged from six rehabilitation programmes	64 spouses (same sample as Anderson et al., 2002) and 29 parental dyads (29 female; M=52 years) Primary caregivers; Living with injured person	93 persons with severe TBI (unknown gender; M=34 years); 4-193 months post-injury (M=41 months)	FAD - General Functioning and Roles subscales
Boyle & Haines (2002)	Examined the effect of severe TBI on family members and family functioning	Australia Families in contact with a support organization	24 family members (12 spouses and 12 parents; 18 female; M=54.5 years, SD=12.5) Primary caregivers; Unclear if living with injured person	25 persons[2] with severe TBI (18 male; unknown age) On average 9.8 years post-injury (SD=9.3)	Family Environment Scale
Brzuzy & Speziale (1997)	Compared family stress, life satisfaction, family satisfaction and social integration in TBI survivors living with family with those living independently	North America Persons with TBI and their families recruited from individuals having taken part in a needs survey of people with brain injuries	22 family members 59% living with injured person No other details provided	66 persons with moderate/severe TBI (Not all had a family member); 48 male; M=33.9 years, SD=6.3) On average 9.3 years post-injury (SD=6.6)	Family Satisfaction Scale (FSS; Olson & Wilson, 1985)

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[2] As reported in original paper; reason for discrepancy between number of family members and persons with TBI unclear.

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Carnes & Quinn (2005)	Investigated how family coping and appraisals, additional stressors, kinship and premorbid relationship quality and neurobehavioural problems influence family adaptation	North America Patients receiving inpatient rehabilitation and their family members	123 family members (29 spouses, 70 parents, 15 (adult) children, 9 siblings) 84 female, 18-68 years (M=45 years) 63% primary caregivers; Inpatient at assessment	65 persons with acquired brain injury (majority TBI and severe)[3]; 49 male, 15-65 years (M=34.5 years) 16-411 days post-injury (M=57.5 days)	The Family Adaptation, Partnership, Growth, Affection and Resolve (APGAR) Scale
Coy et al. (2013)	Assessed impact of the injured person's social functioning and family functioning on emotional well-being and burden of Mexican family caregivers	Mexico Recruited from a medical centre that provides rehabilitation	42 family members (15 spouses, 23 parents, 1 adult child, 3 siblings); 36 female; M=51.7 years (SD=11.3) Primary caregivers; unclear if living with injured person	42 persons with moderate/severe TBI (34 male; M=38.8 years, SD=13.44); Median time post-injury = 29.5 months	Family Satisfaction Scale (Olson, 2010)
Curtiss et al. (2000)	Examined changes in family structure and coping strategies during the acute phase of recovery from TBI	North America Spouses of military veterans participating in a Defence and Veterans Head Injury Program	20 spouses (20 female; 18-56 years, M=33.6 years) ? primary caregivers Person with TBI inpatient at time of assessment	20 persons with TBI (majority severe) 20 male; 19-69 years (M=36.8 years) Time of admission	Family Adaptability & Cohesion Scale (FACES II - couple version)[4]

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[3] Retained in the review despite (due to paper editing) being unable to determine the exact proportion of the injured relatives who had had a TBI. The majority had had a TBI and the authors reported no significant difference in family functioning in family members of stroke patients and family members of TBI patients.
[4] Included in the review despite use of couple version having adopted a family systems approach; this questionnaire contains the same items as the family version merely adjusted to reflect the absence of children in the household.

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Douglas & Spellacy (1996)	Aimed to identify indicators of family functioning following severe TBI	Australia Patients who had previously been admitted to hospital following injury and their family members	30 family members (17 spouses, 13 parents); 25 female; 23-67 years (M=46.9 years); Primary caregivers; Living with injured person	30 persons with severe TBI (18 male; 22-71 years, M=36.8 years) ;3.5-10.5 years post-injury (M=7 years)	Family Environment Scale
Ergh et al. (2002)	Examined predictors of caregiver distress and family functioning	North America Individuals with brain injury taking part in a larger multicentre research project and their primary caregivers	60 family members (12 spouses, 31 parents, 2 adult children, 9 siblings, 6 other) 43 female; 24-79 years (M=54.1 years) Primary caregivers; 90% living with injured person	60 persons with TBI (majority mod./severe) 49 male; M=40.9 years (SD=13); 4 months-9 years post-injury (M=4.8 years)	FAD-GF
Groom et al. (1998)	Investigated relationship between family functioning and neurobehavioural problems	North America Family members who attended local support groups	153 family members (majority spouses/parents) 123 female; M=49.2 years (SD=13.3) Unclear if primary caregivers or living with injured person	153 persons with TBI (majority mod./severe) 96 male; M=36.1 years (SD=15.3); 1 month-40 years post-injury (M=7.7 years)	FAD-GF
Hanks et al. (2007)	Investigated relationship between caregiver appraisals and characteristics of person with brain injury, perceived social support, coping styles and family functioning	North America Primary caregivers of persons with TBI admitted to one of the project centres after injury and transferred for inpatient rehabilitation	60 family members (13 spouses, 26 parents, 4 adult children, 7 siblings, 10 other); 46 female; 18-78 years (M=50.8 years) Primary caregivers; unclear if living with injured person	60 persons with TBI (Complicated Mild TBI to Severe); Unknown gender and age; 0.5-15 years post-injury (M=4.2 years)	FAD - General Functioning and Behavioural Control subscales

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Kaplan (1991)	Looked at relationship between social support (family environment and functioning) and outcomes of people with TBI	North America Individuals referred to an inpatient rehabilitation psychology service and followed up at three years and their family members	25 family members Primary caregivers; Living with injured person No other details provided	25 persons with severe TBI (18 male; 16-59 years, M=27.9 years); Seen at inpatient admission and 1 and 3 year follow-up	Family Environment Scale (at 3 years), Structured Interview (at admission)
Kolakowsky-Hayner & Kishore (1999)	Investigated prevalence of unhealthy family functioning and psychological distress in primary caregivers of adult outpatients with traumatic injuries	North America Caregivers of individuals treated in an urban trauma centre and inpatient rehabilitation programmes	14 family members of persons with TBI and 14 family members of persons with SCI Primary caregivers No other details provided	14 persons with TBI (unknown severity); 11 male; M=29.7 years, SD=12.13); 12 months post-injury	FAD
Kosciulek (1994)	Examined coping strategies used by families of people with head injury and the relationship between coping and family adaptation	North America Family members in contact with a support organization	150 family members (39 wives, 77 mothers); Majority female; 22-79 years (M=48.9 years) Primary caregivers; unclear if living with injured person	150 persons with TBI No details provided	FAD-GF
Kosciulek (1995)	Aimed to identify family types in a sample of families with one member having experienced a head injury	North America Family members in contact with a support organization	150 family members (39 wives, 77 mothers) Majority female; 22-79 years (M=48.9 years) Primary caregivers; unclear if living with injured person	150 persons with TBI No details provided	FAD

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Kosciulek (1996)	Tested hypothesis that families classed as balanced will have better family functioning and better communication that families classed as extreme	North America Family members in contact with a support organization	82 family members (18 wives, 50 mothers); Majority female; 20-71 years (M=46.7 years) Primary caregivers; unclear if living with injured person	82 persons with TBI No details provided	FAD - General Functioning and Communication subscales; FACES-II
Kosciulek (1997)	Examined whether family schemas affect family adaptation following brain injury	North America Family members in contact with a support organization	87 family members (20 wives, 44 mothers); 72 female; 26-71 years (M=50.7 years) Primary caregivers; unclear if living with injured person	87 persons with TBI (unknown severity); 62 male; 20-69 years (M=36.2 years); 3-30 years post-injury (M=8.2 years)	FAD-GF
Kosciulek & Lustig (1998)	Investigated whether family adaptation could be predicted from brain-injury related demands on the family	North America Family members in contact with a support organization	92 family members (52 mothers); Unclear gender; 25-85 years (M=49.9 years) Primary caregivers; 80% living with injured person	92 persons with TBI (unknown severity); 61 male; 9-73 years (M=30.6 years); 1-34 years post-injury (M=8.0 years)	FAD-GF
Kosciulek & Lustig (1999)	Looked at factors that distinguish between balanced, midrange and extreme family types (differing in levels of cohesion and adaptability)	North America Family members in contact with a support organization	76 family members (42 mothers); 62 female; 27-82 years (M=49.8 years) Primary caregivers; 80% living with injured person	76 persons with TBI (unknown severity); 54 male; 16-68 years (M=30.3 years); On average 7.8 years post-injury (SD=4.2)	FAD-GF; FACES-II
Kreutzer et al. (1994a)	Explored extent of caregiver distress and family functioning in acute stage recovery of brain injury	North America Family members of outpatients with TBI evaluated at a medical college	62 family members (28 spouse, 34 parents) 53 female; unknown age Primary caregivers; 97% living with person	62 persons with TBI (majority mod./severe); 50 male; 16-65 years (M=30.5 years); 1.5-60 months post-injury (M=16 months)	FAD

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Kreutzer et al. (1994b)	Examined (patient) predictors of caregiver distress and family functioning	See Kreutzer et al. (1994a)	See Kreutzer et al. (1994a)	See Kreutzer et al. (1994a)	FAD
Lehans et al. (2012)	Explored relationships between levels of family adaptability, cohesion, communication, and family satisfaction	Mexico Individuals with TBI who had received rehabilitation at an inpatient medical facility and their family members	38 family members (15 spouses, 19 parents, 1 adult child, 3 siblings); 32 female; M=51.4 years (SD=11.44) Primary caregivers; unclear if living with person	38 persons with TBI (mild to severe); 30 male; M=39.6 years (SD=13.6); Median time post-injury = 29.5 months	FACES IV; Family Communication Scale; FSS (Olson, 2010)
Nabors et al. (2002)	Assessed relationship between caregiver demographic factors and caregiver burden, family functioning and family needs	North America Caregivers of patients with TBI who received inpatient or post-acute rehabilitation	45 family members (15 spouses, 21 parents, 2 adult children, 7 other); 41 female; 21-73 years (M=50.7 years) Unclear if primary caregivers or if living with person	45 persons with mod./severe TBI (33 male; 15-67 years, M=36 years); 12-52 months post-injury (M=29.8 months)	FAD-GF
Perlesz et al. (2000)	Assessed family satisfaction and psychological well-being in family members of people who had experienced TBI from perspective of multiple family members	Australia Individuals with TBI who had attended one of three acute rehabilitation centres and their family members	137 family members (from 79 families; 24 spouses, 69 parents, 13 adult children, 24 siblings, 7 other) 81 female; Primary carers M=44.7 years (SD=10.9); secondary carers M=43.8 years (SD=13.9); Tertiary carers M=28.3 years (SD=12.5); 65% living with person	Majority severe TBI; 43 male, M=33.8 years (SD=15); average time post-injury = 9.3years (SD=6.22)	FSS (Olson & Wilson, 1985)

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Ponsford et al. (2003)	Investigated emotional and family adjustment and its relationship with injury severity, disability, cognitive, behavioural and emotional changes, kinship and caregiver status	Australia Individuals with TBI who had received rehabilitation and their family members	143 family members (49 spouses, 56 parents, 6 adult children, 16 siblings) Unknown gender or age 49% primary caregivers; 71% living with person	143 persons with TBI (majority mod./severe) 100 male; 18-69 years (M=33.6 years) 2-5 years post-injury (M=3.3 years	FAD
Ponsford & Schönberger (2010)	Investigated family functioning and psychological distress in caregivers and predictors of this at 2 and 5 years post-injury	Australia Persons with TBI who received rehabilitation as part of a no-fault accident compensation system and their families	At 2 year follow-up: 301 family members (108 spouses, 126 parents, 18 adult children, 24 siblings) 42% primary caregivers, 73% living with injured person; At 5 year follow-up: 266 family members (unclear kinship) 64% living with injured person. Unknown age and gender	At 2 year follow-up: 301 persons with TBI (majority mod./severe) 210 male; 15-82 years (M=34.5 years) At 5 year follow-up: 266 persons with TBI (majority mod./severe) 172 male; 14-87 years (M=34.6 years)	FAD-GF
Schönberger et al. (2010)	Looked at family functioning and the emotional well-being of family members and at the relationship between this and neurobehavioural difficulties between two and five years post-injury	Australia Family members of patients who had received rehabilitation at a local hospital	66 family members (27 spouses, 27 parents, 5 adult children, 3 siblings, 3 other) 52 female; 20-71 years (M=45.0 years) Unclear if primary caregivers or if living with person	66 persons with TBI (majority severe); 46 male; 18-72 years (M=35.7 years) Followed up from rehab at 2 and 5 years	FAD-GF

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Stanescu & Romer (2011)	Looked at the relationship between family functioning, family coping and emotional wellbeing of children of parents with TBI	Romania Families with a parent with TBI who had previously been hospitalised in a neurosurgery ward at an emergency hospital	46 spouses (20 female; Wives 33-58 years, M=41.0 years; Husbands 33-52 years, M=44.4 years) and 46 children (28 female; 11-18 years, M=14.7 years) Spouse primary caregivers; living with person	46 parents with mod./severe TBI (20 male; unknown age) Time post-injury unclear	FAD
Testa et al. (2006)	Examined if the quality of family functioning differed in two medical populations (TBI and Orthopaedic Injury (OI) and with brain injury severity at two time points. Looked at relationship of neurobehavioural problems to family functioning	North America Individuals with TBI admitted to an emergency or acute care facility who were severe enough to require hospitalization and their family members	At Discharge: 122 TBI family members At 1 year: 73 TBI family members No further details provided	At Discharge: 47 persons with mild TBI (24 male; M=35.2 years, SD=19.2); 75 persons with mod./severe TBI (49 male; M=37.5 years, SD=19.4); At 1 year follow-up: 24 persons with mild TBI (11 male; M=37.0 years, SD=19.7); 49 persons with mod./severe TBI (25 male; M=39.0 years, SD=21.2); 406-441 days post-injury	FAD-GF
Winstanley et al. (2006)	Investigated relationships between participation of person with TBI, neurobehavioural impairment, social support and family member distress and family functioning	Australia Relatives of individuals with TBI admitted to one of 11 units of a brain injury rehabilitation programme	134 family members (52 spouses, 67 parents); 109 female; M=45 years, SD=10.6 Unclear if primary caregivers; 78% living with injured person	134 persons with severe TBI (103 male; M=31.9 years, SD=13.1); Inpatient admission (Median days post-injury = 31 days) and 18 months post-injury	FAD-GF

Study	Aims of Study	Location and Setting	Family Member Respondents	Injured Person	Measure of Family Functioning
Zarski et al. (1988)	Examined differences between families classed as balanced, midrange and extreme in relation to family functioning, family satisfaction, family capabilities.	North America Family members of individuals with TBI seen by speech and language therapists working in hospitals, rehabilitation centres, outpatient clinics	45 family members (6 spouses, 39 parents); 38 female; 28-66 years , M=47.4 years Unclear if primary caregiver; living with injured person	45 persons with TBI (unclear severity); 33 male; 14-53 years (M=26.6 years) 22% considered to be in acute recovery stage, 77% in the rehabilitation stage	FAD; FACES-III

Note. Some studies included data from the same samples, including Coy et al. (2013) and Lehan et al. (2012), Kreutzer et al. (1994a) and Kreutzer et al. (1994b); Anderson et al. (2002) and Anderson et al. (2009); Kosciulek (1994) and Kosciulek (1995); and Ponsford et al. (2003), Ponsford & Schönberger (2010) and Schönberger et al. (2010).

Most studies recruited family members of individuals receiving or having received rehabilitation or families in contact with support organisations. Typical of the TBI population, a high proportion of the injured family members were male, with average ages ranging from 28 to 46 years. Family member respondents tended to be female, were predominantly the primary caregiver, mostly mothers and wives, with average ages ranging from 41 to 55 years. Only 17/31 studies specified whether the family member was living with the injured person. In two studies the injured person was an inpatient at the time of assessment and in the remaining studies between 59% and 100% of family member respondents were living with the injured person. In the majority of cases the injured person had suffered a moderate or severe TBI, with time post-injury varying from 1 month to 118 months. Where specified, samples tended to be predominantly Caucasian.

Study quality & methodological issues

An overview of the degree to which the included studies fulfilled the criteria in the quality checklist is presented in Table 5. Almost all studies presented a clear rationale and used a design appropriate for the specified objectives, though the cross-sectional design, used by most studies, makes it difficult to infer the causality and direction of relationships. It is possible, for example, that family dysfunction may influence and reinforce the presence of emotional and behavioural problems (Weddell, 2010; Zarski et al., 1988).

Most studies recruited families from rehabilitation and family support services, introducing possible sampling biases by neglecting families who are unable or choose not to access such services (Douglas & Spellacy, 1996). This may include families not in need of support or families who are very dysfunctional and who may be less able to access such services. In addition, few studies reported the number of non-responders and it is possible

that more chaotic and less supportive families may have been more difficult to gather data from (Sady et al. 2010).

With few exceptions, studies were characterised by small and heterogeneous samples, yet many attempted to examine the impact of a large number of variables or complex relationship between variables. These factors raise the risk of Type 2 errors, while the possibility of Type 1 errors is increased by the failure of many studies to control for multiple comparisons. Very few studies included a control group, with most studies relying on clinical cut-offs to determine healthy versus unhealthy functioning. It is unclear to what extent the normative samples these cut-offs are based on are representative of TBI families pre-injury. Together with the lack of pre-morbid measures, this makes it difficult to confidently attribute poorer functioning to the TBI (Sander et al., 2003; Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012). Notably, it has been observed that individuals who go on to sustain a TBI may not be representative of the general population pre-morbidly (e.g. being more likely to have a history of substance misuse; Seaton & David, 1990).

All studies provided an adequate description of outcome and predictor variables and how these were measured and most commented on the quality of the measures used. However, many studies tested relationships between two self-reported measures completed by the same family member within the same session. Global negative ratings and common method variance may have artificially increased associations between variables. Some measures contained similar items that may help explain correlations observed between them. Anderson et al. (2009), for example, pointed out that many measures of social support also tap into support from family. Nonetheless the majority of studies clearly summarised their findings, considered the limitations and generalizability of the study and all studies commented on the clinical implications of their findings.

Table 5

Critical Appraisal of the Literature Using Purpose Designed Quality Checklist (A full description of the quality criteria can be found in Appendix iii)

№	Criterion	Anderson etal. (2002)	Anderson et al. (2009)	Boyle & Haines (2002)	Brzuzy & Speziale (2007)	Carnes & Quinn (2005)	Coy et al. (2013)	Curtiss et al. (2000)	Douglas & Spellacy (1996)	Ergh et al. (2002)	Groom et al. (1998)	Hanks et al. (2007)	Kaplan (1991)	Kolakowsky-Hayner & Kishore (1999)	Kosciulek (1994)	Kosciulek (1995)	Kosciulek (1996)	Kosciulek (1997)	Kosciulek & Lustig (1998)	Kosciulek & Lustig (1999)	Kreutzer et al. (1994a)	Kreutzer et al. (1994b)	Lehan et al. (2012)	Nabors et al. (2002)	Perlesz et al. (2000)	Ponsford et al. (2003)	Ponsford & Schönberger (2010)	Schönberger et al. (2010)	Stanescu & Romer (2011)	Testa et al. (2006)	Winstanley et al. (2006)	Zarski et al. (1988)
1.	Objectives stated?	√	√	?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
2.	Rationale/ theoretical framework described?*	√	√	√	X	√	√	√	√	√	√	?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
3.	Appropriate design?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
4.	Setting described?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	X	√	√	√	√	√	√	√	√	√	√	√	√	√	√
5.	Eligibility criteria given?	√	√	√	X	X	√	X	√	√	X	√	X	X	√	√	√	√	√	√	X	X	X	√	√	√	?	?	?	√	√	X
6.	Description of patients?	√	X	√	√	?	√	√	√	√	√	X	√	X	X	X	X	?	?	?	√	+	√	√	√	√	√	X	√	√	√	√
7.	Description of informants?	√	√	√	X	√	√	√	√	√	√	√	X	X	√	√	√	√	√	√	√	+	√	√	√	?	?	√	√	X	√	√
8.	Adequate sample?**	?	√	X	?	?	?	X	?	?	√	?	X	X	√	√	?	√	√	?	?	?	?	?	?	√	√	?	?	?	√	?
9.	Variables described?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
10.	Description of measures?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
11.	Quality of measures considered?	√	√	√	X	√	√	√	√	√	√	√	?	√	√	√	√	√	√	√	√	?	√	√	X	√	√	√	√	?	√	√
12.	Comparison group/data?	X	X	√	√	X	X	X	X	X	√	X	X	√	X	X	X	X	X	X	√	+	X	X	X	√	√	X	X	√	X	X

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		Anderson etal. (2002)	Anderson et al. (2009)	Boyle & Haines (2002)	Brzuzy & Speziale (2007)	Carnes & Quinn (2005)	Coy et al. (2013)	Curtiss et al. (2000)	Douglas & Spellacy (1996)	Ergh et al. (2002)	Groom et al. (1998)	Hanks et al. (2007)	Kaplan (1991)	Kolakowsky-Hayner & Kishore	Kosciulek (1994)	Kosciulek (1995)	Kosciulek (1996)	Kosciulek (1997)	Kosciulek & Lustig (1998)	Kosciulek & Lustig (1999)	Kreutzer et al. (1994a)	Kreutzer et al. (1994b)	Lehan et al. (2012)	Nabors et al. (2002)	Perlesz et al. (2000)	Ponsford et al. (2003)	Ponsford & Schönberger (2010)	Schönberger et al. (2010)	Stanescu & Romer (2011)	Testa et al. (2006)	Winstanley et al. (2006)	Zarski et al. (1988)
13.	Description of analysis?	√	√	√	√	√	√	√	√	√	√	√	X	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
14.	Outcome data reported?	√	√	√	√	X	X	√	X	√	√	√	X	√	X	√	√	X	X	√	√	X	√	X	√	√	√	√	X	√	√	X
15.	Estimates of random variability?	√	√	√	√	X	X	X	X	√	√	√	X	X	X	X	X	√	X	X	√	√	X	√	X	√	√	√	√	X	√	X
16.	Controlled for multiple comparisons?	-	√	√	X	X	-	-	X	√	X	X	X	X	-	-	-	-	-	-	√	√	-	X	X	√	X	-	√	√	-	X
17.	Summary of findings	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	?
18.	Considered limitations?	√	√	√	X	X	√	√	√	√	√	X	X	X	√	√	√	√	√	√	√	√	√	√	√	?	√	√	√	√	√	√
19.	Conclusions justified?	√	√	√	X	?	√	√	?	√	?	X	X	?	√	√	√	√	?	√	√	√	√	√	√	√	√	√	√	√	√	?
20.	Considered generalizability?	√	√	√	X	X	√	?	√	√	X	√	X	X	√	√	√	√	√	X	√	?	√	√	?	√	√	?	√	√	√	√
21.	Clinical implications discussed?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√

Key: Met Criteria (√); Did not meet criteria (X); Partially met criteria (?); Not applicable (-)

+ In sister paper, Kreutzer et al. (1994a)

* The rationale was described in the majority of studies, though few provided a theoretical framework.

** Based on whether the study had a sample large enough to detect a large (√) or moderate (?) size correlation according to g-power where a sample of 29 would be required to detect a large correlation (r=0.5) with power set at 0.90 and alpha at 0.05, and where a sample of 84 would be required to detect a moderate correlation (r=0.05). Multiple regressions (used by some of the studies included) would require even larger samples than this.

Status of family functioning in TBI families

The Family Assessment Device (FAD) was the most commonly used instrument to assess family functioning, with reported levels of unhealthy family functioning ranging from 25% to over 60%[5] of TBI families (e.g. Anderson, Simpson, Morey, Mok, Gosling, & Gillett, 2009; Testa, Malec, Moessner, & Brown, 2006). Several studies found greater family dysfunction in TBI families than in non-clinical samples, though less than in psychiatric samples (Anderson et al., 2009; Kreutzer, Gervasio, & Camplair, 1994a; Groom, Shaw, O'Connor, Howard, & Pickens, 1998; Ponsford & Schönberger, 2010). Other studies, however, reported family functioning to be comparable to non-clinical samples and to families with a member with a spinal cord or orthopaedic injury (Kolakowsky-Hayner & Kishore, 1999; Testa et al. 2006).

In general, a greater picture of family dysfunction emerged when looking at the proportion of families scoring in the unhealthy range (Kolakowsky-Hayner & Kishore, 1999; Ponsford et al., 2003), with average family functioning scores often falling in the healthy range (Douglas & Spellacy, 1996; Ponsford, Olver, Ponsford, & Nelms, 2003; Ponsford & Schönberger, 2010; Schönberger, Ponsford, Olver, & Ponsford, 2010; Testa et al., 2006). This might be explained by the presence of families who continue to function well after TBI, lowering group means and masking dysfunction in other families. Compatible with this, in a study describing different family types following TBI, Kosciulek (1995) identified a group of families who were coping well, described as 'regenerative'.

Other studies have also draw attention to positive family functioning after TBI. Curtiss, Klemz, and Vanderploeg (2000) noted that three spouses in their sample reported greater cohesion and adaptability post-injury. Douglas and Spellacy (1996) observed high

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[5] Based on scores on the general functioning subscale of the Family Assessment Device

levels of cohesion in their sample of TBI families. Perlesz, Kinsella, and Crowe (2000) found relatively low levels of family dissatisfaction in a large sample of caregivers. Similarly, in a study of Mexican families, Lehan et al. (2012) reported relatively high levels of family satisfaction and communication. Interestingly, a much higher proportion of families were classed as balanced than in other studies using the FACES (Kosciulek, 1996, Kosciulek & Lustig, 1999). This may reflect differences in family organisation and values in Latin American families, described as having high levels of cohesion (Lehan et al., 2012). However, given the large number of families who refused to take part or who failed to attend for assessment, it is also possible that more dysfunctional families did not take part. The discrepancy may also relate to differences in the versions of the measure used. In the only study that compared family functioning in different ethnic groups, Nabors, Seacat, and Rosenthal (2002) did not observe significant differences in family functioning in African American and white caregivers of persons with TBI.

Fewer studies have explored whether certain aspects of family functioning may be more vulnerable to dysfunction after TBI (Kreutzer et al., 1994a; Ponsford et al., 2003; Ponsford & Schönberger, 2010). The most commonly area identified as being problematic for TBI families was communication (Boyle & Haines, 2002; Kolakowsky-Hayner & Kishore, 1999; Kosciulek, 1995; Kreutzer et al., 1994a). Other studies, however, highlighted difficulties in roles (Anderson et al., 2009), affective involvement and affective responsiveness (Kolakowsky-Hayner & Kishore, 1999; Kreutzer et al. 1994a). Greater reliance on structure and rules and regulations for guiding behaviour has also been described as a characteristic of some TBI families (Boyle & Haines, 2002; Douglas & Spellacy, 1996; Ponsford & Schönberger, 2010).

Overall, higher rates of poor family functioning in the TBI population than in the general population were indicated, though many families may continue to function well

after TBI. More limited evidence suggested that TBI families may especially struggle in the area of communication.

Predictors of family functioning

Injury severity

       In general no significant association has been observed between injury severity and family functioning (Ergh, Rapport, Coleman, & Hanks, 2002; Groom et al., 1998; Hanks, Rapport, & Vangel, 2007; Kreutzer, Gervasio, & Camplair, 1994b; Ponsford et al., 2003; Ponsford & Schönberger, 2010; Testa et al., 2006; Winstanley, Simpson, Tate, & Myles, 2006; though for two exceptions see Douglas & Spellacy, 1996; Ponsford et al., 2003). This may be unsurprising as indices of injury severity, such as duration of PTA, are not always reflective of the patient's disability and needs after TBI, factors more likely to be of concern to families.

Physical and functional disabilities

       Research looking at the relation between family functioning and the patient's level of physical and functional needs is more limited and difficult to evaluate due to differences in the measures used and the abilities aggregated. Kaplan (1991) found that families of patients with more severe physical impairments reported more conflict. Douglas and Spellacy (1996) found that caregivers' perception of the injured person's competence in achieving daily activities was significantly related to their reports of problematic communication and conflict in the family. Ponsford and Schönberger (2010) also observed a relationship between family functioning at two years post-injury and patient-reported disability, although this relationship almost disappeared at five years and was not

observed by Ponsford et al (2003) with a smaller sample. Other studies have similarly failed to find a relationship between family functioning and caregiver- or clinician-rated assessment of the injured person's physical impairments or functional abilities (Hanks et al., 2007; Kosciulek & Lustig, 1998, 1999; Kreutzer et al., 1994b; Ponsford et al., 2003).

Overall, physical and functional disability has shown little consistent relationship to family functioning.

Neurobehavioural & cognitive problems

A much stronger and more consistent association has been observed between family functioning and neurobehavioural problems (Anderson, Parmenter, & Mok, 2002; Anderson et al., 2009; Douglas & Spellacy, 1996; Ergh et al., 2002; Groom et al., 1998; Kaplan, 1991; Kosciulek & Lustig, 1998, 1999; Kreutzer et al., 1994b; Ponsford et al., 2003; Ponsford & Schönberger, 2010; Schönberger et al., 2010; Testa et al., 2006). For example, Ponsford et al. (2003) found that healthy and unhealthy families were best distinguished by the number of cognitive, behavioural and emotional changes reported by relatives. Poorer family functioning has also been reported in families where the injured person has greater cognitive impairment (Kreutzer et al., 1994a; Testa et al., 2006), though family perceptions of behavioural problems have been found to explain three times as much variance in family functioning as perceived cognitive problems (Anderson et al., 2002).

While most studies reported a strong relationship between the presence of neurobehavioural problems and family functioning, there were a couple of exceptions. Carnes and Quinn (2005) failed to observe a relationship between neurobehavioural difficulties and family functioning assessed during inpatient admission. It may not be until the injured person returns home that neurobehavioural problems start affecting family

functioning. Similarly, Winstanley et al. (2006) failed to find a significant association between neurobehavioural impairments and family functioning at 18 months post-injury. One explanation for this discrepancy may be that the measure used to represent neurobehavioural disturbances in the path analysis model examined. This was a composite of the emotion and cognition subscales from the Mayo-Portland Adaptability Inventory (MPAI; Malec & Thompson, 1994), with the behaviour and social behaviour subscales of this measure excluded from the analysis (reported as having poor measurement properties). This limited the range of neurobehavioural disturbances examined when looking at relationships to family functioning and may have diluted any association that might have been observed, especially given that cognitive difficulties have been shown to have a weaker relation to family functioning (Anderson et al., 2002). The MPAI is also a clinician-rated measure, where most other studies relied on family members' reports of neurobehavioural problems.

In general, findings suggested that family members' perception of neurobehavioural problems is associated with poorer family functioning after TBI.

Time since injury

Overall, no consistent relationship has been observed between family functioning and time post-injury. Groom et al. (1998), Hanks et al. (2007) and Zarski et al. (1988) found no relationship between time post-injury and family functioning whilst other studies have reported small effects of time post-injury on family functioning suggesting both better and worse adjustment over time (Ergh et al., 2002; Kreutzer et al., 1994b).

Sample variability in cross-sectional studies may limit the power to be able to detect consistent associations with time. However, the few existing longitudinal studies have produced a similarly mixed picture. Winstanley et al. (2006) observed deterioration

in family functioning from inpatient rehabilitation to 18 months post-injury. Testa et al. (2006) found little change in family functioning across a similar timeframe. Likewise, two other papers (based on the same pool of participants) observed no change in the level of family dysfunction from two to five years post-injury (Ponsford & Schönberger, 2010; Schönberger et al., 2010).

In sum, poor family functioning has been reported in families from soon after injury to nine years and longer after injury, with little consistent evidence of either better or worse family functioning over time.

Provision of direct care

Family respondents tended to be the primary caregivers; very little is known about how other family members experience family functioning (Perlesz et al., 2000). In one exception, Perlesz et al. (2000) found greater family dissatisfaction in tertiary caregivers than in primary or secondary caregivers. However, the small sample necessitates caution and as the tertiary caregivers were mainly adolescents or young adult siblings, it is unclear to what extent their dissatisfaction related to their age (Perlesz et al., 2000). Ponsford et al. (2003) observed little difference in family functioning reported by family members providing direct care compared to those who did not. Conversely, in an extension to this study, evidence of poorer family functioning in direct caregivers was found (Ponsford & Schönberger, 2010).

Very few studies distinguished between family members who lived with the injured person and those who did not. In one study that compared family satisfaction in families where the person with TBI lived separately or with family members, small samples prevented reliable statistical analysis, though visual inspection revealed little group differences in family satisfaction (Brzuzy & Speziale, 1997). Similarly, Ponsford et al.

(2003) and Ponsford and Schönberger (2010) failed to observe a significant difference in family functioning according to whether the family member lived with the injured person or not.

Overall, current evidence on whether the impact of TBI on family functioning is moderated by whether the family member is involved in direct care and living with the injured person is very limited.

Kinship of family member to injured person

While it has been suggested that TBI may have a greater impact on spouses than on parents (Perlesz et al., 1999), evidence for this was mixed. Although Kreutzer et al. (1994a) found spouses tended to report higher levels of unhealthy functioning than parents, no statistical difference was found. Similarly, other studies have observed little difference in family functioning reported by spouses and parents (Carnes & Quinn, 2005; Ergh et al., 2002; Kreutzer et al., 1994b, Ponsford et al., 2003; Ponsford & Schönberger, 2010). Conversely, Perlesz et al. (2000) found that wives had lower family satisfaction than mothers of persons with TBI. Similarly, Anderson et al. (2009) observed significantly higher levels of family dysfunction in spouses than in parents of persons with TBI. One explanation for why family functioning was greater for parents than spouses in this study may be the parent sample used. This differed from other studies in that it was composed of parental dyads and as Anderson et al. (2009) proposed, having another healthy adult to share the burden may have helped maintain healthier family functioning.

Pre-existing family characteristics

It has been proposed that certain families may be better placed to cope with stressful events like TBI (Kosciulek & Lustig, 1999). Specifically, the Circumplex model

suggests that families that are close but not enmeshed, and structured but flexible will function more effectively than those very high or low in cohesion and adaptability (Olson et al., 1983). Early studies testing this prediction in TBI families found more support to suggest that healthier family functioning (as measured using the FAD) and better communication is associated with higher levels of family cohesion and adaptability (Kosciulek, 1996; Kosciulek & Lustig, 1999; Zarski et al., 1988). However, a recent study of TBI families using the FACES-IV (Olson, 2010) and its new scoring structure found families reporting more balanced (moderate) levels of cohesion and adaptability reported better family communication and greater family satisfaction (Lehan et al., 2012).

It is unclear, however, how much the adaptability and cohesion measured was pre-existing or a reflection of the consequences of the TBI. Curtiss et al. (2000), for example, found that families perceived changes in family adaptability and cohesion from pre-injury levels as early as admission for inpatient rehabilitation.

Clearer evidence that family functioning after TBI may be influenced by pre-existing family qualities was obtained by Kaplan (1991) who found that estimates of pre-injury cohesion were strongly related to family cohesion three years post-injury. Although based on retrospective ratings and different assessment tools, this finding is consistent with premorbid relationships being important in understanding family adjustment post-injury. Similarly, Testa et al. (2006) found that the most consistent predictor of family functioning at one year was family functioning at hospital discharge, which might indicate that a significant component of family functioning after TBI may be accounted for by factors unrelated to the brain injury. Moreover, Carnes and Quinn (2005) found that respondents who had a better premorbid relationship with the injured person perceived better family functioning post-injury.

Family functioning and caregiver distress

A small number of studies have explored the possible link between family functioning and caregiver distress. Though not a universal finding (Douglas & Spellacy, 1996; Nabors et al., 2002; Winstanley et al., 2006), there was evidence that poor family functioning may be associated with high levels of caregiver distress (Anderson et al., 2002; 2009; Ponsford et al., 2003; Ponsford & Schönberger, 2010).

Anderson et al. (2002) went further and proposed a model in which family functioning was hypothesised to mediate in the relationship between behavioural problems and caregiver distress. Using path analysis, Anderson et al. (2002) found support for this model in a sample of spouses (though not in parents; Anderson et al., 2009; see also Schönberger et al., 2010). In a second path analysis study of TBI families, family functioning was also observed to perform a protective function (Coy et al., 2013). It was found that caregivers with high levels of family satisfaction tended to report lower levels of subjective burden regardless of the social functioning of the injured person. Conversely, poor social functioning in the injured person was related to increased subjective burden in family members with low levels of family satisfaction. In a third, and longitudinal, study, Schönberger et al. (2010) observed an indirect relationship between behavioural changes in the injured person at two years and caregiver distress at five years, mediated by family functioning at two years. Conversely, an indirect relationship was observed between mood changes in the injured person at two years and family functioning at five years, mediated by caregiver distress at two years. Schönberger et al. (2010) argued that family dysfunction and caregiver distress may be mutually reinforcing; poorer family functioning may make family members more vulnerable to distress as a result of the demands of TBI and conversely the distress of family members may make families more vulnerable to dysfunction.

Social support and family resources

The ability of the family to cope with the demands of TBI may also depend on external family resources. Findings suggested that this may relate less to material resources (Carnes & Quinn, 2005; Kosciulek & Lustig, 1999) than to social support. Social support was strongly and consistently related to healthier family functioning (Carnes & Quinn, 2005; Douglas & Spellacy, 1996; Ergh et al., 2002; Hanks et al., 2007; Winstanley et al., 2006; though see Zarski et al., 1988). For example, in a study of 60 family members, perceived social support was found to be the largest predictor of family functioning, with neurobehavioural problems, cognitive impairment, time post-injury and patient insight making much smaller contributions to variance in family functioning (Ergh et al., 2002; see also Douglas & Spellacy, 1996).

Coping & appraisals

Only a small number of studies have explored the link between the coping strategies used by family members and family functioning. Curtiss et al. (2000) described differences in coping strategies used by TBI families classed as balanced and extreme, based on their adaptability and cohesion scores on the FACES II, though this is difficult to interpret due to the small number of families in each group. Douglas and Spellacy (1996) and Hanks et al. (2007) failed to observe a significant relationship between family functioning and caregivers' use of task-, avoidant- or emotional-oriented coping strategies. However, Kosciulek (1994) found that the use of positive appraisals and, to a lesser extent, family tension management (e.g. continued family involvement in activities) was positively related to family functioning after TBI. Carnes and Quinn (2005) found that the use of reframing and spiritual support was related to better family functioning. Similarly,

in a study of families with a parent with TBI, Stanescu and Romer (2011) found that the healthy parent's use of reframing was related to their adolescent child's perception of healthier family functioning. Conversely, the use of passive appraisal was related to poorer functioning. In addition, caregiver appraisals of both their own and their family's capacity to manage problems have been observed to be associated with family functioning (Hanks et al., 2007; Kosciulek, 1997).

More research is needed to explore how coping styles and cognitive appraisals affect family adaptation after TBI, though preliminary evidence suggests that positive appraisal and reframing and self- and family efficacy beliefs may be associated with better family functioning.

DISCUSSION

Summary of findings

Many of the studies on family functioning after TBI reviewed here share similar methodological problems that may limit confidence in the conclusions drawn. These include the use of small samples, the lack of pre-injury estimates of family functioning, possible sampling biases and the use of cross-sectional designs. Due to the commonality of methodological issues, conclusions were based on the volume and consistency of support for a finding across studies.

Estimates of the extent of poor family functioning varied, but findings generally suggested higher rates of dysfunction in TBI families than in the typical population. There was no clear link between the extent of poor functioning found and study quality, though the conclusion drawn by studies about family functioning may have been affected by the

way in which scores were reported (e.g. proportion of families scoring in unhealthy range on one subscale/on general functioning versus use of mean scores),   In the small proportion of studies that considered difficulties in specific aspects of family functioning, communication was most consistently identified as problematic for TBI families. It has been suggested that this may be a result of the injured person's communication impairments as well as caregiver efforts to protect their loved ones from the expression of negative emotions and difficulties (Kreutzer et al., 1994a). The increased reliance on structure and rules for behaviour in TBI families reported by three studies may also be a response to the cognitive and behavioural legacies of brain injury (Boyle & Haines, 2002).

Neurobehavioural changes in the injured person proved to be a stronger and more consistent predictor of family functioning than other patient and injury characteristics. A relationship between family functioning and neurobehavioural disturbances was reported by a large number of studies, and with few exceptions. This has also been observed in relation to distress and burden in family members (e.g. Brooks et al., 1986; Marsh et al., 1998). Again comparable to research on caregiver distress and burden (Ennis et al., 2013), evidence for differences in family functioning in parents and spouses was mixed.

It has been argued that premorbid family qualities may influence how well families adjust and function after trauma such as TBI (Seaton & David, 1990; Vangel, Rapport, & Hanks, 2010). Consistent with this, there was evidence that families who were cohesive and functioning well before the injury, and who had good relationships with the injured person, remained better functioning post-injury (Kaplan, 1991). While this finding came from poorer quality studies, the observation that families who display unhealthy family functioning very early after injury (which may provide an indication of pre-morbid functioning) tend to continue to show dysfunction (Testa et al., 2006) may provide additional (albeit weaker) support for this idea.

There was no consistent evidence that levels of family dysfunction change over time. Conversely, there was consistent evidence across studies that families with good social support tend to function better. There was also some limited evidence to suggest that families who make greater use of positive appraisal and reframing and who hold greater confidence in their capacity to manage the demands of TBI may adapt better, though the literature base would benefit from additional good quality research to corroborate the importance of appraisals to family functioning,

Conceptual issues

Most studies were characterised by an absence of a theoretical framework. This may contribute to the lack of clarity as to whether poor family functioning measured by questionnaires such as the FAD should be considered an outcome of family stress (Carnes & Quinn, 2005; Kosciulek, 1994) or a resource that might act as a buffer against demands placed on the family (Anderson et al., 2002, 2009; Coy et al., 2013; Hobfoll & Speilberger; Nabors et al., 2002; Stanescu & Romer, 2011; Vangel et al., 2010). Viewed as a mark of family stress, the findings of the studies reviewed may be considered compatible with models of family adaptation that highlight the role of demands (e.g. neurobehavioural problems), family capabilities (e.g. social support, pre-existing characteristics) and appraisals (e.g. reframing and confidence in the capacity to manage demands) in determining how successfully families adapt (Hobfoll & Spielberger, 1992; Kosciulek et al., 1993; Patterson, 1988). However, findings from path analysis studies have also been used to support the idea that positive family functioning may act as a buffer to the demands of TBI, making family members less vulnerable to distress (Anderson et al., 2002, Coy et al., 2013).

A broader question raised by the research is what should be considered healthy. TBI families may be organised differently than the families on which the McMaster's model of family functioning is based, but this may be adaptive (Curtiss et al. 2000; Zarksi et al., 1988). Greater reliance on behavioural control and rules may be necessary to contend with the behavioural problems of the person with TBI (Ponsford & Schönberger, 2010). Higher family cohesion found in TBI families may be adaptive given the increased dependence of people with TBI (Frank et al., 1990). Kouneski (2000) has suggested that even a family organisation classed as extreme may be functional for the situation the family finds itself in at least for a period. Moreover, the Circumplex model predicts that it is those families who are unable to change who may become dysfunctional (Kosciulek et al., 1993). Furthermore, it has also been suggested that the exact organisation of the family may be less important than whether it meets the expectations of and is acceptable to all family members (Olson et al., 1983; Zarski et al., 1988).

Further methodological issues

There has been a lack of empirical support for the curvilinear relationship of the Circumplex model as assessed by the FACES-II and FACES-III (Olson, 2011). Although attempts have been made to address this in the latest version of the measure, this has yet to be extensively tested in the TBI population. The studies reviewed also bear the limitations of having used self-report to assess family functioning. Social desirability and lack of insight, for instance, may have influenced family members' responses, reducing their validity. The use of retrospective reports to estimate pre-injury functioning may be especially vulnerable to biases such as those resulting from poor recollection and a tendency to have an overly positive view of life before the injury. Another criticism that has been levelled at measures of family functioning is that they are attempting to measure

functioning at a systems level, while being based on the report of a single family member (Koscieluk, 1995; Koscieluk, 1996). Although a couple of studies included multiple individuals from the same family (Perlesz et al., 2000; Carnes & Quinn, 2005), no study looked at whether different members from the same family hold similar perceptions of family functioning. This would be a valuable addition in efforts to adopt a systemic approach to assessing family functioning after brain injury.

Although family adjustment has been construed as a dynamic process (Lehan et al., 2012), most studies only provided a snapshot of family functioning. Families of people with traumatic brain injury may undergo ongoing adjustment, with different challenges presenting themselves at different stages in the injured person's recovery and according to the family lifecycle (Leaf, 1993; Moore et al., 1993). While changes in family functioning have not been consistently observed over time, this may be because it is difficult to capture the process of adjustment by examining group data and by assessing families on just two occasions.

Finally, the review itself has a number of limitations that need bearing in mind. Some of these relate to the inclusion criteria, such as the exclusion of studies that did not use an established measure of family functioning. This may narrow the picture gained to areas of family functioning assessed by such measures. The synthesis will also be influenced by any publication biases and may be culturally biased having only included peer-reviewed articles published in the English language. The synthesis may have been broadened by including studies using other relational measures, such as those assessing marital adjustment and by incorporating the injured person's view of family functioning. Bringing in family intervention studies would have also added another dimension, though these have been reviewed elsewhere (Boschen et al., 2007). Finally, the process of using

the quality appraisal checklist was inevitably subjective and would have benefitted from a check of inter-rater reliability. Nevertheless, no study was excluded on the basis of this.

Clinical implications

A consistent recommendation across studies was the need to support family networks to enable them to better care for their injured relatives (Kaplan, 1991). Family interventions have taken the form of education, support groups and counselling. However, it has been argued that family therapy approaches may be important in order to help families with relational issues and conflict, problems with communication and with adapting to new roles or re-establishing old ones (Kreutzer, Stejskal, Ketchum, Marwitz, Taylor, & Menzel, 2009; Laroi, 2003; Oddy & Herbert, 2003; Oddy & Herbert, 2008; Stejskal, 2012). Decisions about the most appropriate interventions may benefit from an assessment of the impact of TBI at an intrapersonal (emotional distress in individual members), an interpersonal (relationship quality) and a system level (family structure and organisation), while recognising the interrelations between the different levels.

The research reviewed particularly points to the need to help families in the area of communication and interventions that focus on helping families understand neurobehavioural problems and increasing their confidence in managing these. The value of social support in helping families manage the impact of TBI was also highlighted. Social networks may shrink after TBI, with extended families, who may initially be very supportive, pulling away over time resulting in greater pressures on primary caregivers (Willer, Flaherty, & Coallier, 2001). While it may be hard for professionals to directly help families maintain social support, they may be able to assist in identifying and addressing possible barriers to accessing such support (e.g. a need to supervise patient).

Finally, the finding that family functioning at discharge is strongly related to functioning at one and three years (Kaplan, 1991; Testa et al. 2006) suggests it may be possible to identify families who may be at risk and in need of additional support early on.

Further directions for research

The stage in the family life cycle at which the injury is incurred and the composition of the family might be expected to influence the issues faced and how well families function post-TBI (Douglas & Spellacy, 1996). Although Douglas and Spellacy (1996) found no significant effect of family composition and the role of the injured person on family functioning, this was only a small study. Greater emotional distress has been observed in wives of men with TBI who have younger children (Moore et al., 1993). Moreover, one study found that families functioning effectively after TBI were more likely to have older primary caregivers, which might indicate that more established families may be more stable and resilient to the stress of TBI (Kosciulek & Lustig, 1999). More studies are needed to evaluate the influence of the developmental stage of the family.

Most studies of family functioning have involved spouses or parents of the person with TBI. There is a lack of research examining the impact on other family members such as siblings (Gill & Wells, 2000; Orsillo, McCaffrey, & Fisher, 1993), children of parents with TBI (Stanescu & Romer, 2011; Urysal, Hibbard, Robillard, Pappadopulos, 1998) and those not providing direct care (Perlesz et al., 2000). In addition, given what is known about cultural differences in family organisation and attitudes and values relating to informal care, it may be important to explore how TBI affects family functioning across different cultures (Coy et al., 2013; Sander et al., 2007; Watanabe, Shiel, McLellan, Kurihara, & Hayashi, 2001).

More longitudinal studies (and those that attempt to estimate pre-injury functioning) would be worthwhile in trying to clarify causes and effects of poor family functioning. Intervention studies might also be valuably applied in efforts to clarify causal relationships between family functioning and neurobehavioural problems and other patient/family outcomes. Other directions for future research might consider the need for measures developed specifically for TBI families and whether self-report measures of family functioning might usefully be complemented by the development of observational measures.

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Chapter II

Personality and Identity Changes Following Traumatic Brain Injury: The Lived Experience of Partners

ABSTRACT

Background: Behavioural and emotional changes in persons following traumatic brain injury (TBI) may place particular strain on marital relationships. For some spouses the changes are perceived to be so great that the person is felt to be a different person. The aim of the current paper was to explore partners' experiences of personality changes and the impact of such changes on perceptions of the person and relationship.

Method: Interpretative phenomenological analysis of interview data explored five women's experiences of personality changes in their partners following TBI.

Findings: Themes identified described participants' experiences of living with the emotional and behavioural changes (*the emotional toll*, *managing behaviours*, *making sense of behaviours*) and the broader meanings of changes (*he's not the person he was*, *impact on the couple relationship*, and *wishing, hoping & grief*).

Conclusion: The presence of volatile, aggressive, and obsessive behaviours appraised as new and difficult to manage, and the loss of characteristics valued in the premorbid person and relationship contributed to four participants' sense of their partner no longer being the same person. Their experiences are contrasted with that of one participant who perceived positive changes in her partner whilst considering him to be fundamentally unchanged.

Keywords: *Traumatic brain injury, personality changes, couple relationship, qualitative research*

INTRODUCTION

After traumatic brain injury, the experience of some family members is that of suddenly and unexpectedly being presented with a person very different to whom they knew and loved before the injury (Lezak, 1986; Oddy, 1995). The person may display a range of bewildering, upsetting and frightening behaviours that are hard to make sense of and difficult to manage (Braine, 2011; Lezak, 1986). Increased dependence and difficulties in performing old roles may result from such changes in the person's emotional, behavioural and social functioning (Frosch, Gruber, Jones, Myers, Noel, Westerlund, & Zavisin, 1997; Lezak, 1987). In such cases, life is unalterably changed not just for the person with the injury but for family and loved ones also.

The term 'personality change' has been adopted in the literature to describe the behavioural, emotional and motivational features of brain injury (Prigatano, 1992). Changes commonly listed under this rubric include increased irritability, mood swings, aggression, inappropriate behaviour, insensitivity, lack of interest, poor judgment, lack of awareness and depression (Brooks & McKinlay, 1983; Prigatano, 1992). Some of the changes listed may be surprising and may alternatively be construed as representing cognitive changes due to direct effects of damage to the brain or temporary mood states that may relate to adjustment to the injury and its consequences (Yeates, Gracey, & Collicutt Mcgrath, 2008). It is less clear if there are permanent changes to core personality traits following TBI (Kurtz, Putnam, & Stone, 1998; Rush, Malec, Brown, & Moessner, 2006; see Yeates et al. (2008) for a deconstruction of the term "personality change" after brain injury). Nevertheless, such neurobehavioural changes may contribute to some relatives' sense of the person as being changed and for some to such a degree that the injured person feels like a stranger (Oddy, 1995; Thomsen, 1984; Wedcliffe & Ross, 2001). In other words the presence of emotional and behavioural changes after TBI

(labelled as personality changes in the literature) may (but not always) result in perceived identity change (a sense of discontinuity in the personhood of the injured person; Yeates et al., 2008). This distinction has not always been made clear in the literature. A parallel literature has explored loss of sense of self in TBI survivors. This is out of the scope of the current paper, but see, for example, Nochi (1998).

Personality (or neurobehavioural) changes have been found to pose a particular challenge to family members, placing strain on the very relationships that so often are central to the injured person's well-being and ongoing care (Barclay, 2013; Stejskal, 2012). One of the most consistent findings in family outcome literature is that the best predictors of caregiver well-being and family functioning are not the physical and cognitive consequences of brain injury, but the emotional and behavioural legacies (Brooks & McKinlay, 1983; Knight, Devereux, & Godfrey, 1998; Kreutzer, Gervasio, & Camplair, 1994; Marsh, Kersel., Havill, & Sleigh, 1998; Ponsford, Olver, Ponsford, & Nelms, 2003; Wells, Dywan, & Dumas, 2005). Such changes are almost exclusively perceived as negative, though positive changes have been reported by some family members (Gill, Sander, Robins, Mazzei, & Struchen, 2011; Kaitaro, 1995). Furthermore, the burden and distress associated with such changes has been found to persist or even worsen over time (Blais & Boisvert, 2005; Brooks, Campsie, Symington, Beattie, McKinlay, 1986; Thomsen, 1984).

It has been suggested that the impact of TBI may be greater for spouses than for parents (Blais & Boisvert, 2005), and whilst there remains a lack of consensus in this debate (Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013), the issues faced by spouses may be different (Knight et al., 1998). High rates of marital breakdown have been reported following brain injury (Arango-Lasprilla, Ketchum, Dezfulian, Kreutzer, O'Neil-Pirozzi, Hammond, & Jha, 2008; Wood & Yurdakul, 1997). Moreover, even if the

relationship survives, the quality of many behavioural and emotional consequences of brain injury may mean that it is radically altered in such a way that it is viewed negatively by the uninjured spouse (Blais & Boisvert, 2005; Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011; Peters, Stambrook, Moore, & Esses, 1990; Wood, Liossi, & Wood, 2005).

In light of the impact of personality changes on caregiver well-being and on relationships also vital to the wellbeing of the injured person, it is important to understand what it is about such changes that are so devastating for spouses. Research in neurological populations in which neurobehavioural changes are common (e.g. stroke, TBI and dementia) have highlighted the challenging nature of such behaviours for family members forced to manage and cope with these on a daily basis (Connelly & O'Dowd, 2001; Harvath, 1994; Riley, 2007). A variety of neurobehavioural changes have been identified as being particularly troubling to spouses after TBI including volatile and unpredictable behaviour (Marsh et al., 1998; Wood et al., 2005), changes in expressed affection and emotional responsiveness (Gosling & Oddy, 1999; Peters, Stambrook, Moore, Zubek, Dubo, & Blumenschein, 1992), and a lack of empathy and insight (Burridge, Williams, Yates, Harris, & Ward, 2007; Wells et al., 2005).

However, research has suggested that the response of family caregivers may not always be proportionate to the frequency, nature and severity of emotional and behavioural changes in the injured person (Blais & Boisvert, 2005). Caregiver responses to challenging behaviours have been found to be moderated by their beliefs about the behaviour (Riley, 2007) and their confidence in their ability to cope (Wells et al., 2005). Based on the findings of a large survey of partners, Wood et al. (2005) has also proposed that factors relating to the injured person's premorbid personality may help explain variations in the specific neurobehavioural features that place greatest burden on spouse relationships.

Equally family members' perception of the person as being different may not depend solely on the nature or degree of objective changes in the injured person's behaviour (Oddy, 1995; Weddell & Leggett, 2006). Judgments of identity change may also be influenced by the attributions made by families about the injured person's behaviour, by the nature of their relationship with the injured person, and by the pre-morbid identity of the injured person. McKinlay and Brooks (1984) reported that relatives scoring high in neuroticism were more likely to make global judgments of personality change on the part of the injured person. One explanation given was that these individuals may be more prone to making negative attributions of the person's behaviour, resulting in greater perception of difference in the injured person. A slightly alternative explanation might be that individuals high in neuroticism may focus more on the (negative) changes than those aspects of the person that remain familiar (Oddy, 1995).

Interestingly, Weddell and Leggett (2006) observed that the presence of comparable emotional and behavioural changes did not predict spouses' judgments of personality change in the same way as they did parental judgments. It was suggested that the meaning of specific changes may differ for parents and spouses, with those changes assessed in their study (e.g. low social constraint) being more relevant to parental judgments. Thus the appraisal of behaviours made by family members and the meaning behaviours have for the relationship may be important in determining whether the person is perceived as different. In addition, whether the person is perceived as different may depend on the centrality of changes to the injured person's pre-injury identity. For instance, Oddy (1995) proposed that less change may be perceived by family members still able to recognise positive characteristics that they valued in the person prior to injury.

Perceiving the person to be different may be associated with a number of negative consequences. This has been particularly expounded upon in the dementia literature, where

perception of the person with dementia as fundamentally different has been linked with negative feelings towards the person and the relationship, and a sense of the couple relationship as being over or at least significantly transformed (Riley, Fisher, Hagger, Elliott, Le Serve, & Oyebode, 2013; Walters, Oyebode, & Riley, 2010). Within the TBI population, feeling that the person is different has been associated with a reduced wish for intimacy and closeness with the injured spouse (Gill et al., 2011) and with marital separation (Thomsen, 1984). In addition, anecdotal and empirical literature has observed how strong feelings of loss and grief may follow the experience of the person as being essentially and irrevocably changed (Braine, 2011; Chwalisz & Stark-Wroblewski, 1996; Godwin et al., 2014; Lezak, 1986; Oddy, 1995).

The salience of personality change to families after TBI is evident through the many mentions it receives in qualitative studies in which personality changes were not the primary focus (Chwalisz & Stark-Wroblewski, 1996; Godwin et al., 2014; Gosling & Oddy, 1999; Hammond et al., 2011; Jumisko et al., 2007; Wedcliffe & Ross, 2001). However, there is very limited qualitative research focused specifically on the behavioural and emotional changes that underlie some family members' sense of the person as different after TBI. In an acquired brain injury sample (with unspecified aetiologies), Braine (2011) used a descriptive phenomenological approach to explore one mother's and four wives' experiences of such changes. Both passive (e.g. apathy) and active changes (e.g. emotional lability and aggression) were found to be associated with a range of negative feelings. This study also highlighted experiences of loss, loneliness, uncertainty and coping, as well as the impact of changes on family functioning. However, it did not comment on the possible relation between the meanings changes had for participants and perceptions of the person as being the same or different, or on divergences between participants. Given the potential impact of perceiving the person to be different on couple

relationships, further exploration of the meanings of personality changes for partners was considered worthwhile and important.

The purpose of the present study was to explore how personality changes are experienced by partners of persons with TBI. At the interpretative stage, it aimed to consider what (if any) personality changes are challenging to the perception of the pre-morbid person (i.e. what contributes to a sense of the person as different and not just changed). A secondary objective was to consider how perceived changes affect participants' relationship with the injured person. The study was interested in understanding participants' personal experiences of changes in their partner's character and did not seek to establish the objectivity of such changes. It sought to explore the concerns of partners in relation to personality change after TBI (i.e. what changes matter most and what makes them matter most to participants?). As such interpretative phenomenological analysis (IPA) was considered highly suited to the aims of the study. IPA is concerned with understanding the lived experiences of individuals. It is interested in how individuals make sense of their experiences, but also recognises that interpretations are co-constructed by both the participant and the researcher. It therefore acknowledges that the researcher necessarily brings to bear their own conceptions and experiences in their interpretation of participants' meanings (the 'double hermeneutic'; Brocki & Wearden, 2006; Smith, Flowers, & Larkin, 2009).

The research reviewed above strongly hints at the possibility of differences in how individuals make sense of emotional and behavioural changes and in the meaning those changes have for them. The idiographic stance of IPA embraces such divergences, with the detailed examination of small numbers of cases allowing for exploration of convergences and divergences across and within accounts (Smith, 2004).

METHODOLOGY

Ethics and consent

The study was granted ethical approval by the NHS National Research Ethics Service (see Appendix iv). The researcher met or telephoned participants at least a week before the first interview, providing participants with verbal and written information about the study (see Appendix v). Written consent was obtained before the first interview (Appendix vi).

The emotive nature of the interviews was discussed with all participants prior to gaining consent. During interviews the researcher continually monitored participants' distress and responded appropriately. This included moving away from a line of questioning and, for one participant, offering to stop the interview (which she chose not to do). Participants were debriefed after the second interview and, if indicated, avenues of further support were discussed.

Participants

Staying true to IPA's idiographic approach, the study recruited a small, relatively homogenous group of partners/spouses of persons with traumatic brain injury (Smith et al., 2009). Participants were identified through an NHS outpatient brain injury service and local branches of Headway (a support organisation for individuals affected by brain injury).

A local collaborator identified potential participants based on the set of inclusion/exclusion criteria listed in Table 6. Further details of the recruitment process are presented in Appendix vii.

Four participants were recruited from three different branches of Headway, with a fifth participant recruited from the NHS outpatient service. All five participants were female partners of men who had experienced a traumatic brain injury. Characteristics of participants, the injured partner and their circumstances are presented in Table 7. Although no medical data were obtained, participants' descriptions of the circumstances of the injury and the early care received are suggestive of at least moderate TBI and likely severe in some cases (Table 7).

Table 6
Participant Inclusion Criteria

Inclusion Criteria
- Partners of individuals who had experienced a traumatic brain injury resulting in possible personality changes
- The person with TBI experienced the injury at least 6 months and no more than eight years prior to interview
- The participant co-habited currently and at time of injury with the individual with TBI and was in a relationship with them for at least 1 year prior to injury
- The participant was between the age of 25 and 65 years old
- The participant had the capacity to give informed consent and to contribute meaningfully to discussions about their experience

Exclusion Criteria
- A current diagnosis of a severe mental illness or other indications to suggest that the participant was not emotionally robust (or the relationship was not robust enough) to cope with the interview
- The individual with TBI had a diagnosis that predated their injury of a severe mental illness or personality disorder that would make it difficult to determine whether any changes were a result of the brain injury

Table 7

Characteristics of Participants and Their Partners[6]

Participant		Partner		Injury		Relationship				
ID	Age	ID	Age	Cause	Time post-injury	Length of relationship	Children	Early care received		Current physical and cognitive difficulties and rehabilitation
Lisa	39	Mike	43	Sporting accident	1 year	9 years	1 daughter, pre-school aged	6 weeks in acute hospital (induced coma for 2.5 weeks). Received inpatient rehabilitation for 3 months with further community rehabilitation.		No ongoing physical difficulties. Ongoing memory and word-finding difficulties. Returned to work with some difficulties managing temper with colleagues.
Helen	42	Chris	49	Fall	2.5 years	15 years	2 primary school aged daughters. 3 grown sons.	6 weeks in acute hospital (time in induced coma). Significant physical injuries; brain injury not recognised until much later. No rehabilitation received initially.		Physically mobile, dizziness, changes to smell and taste. Ongoing short-term memory problems. Attending a work skills rehabilitation programme
Anita	38	Tony	27	Fall	9 months	8 years	1 primary school aged son, 2 teenage daughters	2 weeks in acute hospital (1 week in a coma). No support for first 3 months.		Physically mobile but right-sided weakness, dizziness. Improving memory. Receiving rehabilitation as day patient four days a week.
Diane	39	Greg	41	Fall	7 years	22 years	No children	2 months in acute hospitals (2 weeks in a coma). Received community and outpatient rehabilitation		Physically mobile. Speech and memory problems. Requiring close supervision, assistance with activities of daily living. Attending daycentre 3 days/ week
Clare	29	John	43	Assault	5 years	6 years	Baby under 1 year (post-injury)	16 weeks in acute hospital (1 month in induced coma). Received inpatient rehabilitation for 11 months, with further community rehabilitation.		Walking short distances, swallowing difficulties. Memory and significant speech problems. Attending daycentre 3 days/week, still receiving some rehabilitation.

[6] All names have been changed to protect confidentiality

Interviews

Participants were interviewed on two separate occasions to facilitate collection of data with richness and breadth (Polkinghorne, 2005). Interviews were held one to three weeks apart in quiet and private venues agreed in collaboration with participants. Interviews ranged from 51 to 66 minutes in length (or from 108 to124 minutes for the two interviews combined).

In keeping with the ethos of the phenomenological approach, interviews were conducted flexibly, being as much as possible led by the participant, but using an interview schedule as a guide to ensure areas of interest were covered (see Appendix viii). Efforts were made to use open and non-directive questioning where possible, with prompts used to encourage elaboration and for clarification (Willig, 2008).

All participants were first asked to explain what happened to their partner, which, as well as providing useful background data, was thought likely to be a well-rehearsed story that would help participants feel at ease. Broadly, questions in the first interview tended to take a more descriptive and narrative slant, while the second interview had a more evaluative focus (e.g. How has ____affected how you feel about _____?). The first interview provided information about changes, the impact of which was further explored in the second interview. The first interview was transcribed before the second took place to get ideas about possible concerns and questions. The second interview began with a summary of the main issues discussed in the first interview, providing participants with an opportunity to correct the researcher's understanding of what had already been discussed.

Towards the end of the second interview, participants were asked about specific personality changes described in the literature, but not mentioned by the participant herself up to that point. Participants' responses to these questions tended to be less rich and some participants seemed to agree that a change was present only on reflection. Therefore, less

weight in the interpretation was given to changes only mentioned on specific questioning, assumed to be of lesser concern to participants.

Interviews were audio-recorded and transcribed verbatim by the researcher. As well as the semantic content, unfinished sentences, hesitations, repetitions, pauses and background events were recorded. Tone and stress given to words or phrases was not transcribed. Potentially identifying information was changed and abbreviations or references to places were clarified in brackets.

Analysis

Interview transcripts were analysed using IPA guided by the framework described by Smith et al. (2009). In general, this involved "moving from the particular to the shared, and from the descriptive to the interpretative" (pp. 79, Smith et al., 2009). Each case was analysed in detail in turn. This involved reading and re-reading of the interview transcript. The first reading was done whilst listening to the audio-recording, with the added nuances of speech facilitating immersion in the participant's world and bringing back salient recollections of the interview. The first readings attempted to remain as open as possible to participants' concerns, making comments without reference to the planned purpose of the study. Comments and text clearly not relevant to the focus of the study were gradually shelved and not developed further. Throughout the process of reading and re-reading the transcript, comments were made on copies of the transcript, with later readings moving from descriptive comments to more conceptual ideas as the researcher gained familiarity with the complete transcript and possible connections held within. Possible emerging themes were gradually identified and noted on transcripts. This was a dynamic process that involved returning to earlier parts of the transcript, as later text gave way to new possible meanings.

The next stage involved clustering and organising themes emerging from the data. As part of this process the researcher moved continually between comments, codes and transcripts to help keep themes grounded in the meanings of participants. At the case level, groupings of themes remained elastic, recognising various alternative ways of organising and labelling themes.

This process was repeated for each case. Whilst attempting to remain open to each participant's concerns, comments were inevitably influenced by analysis of preceding cases. Likewise, subsequent cases could offer new possible meanings to earlier cases. The researcher therefore moved between transcripts and theme clusters as new ideas and connections emerged. An extract of an annotated transcript at two stages in coding is presented in Appendices ix and x. Following case level analysis, patterns across cases were examined, looking for convergence and divergence and themes were dropped to produce a manageable number of themes. Theme selection was influenced by a wish to encapsulate something of as many participants' experiences as possible, whilst highlighting potentially interesting divergences. As the final structure was produced the transcripts were revisited to identify extracts relating to each theme from different participants to ensure that themes reflected participants' concerns and meanings.

Credibility

IPA, like other qualitative approaches, acknowledges the preferences and biases the researcher brings to the process (Willig, 2008). In efforts to reduce the influence of researcher bias, at different stages in the analysis the researcher discussed ideas and possible themes with the research supervisor who had also read several of the interview transcripts. Quotations are also presented throughout the findings section to give the reader confidence that themes are grounded in the data of participants. Reflexivity was

supported by keeping a research diary throughout the interview and analysis process, noting thoughts, impressions, tendencies and insights into possible preconceptions. For the reader making sense of the interpretations presented, a brief statement is offered outlining the background to the choice of topic and some possible influences of the researcher on the interview process and analysis (Elliot, Fischer, & Rennie, 1999).

Researcher

This study sprang from a longstanding academic interest in brain injury and in particular a curiosity about the sometimes dramatic changes in behaviours that can result from frontal lobe damage. The researcher was aware of a pull to understand behaviours of the person with TBI in relation to neuropsychological and psychological processes both in questioning during interviews and in interpretation. Efforts were made to remain attentive to how the behaviours were experienced and understood *by participants* but influences of this pull may remain. The supervisor's interest in perceptions of (dis) continuity in spousal relationships in such populations also likely influenced the design and thinking about the data.

FINDINGS

The main themes discussed in this paper are displayed in Table 8. Four participants described similar experiences of struggling to cope with negatively perceived changes in their partners since the brain injury. The experience of the fifth participant was more positive. Clare seemed to have adjusted well to changes in her partner and was able to appreciate positive changes that had arisen out of the brain injury.

Table 8

Main Themes Describing Participants' Experiences of Personality Changes in Their Partner

Superordinate Theme	Subtheme
Living with behavioural and emotional changes	The emotional toll
	Managing behaviours
	Making sense of behaviours
Broader personal meanings of changes	He's not the person he was before
	Impact on the couple relationship
	Wishing, hoping & grief

Living with the behavioural and emotional changes

Participants had observed a host of changes in their partners, including short-temperedness, aggression, obsessive behaviours, obstinacy, poor judgment, selfishness, inappropriateness, lack of interest, lack of empathy and caring, changed humour and depression. The changes experienced overlapped significantly for four participants. Clare's experience was different; unlike the other participants she had not experienced any volatility or aggression in her partner. The changes she described were more of a passive nature (lack of initiation, poor judgment, difficulty recognising other people's feelings), though social inappropriateness and tactlessness also featured. Clare experienced these changes with greater acceptance and with less negative feelings.

The emotional toll

This theme attempts to capture participants' emotional experiences of the behavioural and emotional changes they had observed in their partners following the TBI. For most participants these changes were associated with many negative emotions including frustration, hurt, disgust, anger, shame, fear and sadness.

With the exception of Clare, all participants perceived their partners to have suddenly become very short-tempered and aggressive, "he'd gone from being, gone from being a really kind, well-mannered, funny, very caring, very hands on dad to very short-tempered, very angry, very aggressive" (Helen, line 1:340). Lisa's description of her partner as like a bomb primed to go off gives an indication of how uncontrollable and destructive outbursts were experienced to be, "He was blowing every five minutes and he was throwing - trashing my house" (line 1:525).

The unpredictability ("he's like Jekyll and Hyde;" Diane, line 2:441) and frightening quality of their partners' outbursts had made Diane, Lisa and Anita highly sensitive to the possibility of triggering an outburst. The phrase "treading on egg shells" was used by each of these participants who now felt the need to watch what they said and did, all expressing how uneasy they felt in their partner's presence, "I'm constantly stressed out when I'm in the house with him, constantly. It's like my heart's coming out of my chest, beating that fast" (Anita, line 1:604).

For Diane, her partner's violence was also associated with embarrassment and shame, "I didn't want other people to see erm that actually I'm stopping with Greg [*partner*] because – and he does all this to me. Erm and I used to lie – I used to lie for him" (line 1:717). In addition, verbal abuse from their partners was experienced by participants as extremely hurtful, "Your feelings take a beating when that – when somebody's calling you such nasty horrible names all the time" (Anita, line 2:158).

Three participants talked about the appearance or exaggeration of obsessive and controlling behaviours, "I mean he has always been tidy but it's just got to the point of ridiculous" (Lisa, line 2:25). The repetitiveness and constancy of these behaviours could be a wearing experience, "the controlling literally wears me into the ground. The amount of phone calls I get. I've got to do this. I've got to do that. And it's wearing me out to be

honest" (Anita, line 2:369). Some participants were left feeling controlled and like they had lost their sense of agency and freedom. Diane described how even the structure of her day was controlled by her partner:

'Cause I think, well why can't I just not do that on that day and I could do something else erm but I can't. I have to do – I have to work round Greg [*partner*] basically. He's in control of everything I do. So that's what's really, really difficult. (Diane, line 1:826)

Moreover, the constant rechecking of their actions and fault-finding took its toll on participants' self-esteem, making them feel useless and like they could not do anything right, "I feel I have to look at what I am doing all of the time and if I haven't done stuff, I start to feel guilty that I haven't done stuff" (Lisa, line 2:42).

It was not just active behaviours that were hard to accept; participants found their partner's lack of interest, absence of caring, lack of spontaneity and lost humour extremely upsetting. Helen, for example, expressed sadness at the loss of her partner's spontaneity, "It's like that spontaneity, that's all gone. That's just – that's not there anymore. And I really miss that" (line 1:916).

Facing these changes every day was experienced as exhausting and exerted an emotional toll on participants. Whilst adjusting to the changes in the early days was described as particularly difficult, changes continued to exert a lasting and persisting emotional impact that affected how some participants felt about themselves, as Diane's quote illustrates:

I looked after myself erm before Greg [*partner*] had his accident. I used to – I felt good about myself. But now, I think to myself, oohh, I can't be bothered to do that.

Oh, god, you know - I ain't bothered if I look a mess. I ain't bothered. (Diane, line 2:673)

This theme highlights the emotional impact on participants in their struggle to cope with their partners since their TBIs.

Managing behaviours

This theme encapsulates the dilemmas and uncertainties participants faced in managing their partner's behaviour.

Participants varied in the extent to which they continued to struggle with their partner's behaviour in their efforts to change or address the behaviour. Frequent attempts at trying to alter their partner's behaviour without success were often met with frustration and despair, as illustrated by Lisa's struggle to get her partner to go out with them as a family, "I've tried to encourage – just the two of us. You know I've said – You know, my mum has Isabelle [*their daughter*] and erm – It's very, very difficult." (line 2:632). For some participants, their partner's lack of awareness particularly contributed to the sense of "fighting a no-win battle" (Helen, line 2:137). The fight was experienced as exhausting and as futile by some, leading participants to give-up either temporarily or completely, "all the time I'm getting frustrated so it'll get to the point where I'll think sod it, just forget it" (Helen, line 2:523).

Intervening in situations was frequently perceived by participants to make things worse and fear of the consequences sometimes made them feel they couldn't challenge behaviours. Although participants spoke about not fighting the behaviour as being the easier option, there was a sense that this was not at all easy. For Diane and Anita, it made them feel like their life was controlled by their partners, "That's what I can't brush off. The fact that he's took control of my life. And I have to do it all for an easy life, I have to

do it" (Anita, line 2:372). It made them feel like they were letting their partners win, engendering feelings of anger and resentment, "I have to be careful not to push him and sort of erm – sort of let him win really, in a way" (Diane, line 1:763). Moreover, giving up could be experienced as frustrating as struggling with the behaviours, resulting in extra work for participants in their efforts to prevent difficulties, "If we're out I try not to put him in a situation where I think he's going to be quick-tempered, short-tempered. So I tend to do everything" (Helen, line 2:572).

There were also times when participants felt behaviours could not be tolerated and when they needed to make a stand. For Anita, these times particularly centred on her partner's treatment of her children, though as her quote suggests, having to protect her children all the time could be an exhausting battle:

> ...this is what a lot of the violence towards me - things like throwing things at me - is because I stick up for them children and I always will and he will not get away with it. He's not going to do that to my kids. No way. And that is just such an effort. (Anita, line 1:415)

Sometimes making a stand was also about fighting for what was important to participants, "this was for Isabelle [*their daughter*] and for us as family and I really put my foot down" (Lisa, line 2:651). At other times participants felt their only option was to escape the situation or to take time away from their partner. However, the responsibility some participants experienced for the safety of the person created a dilemma that put them in an untenable position, "but then I worry because obviously there's the safety part of him being here, if he leaves the gas on or anything like that, so it's a very hard life, it really is" (Anita, line 2:279).

The emotional tensions faced by participants in their choice of approach (or felt lack of choice) and the uncertainty about the effectiveness of such approaches seemed to

contribute to participants' experiences of struggle, "I try and deal with it in different ways and it still doesn't end up to be the right way" (Lisa, line 2:562). Many participants talked about the lack of support they felt they had, expressing how vulnerable this made them feel, "...you've got to help me just – you know at least just do something with him. I can't cope with him" (Diane, line 2:773).

Conversely, Clare expressed greater confidence that her efforts were listened to and had positive effect. This seemed to contribute to her ability to cope with changes:

"I think at least I'm lucky because he does listen when I explain things and tell him, you know, he's got to watch for these cues [*To what she is feeling*]. He does make a big point of it [laughs]" (Clare, line 2:139).

Clare's description of how she taught her partner to recognise how she was feeling also illustrates how she seemed to accept what her partner was unable to do and responded by enabling him to do what he couldn't or by getting her needs met elsewhere, "just found people in my life who I can talk those things through with if John [*partner*] isn't able to" (line 2:348).

This theme highlights the different approaches participants used in their efforts to manage the changes, with some participants left feeling they didn't win with any approach.

Making sense of behaviours

Participants described an increasing awareness of the changes in their partners over the first few weeks and months of their partner coming home. Behaviours seemed to be all the more shocking and upsetting for their inconsistency with their knowledge of their partners pre-injury, "This is someone who I've married, who I love and all of a sudden he is displaying these moods and tempers that I've never seen before in him" (Lisa, line 1:548).

Many participants expressed having had the expectation that changes would be temporary, putting the behaviours down to the recovery process, though they were now coming to or had come to the realisation that the changes may be permanent, "I think that's the only thing I could put it down to, is swelling on the brain. But then you start to kind of think after six months has gone, why isn't he back to Tony [*partner*]" (Anita, line 1:857). Participants did not feel prepared for the changes and even when they were told that such changes were possible, the reality was far beyond what they ever anticipated, "I suppose I was told but erm I didn't think – I didn't think it was going to be like this" (Lisa, line 2:421). Most participants expressed their struggle in making sense of the changes they were observing and for Anita and Helen this was made harder by their responsibility for their children and the uncertainty in what to tell them:

> And then for the children to say to me, "Why does daddy shout at me? Why doesn't daddy do this anymore? Why doesn't daddy…" I didn't know what to do. I didn't know myself. I didn't know how to tell the children. (Helen, line 1:713)

Difficulty making sense of their partner's behaviours sometimes seemed to create doubt in participants' minds as to whether their partner could control their behaviour. For example, Helen could not understand why her partner could spend hours on the computer, yet if she asked him to do an activity with her "his heart wouldn't be in it" (line 2:519), "And it's really strange 'cause I think why – why if can you do that there, can't you apply the same erm power with us. It's just not there. Again it's frustrating" (line 2:537).

For some participants neuropsychological understandings offered by professionals to explain their partner's behaviour did not always fit their felt experience of the behaviour. Lisa appeared to find it hard to accept various explanations of her partner's reluctance to go out as a family, which seemed to be associated with a sense that she was not important to him:

I can remember being told that people find supermarkets really difficult because of the noise and the vast sound thing, I think, and the crowds and stuff. But even going for a walk or going to a country park - he won't do that with us. (Lisa, line 1:228)

For Diane, the ambiguity of her partner's aggressive behaviour seemed to contribute to a lack of conviction in neuropsychological explanations of his behaviour, "And I'm confused. I'll say [*to doctor*], "Well how come erm sometimes he does it one time but then he doesn't do it another? How can that work?" (line 1:950) and to perceptions of malicious intent, "because I think, well obviously he likes doing it" (line 2:560).

Conversely, Clare appeared more confident in the belief that her partner's behaviour was not about his will or intent, though she hadn't always been this confident. She spoke about how hard she found her partner's apparent lack of sensitivity to her feelings until she understood it as an inability as opposed to a lack of care:

It was really hard at first when he didn't – he wouldn't realise I was upset and I would have to tell him. [.…] Erm but once the realisation came that he cared. He just wasn't able to recognise it anymore, it made things a lot easier. (Clare, line 2:86)

Seeing behaviours as being outside the person's control and without negative intent seemed associated with less intense emotional responses, though Helen's need to tell herself this when she got frustrated by her partner's lack of awareness suggests that this could be a more effortful, less immediate, appraisal, "I have to tell myself that his brain is still – as far as he's concerned – he's still the same person, just a little bit more angrier" (line 2:433).

Empathetic understandings of behaviours were also expressed by participants, recognising the difficult adjustment that their partner had had to make and their lack of choice in any of it. However, empathy was hard for participants to sustain in the face of what they were dealing with. Moreover, the perception that their partner could not help their behaviour also made some participants feel hopeless about the possibility of change:

> ...they're [*professionals*] saying he's got to do it himself. That doesn't sound too hopeful. 'Cause he just can't help it. You know, he's not doing it to be horrible, he literally can't help it. I see him with his hands over his head and he just can't help it. (Anita, line 2:433)

Clare's experience again diverged from that of other participants. Whilst seeing changes as being due to an inability, they were still experienced as things that could be worked on and improved. She saw her partner as doing his best and recognised progress as a result of his efforts, "but he's getting better at that now with me identifying and telling him how he's changed and how he needs to erm - how he needs to improve" (line 2:27).

Broader personal meanings of changes

The previous themes illuminated the daily struggle that most participants faced in their efforts to cope with the behavioural and emotional changes in their partner. For these participants, behaviours were not just difficult to manage; they shook the core of their perceptions of the person and the relationship. This is expanded upon in the next three themes.

He's not the person he was

All participants except Clare considered their partners to be different people since their injury. For Helen, this perception was largely characterised by a devastating loss of who her partner was, though new negative characteristics also featured. Both the magnification of existing traits to a level that she found unbearable and the loss of valued characteristics seemed to define Lisa's feeling that her partner's personality had changed. Similarly, Anita and Diane's perceptions of change appeared to rest both on new negative characteristics that they were struggling to cope with and the loss of valued ones. Unlike the other participants, Clare acknowledged changes in her partner, whilst considering him to be fundamentally unchanged ("as himself he's still himself", line 2:38).

Broadly, both the presence of negatively appraised behaviours participants saw as being new or at least radically different in degree or quality and the perceived absence or diminution of valued characteristics idiosyncratic to the person and the relationship seemed to contribute to the sense that their partner was no longer the same person.

Helen's struggle to describe her partner and the way in which she describes him in terms of what he was no longer suggests a sharply felt absence of the person:

It's like the life's been sucked out of him. Erm I would say he was – Err … It's really hard. [.…] "He's very, I wouldn't say shallow, it's like he's very empty now. He's not that happy, bubbly, one liner, jokey person that he was before. (Helen, line 1:817)

Anita and Diane similarly struggled to see anything remaining from the old person, making Diane question why she stayed, "you just think to yourself why – why am I still here?" (line 2:601). Conversely, Lisa's recognition of things that had not changed suggests her experience of a changed person was less absolute, "his love of outdoors is still there" (line 1:630).

Changes that participants found particularly upsetting seemed to relate to alterations to characteristics important to the person's premorbid identity within the relationship. Anita missed her partner's happiness and humour, describing it as central to their relationship before his injury:

…that's how we got on, because we always took the mick out of each other, we'd got that banter. Erm we'd got the sarcasm there and we used to always take the mick out of each other and end up laughing about it. Can't do none of that now. (Anita, line 1:631)

Conversely, whilst Lisa considered her partner's humour to be "completely changed" (line 1:237), seeing it as immature, it was not a change that threatened their relationship. Unlike Anita, Lisa recognised that she was still able to share in enjoyment with her partner despite the change, "We still laugh together, which is important. It's not all bad times" (line 2:271).

Similarly, for Diane who "married Greg [*partner*] because obviously of how loving he was" (line 2:570), the loss of his thoughtfulness and care for her was experienced as particularly upsetting, "he never shows me any feelings. Erm – [Crying]. I'm sorry. [Long Pause] I think it's because of the way he's changed" (line 1:654).

Interestingly, it was not just changes more typically described as personality changes that seemed to affect Helen's perception of her partner's identity; her partner's cognitive difficulties also seemed to contribute to her perception of him no longer being the same person, "He was very manly before his accident. He was very wise, very intelligent, very clever" (line 2:66).

Participants found it hard to see the old person past the negative behaviours, "So bit by bit I suppose yeah there are bits of Tony [*partner*] still there. It's trying to see them through all the horrible bits, isn't it" (Anita, line 1:798), with such sightings experienced as

being all too fleeting, as Diane's comment on how she felt after seeing a sign of the old person illustrates, "it was nice but I sort of think it's nice for a few minutes and then I sort of drift back to what he is" (Diane, line 2:157). However, as Lisa's account below suggests, a sense of connection to the old person could offer some balance to coping with the changes:

> I do see glimpses of him and - and I suppose that's what's held us together as well - you know those glimpses of Mike [*partner*], you know, doing the gardening or washing the car or erm, you know, those kinds of bits I still see and still make me chuckle. (Lisa, line 1:638)

Clare's account diverged significantly from the other participants, expressing a strong sense of continuity in her partner's identity. Her description of her partner focused on who he still was even if traits were not always expressed in the same way:

> He's very erm childlike in the way that he does enjoy a good time, likes to play games with them [*nieces*], likes to watch DVDs and music and have dance parties. So he's very fun loving still. Erm just doesn't go out clubbing [laughs] (Clare, line 1:428)

Clare appeared to integrate behaviours into her partner's pre-morbid personality, for example, seeing his passivity in arguments as part of him being easy-going ("he just isn't a fighter", line 2:322). She also discounted behaviours as being due to the brain injury as opposed to just being him:

> "He is – he now – It's terrible – He makes fun of people with disabilities that he sees on the street. [.…] Erm but that – I don't think that's an effect of his brain injury, I think that's just him being himself" (Clare, line 2:566).

In marked contrast to other participants, the changes Clare did perceive in her partner's personality had been positive ones. This appeared to help her cope with the difficulties associated with his brain injury, "It's weird, but to us the brain injury, although we'd never have wanted it, it has brought a lot of good with it and we just keep focusing on that" (line 1:999). To her mind, the brain injury had caused her partner to settle down, with her description seeming to suggest that this had made Clare feel more secure in the relationship, "now where he is much more erm – yeah just involved with his family. I mean he cares – sounds wrong to say he didn't care about me – but now he's just more focused on building a life together" (line 2:756).

Relating back to the themes of managing and making sense of behaviours, Clare's strong sense of knowing her partner ("I know everything about him", line 1:791) also seemed associated with the confidence she had in managing and understanding difficulties:

> He does get frustrated when he can't do things. Erm so we've noticed that. Where he will – If he can't find the word that he wants [*word-finding difficulties*] – erm I mean there's less of a chance of that happening now just because I know him so well. (Clare, line 2:415)

Impact on the couple relationship

All participants described changes to the couple relationship since the TBI. This theme describes participants' experiences of changed feelings, and the losses of togetherness and instrumental and emotional reciprocity.

Anita, Diane and Helen spoke about how their feelings for their partner had changed, each expressing ambivalence about their relationship. For Anita and Diane, their

partner's difficult behaviours were hard for their love to withstand, changing the nature of their feelings to that more akin to caregiver than wife:

> I lost my husband the day he had the accident because Tony [*partner*] is not my husband, he's just somebody I have to care for now. Although I still love him, I love him as my husband, I don't love the person he is now, I don't even like him. He's so horrible to us. (Anita, line 1:351)

Certain changes also made some participants feel more like a mother than a partner, and this could be threatening to their sense of being in partnership, "now I'm worried when he goes to the shop. So again it does – it does have a big impact. You sort of – Sometimes I feel like I'm his mother, more than his partner" (Helen, line 2:227).

Helen especially was struggling to adjust to the change from "feeling safe and secure" (line 1:920) with her partner to now having to worry about her partner and to carrying the weight of all household responsibilities, "I – I look after him. And I look after everything else" (line 2:69).

Behaviours could be hard for participants to forgive; Lisa, Diane and Anita all expressed how this affected their desire to be intimate and loving with their partners. The repetition of "I can't" in Lisa's quotation that follows seems to reflect an internal struggle she was having with herself; wanting to be close to her partner whilst finding this incredibly difficult, "I know I've put this bridge – not bridge, I suppose this distance between us. To not let him get so close. And I know it frustrates him. … But I just can't, I can't, I just can't" (line 2:467).

Participants expressed feeling torn between their empathy for and their loyalty to their partners, heightened by the understanding of changes as not being the person's fault, and the negative feelings they had towards the behaviours and their partners. This had

added resonance for those participants with children who also had them to think about, "He had an accident and he's woke up like this and he's suffering. He's suffering big time. [….] but … I haven't just got him to think about, I've got my children" (Anita, line 1:574).

Most participants had experienced a shift in the responsibilities within the relationship, with the loss of practical support from their partners. Diane who had poor health herself and whose partner had always taken care of her and the household responsibilities continued to find this adjustment difficult, "I didn't have to worry about anything whatsoever because I knew Greg [*partner*] would deal with that, [….] It's just horrible because I can't trust him to do anything. [….] I have to take on everything" (line 2:306).

Equally, for Anita, who had reluctantly given up her job to be a stay-at-home mother when her son was born, her partner's encroachment into what she now saw as her domain seemed to threaten her identity within the relationship, "he's took over my role as the mum and as a housewife because he'll interfere in everything I do. [….] You know, but I feel like I've got no role here" (line 1:661). Conversely, Clare was able to see her increased responsibility as something that suited her personality and that allowed her to express aspects of her identity that were restricted in other ways:

> I make all the little decisions, the day-to-day runnings where I didn't before. But I am quite bossy so it's nice. If I can't be a [*xxx*] at work all the time at least I can boss him [*her partner*] around (Clare, line 1:763).

Most participants experienced their relationship with their partner to be less than what it was in other ways. Reductions in shared enjoyment and in time spent together appeared to contribute to a loss of togetherness, "We would do everything as a couple and now it is separate" (Lisa, line 1:357). Some participants expressed feeling like their

partner did not appreciate them and what they were having to cope with and having do for the family, "you know I still obviously don't do enough sometimes. That's what is draining really" (Lisa, line 2:551). Participants also described a loss of the emotional support they had once received from their partners, "he doesn't understand that perhaps I get a bit down sometimes and I haven't got no one to talk to" (Diane, line 2:46). Further, many participants spoke about how their partner no longer showed them affection or behaved in ways that demonstrated that they cared, "If he was to go out now he'd come back in, he wouldn't even acknowledge me [Sigh]" (Helen, line 1:850).

Clare's account again diverged significantly to that of the other participants, expressing strong feelings of being supported and appreciated by her partner, "I mean he's always willing to do anything I ask him to" (line 2:386). Although Clare felt unable to get the level of support she wanted from her partner in talking through problems, the perception that he was doing his best and understanding it as a lack of capability, seemed to contribute to her being able to maintain a feeling of being supported, "while he's very supportive, he's not very good at helping me figure– He does his best to figure things out" (line 1:702). Moreover, while she missed aspects of their life before such as the spontaneity and absence of responsibility, she also appreciated how their relationship was now, her description again laying claim to a deep sense of knowing him:

> …we know exactly how to make each other laugh, what looks, what things. Erm how to drive each other slightly nuts erm and then apologise for it like those - It's just really – It is just so nice and easy right now (Clare, line 1:630)

Wishing, hoping and grief

Scattered across participants' accounts were messages of hope, loss of hope and uncertainty as well as a longing for the return of the old person and grief. Helen clearly

articulated a profound sadness for the loss of the person, likening her experience to that of grief:

> …it's really strange because I can look at photos of him before his accident and I'll cry. It's like – It's like he's died. It's like I'm grieving. You know I'll look at a photo and I'll say, "I really miss you." (Helen, line 2:293)

While not all participants expressed this as patently as Helen, evidence of the grieving process was present in the accounts of all participants who had experienced loss of the person. Like Helen, Lisa's questioning of whether the old person would return suggests a strong wish for the old person back:

> I suppose I have that thought … And will it get better? Will these moods subside? Will these rages subside? Will his sense - proper sense of humour come back? Will these kind of little - There not OCDs - but obsessions, - go away? Will he be part of our family again? (Lisa, line 1:619)

Anita, Helen and Lisa all expressed uncertainty in whether their partner would recover, not knowing but desperately holding out hope, "if he was to revert back to Tony [*partner*] tomorrow, he'd be my husband who I loved, but will he get to that point? Will he get there? I don't know. I'm just waiting" (Anita, line 2:182).

Some participants appeared to look to evidence of continuing improvement to support their hope that they might get more of their partner back, "I mean it's been over two years now. But – He's improving. He's improved massively compared to what he was in the early days" (Helen, line 1:323). Even for Clare, who did not see her partner as fundamentally changed, seeing improvement and recognising progress seemed important in coping with changes, "I'm happy when he shows more and more commitment to and

more ability to talk it through. Erm I mean as I miss that part of him, it is really nice as it is starting to come back" (line 2:341).

Glimpses of the old person could give hope and provide a connection to the old person. Whilst such hope could be quickly dashed, Anita's description of how she felt when she saw her partner laugh illustrates how this hope was still held onto by some participants:

> I thought, Oh my God. It was lovely. I thought you know is he going to get back to the way he is and you see a little bit of a hopeful sign and then the next day you might have a really bad day with him again. It's a rollercoaster, it's so up and down, it's unreal. You know you don't want to get too excited but hopefully if – (Anita, line 2:92)

The difficulty in sustaining hope and the "rollercoaster" of hope and disappointment articulated by Anita also seemed to be reflected in Lisa's and Helen's accounts in the way in which they oscillated between statements of hope and lost hope. Loss of hope was often expressed by participants when progress could not been seen or when the promise of progress was not fulfilled, "I always feel that we're making progress and then it gets shot down" (Lisa, line 2:440).

At the most extreme, Diane struggled to see any improvement in her partner and had lost all hope that her partner would show any recovery, "I think his dad still now to this day thinks he's [*her partner*] going to get better and he doesn't understand that he's not going to get better." (line 1:874). The apparent idealisation of her partner and life before, present to a lesser extent in Helen's and Anita's accounts, may reflect Diane's grief and difficulty adjusting to the loss of the person, "It was like erm – Prince Charming [Laughs] – sort of thing – like you know a story sort of thing and - It couldn't have got any better" (line 1:638).

DISCUSSION

All participants described behavioural and emotional features in their partner which have commonly been cited as personality changes after TBI (e.g. Prigatano, 1992). For most participants perceived changes in their partner had resulted in emotional turmoil in their fight to manage the impact they were having on their life and the lives of their children. For these participants, the changes had led them to feel that their partner was a different person since their injury and had altered their perceptions of and feelings towards their relationship with their partner. This struggle to cope was not evident in one participant's account; this warrants some space to draw together the differences in her experience before the findings are discussed in detail.

Unlike the other participants, Clare did not express strong negative emotions in connection with changes, experiencing these with acceptance and equanimity. She had greater confidence in her understanding of behaviours and in her ability to exert influence on behaviours to positive effect. Clare's partner had had the greatest level of initial difficulties and the most physical and communication disabilities currently (Table 7), but she had always seen her partner as essentially the same person, even noticing signs of his personality in the early days when he had minimal functional capabilities. She seemed to focus on those aspects of his person that had not changed, to assimilate behaviours into his pre-morbid personality and to look beyond the appearance of behaviours, making clear distinctions between changes in ability and core changes to personal motivations and attitudes. Clare recognised positive changes in her partner, seeing him now as more hardworking and committed to the relationship. In contrast to other participants, Clare was confident in her partner's love for her. This was helped by her understanding of behaviours as being due to a lack of capability as opposed to a lack of care. Whilst

acknowledging that her relationship with her partner was not an equal one, to Clare the emotional support and love she experienced balanced what she missed out on. Although it is important to be cautious in drawing too much from one case, many of the divergences in Clare's account may illuminate features that may be important in understanding the other participants' less positive experiences in conjunction with existing research.

Consistent with previous literature, problems with emotional and behavioural control (short-temperedness, aggression, and volatility), present in all but Clare's partner, were observed to be being particularly challenging to cope with (Braine, 2011, Gillen, Tennen, Affleck, & Steinpreis, 1998; Marsh et al., 1998; Wood et al., 2005). Obsessive and controlling behaviours also exerted a massive impact on the lives of three participants in this study, making them feel like they had no control over their lives. The findings suggested that these intrusive behaviours were particularly hard for participants to reconcile with the person they once knew and, together with the negative feelings they evoked, made it hard for them to see familiar aspects of the person. Such behaviours threatened participants' positive feelings towards their partner, with some participants shunning intimacy with their partners who they now perceived to be very different (Gill et al., 2011; Rosenbaum & Najenson, 1976). Difficulty forgiving their partners for their actions seemed to create a barrier to closeness. A difficulty in suppressing natural responses to challenging behaviour (e.g. anger, personalised and negative attributions) in favour of more empathetic understandings and uncertainty regarding their partner's control over their behaviour may have contributed to the struggle to forgive behaviours. In general, the current study was in line with research suggesting that believing the person has control over negative behaviours, and a lack of confidence in their own influence over behaviours, can heighten the emotional impact of challenging behaviours on carers (Harvath, 1994; Riley, 2007).

Clare expressed greater confidence that negative changes in her partner were about a lack of capability. She accepted what he couldn't do and responded by enabling him to do what he couldn't or by getting her needs met elsewhere. Evidence on the management strategies used by families in response to challenging behaviours after TBI is scarce. Nevertheless, it is interesting to observe that de Vugt and colleagues (2004) found that caregivers of individuals with dementia who tended to respond to problem behaviours with acceptance using nurturing or supporting strategies (like Clare) tended to have a greater sense of competence than those who responded with anger and impatience and who tended to confront or ignore behaviours. However, responses and strategies used may depend on what problem behaviours are present. In particular, the unpredictability and ambiguity of behaviours such as those displayed by the other participants' partners may undermine efforts to understand and manage changes (Connolly & O'Dowd, 2001; Wood et al., 2005). Such unpredictability may also make it hard to maintain a coherent sense of the person. Further research is needed to explore relationships between spouses' appraisals, emotional responses and use of different management strategies in response to challenging behaviours following TBI.

Perceptions of the person as different also seemed to reflect the perceived absence or loss of characteristics important to participants' perception of the premorbid person and relationship (Wood et al., 2005). Losses of interest, expressed affection, and empathy seemed to weaken participants' connection to the old person and to shake their confidence in their partner's love for them, particularly with the backdrop of anger and abuse experienced by some. These changes have been reported elsewhere as being disruptive to the couple relationship (Gosling & Oddy, 1999; Peters et al. 1992, Wells et al., 2005), and may undermine feelings of companionship and togetherness. Conversely, Clare, who was coping better, felt appreciated, loved and supported by her partner despite his limitations.

Gill et al. (2011) similarly found that feeling loved and appreciated by the injured person was important in helping spouses of persons with TBI cope. Other studies in different medical populations have also found a sense of emotional reciprocity in the relationship to be associated with less negative feelings about the relationship and better mood in caregiving wives (Kleiboer, Kuijer, Hox, Schreurs, & Bensing, 2006; Wright & Aquilino, 1998; Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

Clare did not see her partner as fundamentally changed as a person, tending to make distinctions between his ability and his will in her understanding of his behaviour and recognising his personality even if traits were not expressed in the same way. This shows how behavioural and emotional changes (so called "personality changes") do not always lead to family perceptions of *identity* change. Moreover, findings suggested that perception of the person as different may not only relate to behavioural and emotional changes ("personality changes") in the person. Cognitive difficulties and an inability to fulfil roles also seemed to contribute to at least one spouse's perception of change to the person (Yeates et al, 2008). Similarly, Weddell and Leggett (2006) found that the presence of memory problems was associated with family members' perceptions of personality (identity) change.

For participants perceiving their partner to be different, loss and grief were expressed for the person and the relationship that was, with participants describing many of the emotional reactions elucidated in Lezak's (1986) grief model of adjustment after TBI including shock, bewilderment, anger, depression and despair. The rollercoaster of hope and lost hope within participants' accounts may reflect the ambiguous nature of this loss (Boss & Couden, 2002; Godwin et al., 2014), and the uncertainty about recovery. In a study exploring the dialectical tensions of spouses of individuals with stroke, spouses were similarly observed to swing between realistic and idealistic expectations of recovery and

between uncertainty and acceptance (Brann, Himes, Dillow, & Weber, 2010). In such cases where the person may be physically present but psychologically absent, the loss may be ongoing, making it harder to adjust and accept (Boss & Couden, 2002). Nevertheless, hope may be important in helping spouses cope (Duggleby, Holtslander, Kylma, Hammond, & Williams, 2010).

Summary

The findings of the current study strongly resonate with existing research about the experience of spouses after TBI (e.g. Hammond et al., 2011; Gill et al., 2011; Gosling & Oddy, 1999; Wedcliffe & Ross, 2001). However, it also expands on knowledge about spouses' experiences of living with personality changes and the meanings these changes have for their perceptions and feelings towards the person and relationship. At least for these participants, perceiving the person with TBI to be different was influenced by the presence of behaviours that were appraised as new, negative and difficult to manage and the perceived loss of characteristics that were valued in the premorbid person and relationship. It may also relate to how individuals make sense of behaviours (Brooks et al., 1986), the degree to which they focus on what is different as opposed to what is familiar (Oddy, 1995) and the spouses' (perceived) ability to cope with the changes (Wells et al., 2005). Feeling that the person is different may be associated with ambivalence about the couple relationship and feelings of loss and grief (Riley et al., 2013).

Limitations

IPA studies do not seek to claim that the interpretation offered is the only one possible or aim to develop explanatory level accounts of a phenomenon (Willig, 2008). As such, and given the small number of participants studied, it is not possible to generalise

findings to all family members or even all spouses' experiences of personality change after TBI. In particular, participants were all younger female partners of men with moderate or severe TBI still with their partners, and it is possible that their experiences may less representative of male (Hammond et al., 2011) and older spouses (Layman, Dijkers, & Ashman, 2005), of spouses of partners with mild TBI and of spouses that leave. However, the commonalities their experiences share with existing literature suggest the wider relevance of the findings to clinical practice and research.

The study was concerned with participants' subjective perceptions of change which required participants to reflect on the past; such perceptions may have been coloured by reconstructions of the pre-injury person and relationship. Nevertheless such constructions may still say something about what participants were experiencing as difficult about their partner in the present. It is difficult to establish and equate the degree of neurobehavioural changes in the person with TBI and it is possible that one reason why Clare was coping better and was able to maintain her sense of her partner's identity was that the changes were more subtle. The inclusion criteria and announcement of the study as being about personality change may have favoured the selection of participants who had experienced greater change and may have caused participants to focus more on change than what was familiar. However, even on direct questioning many participants still struggled to identify aspects of their partner's character that had not changed.

The participants' own personality (McKinlay & Brooks, 1984) and coping resources (Harris, Godfrey, Partridge, & Knight, 2001; Katz, Kravetz, & Grynbaum, 2005; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000) may also influence how they respond to behavioural and emotional changes in their partner. There were indications of this, with Clare seeming to have a tendency to focus on the positives of their situation, describing herself as being "naturally very optimistic" and appearing to have access to the greatest

level of professional and informal social support. Moreover, the degree to which

participants were coping at the time of the interviews may have influenced the emotions

and thoughts expressed and may not have captured attributions made at the time of

behaviours that may be important in understanding their response to personality changes.

Participants varied from less than a year to seven years post-injury and although there was

a large degree of convergence in most participants' accounts, it is possible that perceptions

of the person and responses to changes may continue to shift over time. Longitudinal

studies are needed to explore how the perception of the person as same or different evolves

over time.

Future research and clinical implications

Clare perceived continuity in her partner's identity and appeared to be coping

better. In the dementia literature it has been suggested that maintaining a sense of

connection to the old person can help the family cope with the impact of negative changes

(Riley et al., 2013). There is a need for further research to explore relationships between

the perception of the injured person as the same/different, and how spouses cope with

changes after TBI. If continuity enables more effective coping, a clinical implication is the

need to support partners in integrating changes into their pre-existing knowledge of the

injured person in a way that allows them to maintain a sense of the person as the same

despite changes. Additional research with other spouses/partners perceiving the injured

person to be unchanged is also necessary to determine what helps individuals maintain a

connection to the pre-morbid person and relationship when emotional and behavioural

changes are present. There is also a need to further explore cases where positive changes

to the person are perceived and to understand positive responses of family caregivers to

trauma experiences (Braine, 2011; Shim, Barroso, & Davis, 2012).

Both the current paper and previous research have highlighted the strain TBI can place on the family relationships (Wood & Yurdakul, 1997) shown to be important in determining outcomes of persons with TBI (Stejskal, 2012). Without the support and care of spouses and other family members, the injured person may have increased need for health and social care utilisation, with clear cost implications. Furthermore, caring for someone with behavioural and emotional difficulties may result in deterioration in the carer's own mental (and physical) health (e.g. Kreuter et al., 1994), resulting in potential increases in healthcare utilisation in other areas. Crucially, the need to support families and to ensure that they have access to support that meets their needs is recognised in the national service framework for long-term conditions (Department of Health, 2005). This is likely to be best provided by specialist services knowledgeable in brain injury.

In particular, the findings of the current study, in particular, strongly reiterate the need spouses have for help in making sense of and managing behaviours (e.g. Smith & Smith, 2000). This might include helping spouses to develop realistic expectations about what can and can't be changed to prevent the frustration and disappointment that comes with frequent unsuccessful efforts (Harvath, 1994). Support may be required in adjusting to the need to adapt their own behaviour and thinking in relation to things that can't be changed, recognising that this may be hard for spouses to accept. For some of the spouses in this study, someone to just listen would have been helpful, as Lisa's recounting of her experience of ringing someone illustrates: "I was told well this is just how he is going to be. Well, you know, I know that really, but I just want someone to talk to me" (line 1:517). Emotional support for spouses (and their children) may need to recognise the grief and loss associated with perceived changes and the difficulty of living with the uncertainty of recovery (Smith & Smith, 2000). In working with families with TBI it may be important to understand the specific meanings the changes have for the family member and

the relationship and it may be valuable to support them in noticing what may not have changed in the person, helping them to find a sense of connection and way of relating to the person (Oddy & Herbert, 2003).

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Chapter III

Executive Summary

When a person experiences a traumatic brain injury (TBI) it is not just their life that may be disrupted, the lives of those around them, especially spouses and other family members, may also be markedly changed. This paper summarises two pieces of work conducted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology at the University of Birmingham. The first is a review of published research looking at family functioning in families where one adult member has experienced a TBI. The second presents the findings of an original piece of research exploring partners' experiences of personality changes in their injured spouse following TBI.

FAMILY FUNCTIONING AFTER TRAUMATIC BRAIN INJURY: A SYSTEMATIC REVIEW

Background and aims. High rates of anxiety and depression have been reported in family members of individuals with TBI who may now have to deal with a person with physical, cognitive (e.g. poor memory), behavioural (e.g. aggression) and emotional difficulties (Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013). It is perhaps unsurprising that such changes in the person can also have adverse effects on marital and family relationships (Blais & Boisvert, 2005; Florian, Katz, & Lahav, 1989). An increasing number of studies have examined how TBI affects the working of the family as a unit, looking at the family's ability to communicate, problem solve, allocate and perform roles, maintain rules for behaviour and show interest in each other's concerns (Ponsford, Olver,

Ponsford, & Nelms, 2003). A systematic review of this literature aimed to summarise findings on the state of family functioning after TBI and to examine factors associated with poorer family functioning.

Methodology. A search of the literature identified 31 papers using standardised questionnaires to assess the functioning of the family as a system after TBI.

Findings. Although estimates of the prevalence of poor family functioning in TBI families varied, evidence generally suggested higher rates of family dysfunction than in the general population, with communication being a specific area of difficulty. Family functioning showed little relationship to injury severity and physical disability. Conversely, disturbances in behavioural and emotional functioning in the injured person (i.e. neurobehavioural changes such as short-temperedness, lack of motivation and interest etc.) were consistently associated with poorer family functioning. There was little evidence to suggest that family adjustment improved over time. Rather, some findings indicated that family adjustment after TBI may be related to the quality of family functioning prior to injury. Finally, the way in which families think about their situation (e.g. the degree to which they focus on more positive interpretations), their confidence in their ability to manage problems, and their level of social support may be important in how well families adjust after TBI. Methodological issues included difficulty in inferring cause and effect of relationships between family functioning and other factors, possible biases in the recruitment of families and the use of a single family member to comment on the functioning of the whole family. The lack of inclusion of non-TBI families and the absence of pre-injury measures in most studies also make it hard to confidently attribute poorer functioning to the TBI.

Conclusions. Given the findings and the importance of families to the care and rehabilitation of individuals with TBI (Oddy & Herbert, 2003; Stejskal, 2012), there is a need to support families after TBI. The research reviewed particularly highlighted the need to assist families in communicating and in understanding and managing neurobehavioural problems.

PERSONALITY CHANGES FOLLOWING TRAUMATIC BRAIN INJURY: THE LIVED EXPERIENCE OF PARTNERS

Background and aims. As the above review underscored, behavioural and emotional changes in the injured person have been observed to be particularly challenging to family members after TBI (Brook & McKinlay, 1983). Such changes (e.g. aggression, short-temperedness, insensitivity, lack of interest) are also often referred to as personality changes (Prigatano, 1992) and can be so great that the person may feel like a stranger to their loved ones (Oddy, 1995). Despite the well-documented impact of personality changes on the distress and burden of family members (Wells, Dywan, & Dumas, 2005) and the strain these may place on marital relationships (Wood, Liossi, & Wood, 2005), there has been little detailed examination of how these changes are experienced by spouses. This study aimed to explore spouses' experiences of personality changes in their injured partner and the impact of these on their perception of the person and the couple relationship.

Methodology. Five female partners of men who had experienced a moderate/severe traumatic brain injury nine months to seven years previously were interviewed twice about

their experience of personality changes in their partner. Interviews were transcribed and

analysed using Interpretative Phenomenological Analysis (IPA), an approach to

identifying themes in qualitative data that aims to understand the personal meanings a

phenomenon has for the individual (Smith, Flowers, & Larkin, 2009).

Findings. Six interrelated themes were identified. The first three described participants'

experiences of living with emotional and behavioural changes in their partners (*the

emotional toll*, *managing behaviours*, *making sense of behaviours*). The remaining themes

depicted the broader meanings these changes had for participants (*he's not the person he

was*, *impact on the couple relationship*, and *wishing, hoping & grief*). For most

participants, their life had been turned upside down by changes in their partner. Emotional

turmoil had resulted from their struggle to cope with their partners' short-temperedness,

aggression, unpredictability, controlling and obsessive behaviours, and lack of interest and

care. Many participants were left feeling that they could not win whatever they tried in

their efforts to manage behaviours. Participants struggled to make sense of the changes in

their partners and certain behaviours could result in hurt and anger, made worse by

uncertainty about the control their partners had over their behaviour. For four participants,

the changes had led them to feel that their partner was a different person. Both the

presence of behaviours seen as new and negative and the perceived absence of valued

characteristics that defined the pre-injury person and relationship seemed to contribute to

the perception of the person as different. Changes in their partners had also altered their

feelings about their relationship and loss and grief were expressed for the person and

relationship that was. Conversely, one participant described positive changes in her

partner whilst considering him to be essentially the same person. She experienced changes

in her partner's behaviour with acceptance, appearing to have greater confidence in her

ability to understand and influence behaviours. In contrast to the other participants, she was confident in her partner's love for her and whilst acknowledging she did not have an equal relationship with her partner, the emotional support and love she experienced offset what she had lost.

Conclusions. Uncertainties in understanding personality changes after TBI and how to manage them may add to the distress experienced by spouses as a result of such changes and may contribute to negative feelings towards the injured person. Perception of the person as different may be associated with ambivalence about the relationship and feelings of loss and grief.

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Appendix i　　　　　**Aims & Scope of Journal and Instructions for Authors:**
Neuropsychological Rehabilitation

Appendix ii   **Aims & Scope of Journal and Instructions for Authors:**
Brain Injury

Appendix iii

Items in purpose designed checklist used to guide critical appraisal of the literature and identification of methodological issues (based on Critical Appraisal Skills Programme (CASP) checklists, Downs & Black, 1998; Durant, 1994; Sale & Brazil, 2004, Vickers, 1995, von Elm et al., 2007; Young & Solomon, 2009)

1. Objectives and any pre-specified hypotheses clearly stated
2. Rationale and/or theoretical framework of study clearly described and supported by review of existing literature
3. Research design appropriate to address aims
4. Description of the setting in which data was collected
5. Description of eligibility criteria or sampling procedure
6. Adequate description of patients
7. Adequate description of informants
8. Adequate sample size*
9. Clear description of outcome and predictor variables and how these were measured
10. Description of measures used
11. Considers quality of measures used (i.e. psychometric properties)
12. Estimates of random variability provided in data for main outcomes
13. Includes comparison group/data on measure of family functioning
14. Adequate description of how data treated in analysis and methods of analysis
15. Simple outcome data reported for all major findings
16. If appropriate, controlled for multiple comparisons
17. Provided a clear summary of key findings
18. Considered limitations of the study, taking into account sources of potential bias or imprecision.
19. Conclusions and interpretation of results considered limitations, multiplicity of analyses, and results from existing research and was justified by the data
20. Considered the generalisability of the study results
21. Discusses clinical implications of findings

Appendix iv   Letter of Ethical Approval

UNIVERSITY OF BIRMINGHAM

Participant Information Sheet
Traumatic Brain Injury & Personality Change

Researchers: Dr Sarah Bodley Scott & Dr Gerry Riley

We would like to invite you to take part in a research study looking at how spouses or partners' experience changes in individuals who have had a traumatic brain injury. Before you decide whether you would like to take part you should understand what it would involve for you. Please take the time to read the following information carefully. You may wish to talk to your family and friends about the study before you decide.

Part 1 tells you about the purpose of the study and what it would involve for you if you decide to take part.

Part 2 gives you more detailed information about how the study will be run and answers some questions you may have.

Please take time to decide whether or not you wish to take part. We are happy to answer any questions you have or to give more information if something is not clear.

You will be given a copy of the information sheet and a signed consent form to keep if you decide to take part.

PART 1

What is the study looking at?
The consequences of traumatic brain injury can be wide and varied and can be difficult to adjust to for the individual with the injury and their family. Other than the effects of brain injury on physical functioning and abilities such as memory and language, some relatives are left with a sense that the individual has changed as a person. We are interested in finding out what this experience is like for partners or spouses of people with brain injury.

What are the aims of the study?
By doing this study we hope to gain knowledge of what personality changes partners or spouses find most challenging to deal with. This information may help

clinicians to know how best to support family members following traumatic brain injury. This study is also an educational project and will contribute to a postdoctoral thesis.

What will be involved for you?
You will be asked to meet individually with Sarah Bodley Scott on two occasions to take part in two interviews (each lasting 60-90 minutes). These interviews will involve an informal discussion about your experience of living with someone who has had a traumatic brain injury. You will be asked questions about the personality changes you have noticed in your partner or spouse and about the impact of these personality changes on you and your relationship.

The interviews will be audio-recorded and then later transcribed. Direct quotations may be published in academic reports and presentations. However, you will not be named in any publication (a pseudonym will be used) and care will be taken to ensure that any quotes would not personally identify you (see Part 2).

Where and when will the interviews take place?
Interviews will take place at a local clinic or at your home (depending on your preference). Interviews will be arranged at times convenient for you. Where possible, the second interview will be arranged to be held within 10 days of the first.

Who is running the study?
The study is sponsored by the University of Birmingham, with the support of Birmingham Community Healthcare NHS Trust, and will be co-ordinated by members of the School of Psychology at the University, Sarah Bodley Scott (Trainee Clinical Psychologist) and Dr Gerry Riley (Senior Academic Tutor).

Why have you been invited?
You have been identified as a partner/spouse of a person who has had a traumatic brain injury and may have had some personality changes as a result. We will be interviewing 5-8 individuals who are in a similar position to you.

Do you have to take part?
Participation in the study is entirely voluntary. Even after giving consent you will be free to end your involvement in the study at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or your partner receives.

What are the possible risks & benefits?
We do not anticipate any negative effects of taking part, though we recognise that talking about the changes that have occurred following a brain injury can be an emotional experience for relatives. However, you will be given plenty of time to

answer questions and will not have to answer any questions you don't wish to. You may choose to stop the interview at any time and choose to either reschedule the interview or to end your involvement in the study. This would not affect the standard of care you or your partner receives.

If you become very distressed during the interviews, the researcher may ask you for your consent to discuss her concerns with the research team in order that we might identify appropriate further support for you.

We do not expect you to directly benefit from taking part in the research. However, we hope that the information we gain will help clinicians in the future to know how best to support other people in your position.

Will I be reimbursed for any expenses?
Yes. You will receive reimbursement for any travel costs incurred as a result of participation in the study.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes Part I.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Will my taking part in this study be kept confidential?
With your permission we would like to write to your GP to let them know you will be participating in the study. Otherwise, your participation in the study will be kept strictly confidential and known only to members of the research team and the local collaborator who approached you about the study. Your data will be stored in accordance with the Data Protection Act 1998. All data collected from you (e.g. interview scripts and recordings) will be anonymous and will be stored on password-protected University computers in a secured locked office. Your personal data (address, telephone number) will be stored in a separate password-protected file. Copies of your signed consent form will be stored in a secured locked office at the University of Birmingham. Study documentation may be

looked at by authorised representatives of the University or regulatory authorities to check that the study is being carried out correctly. Otherwise, only members of the research team will have access to your data. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.

Audio-recordings will be transferred onto a password-protected computer as soon as practical and erased off the recording device. Audio-recordings will be retained until the award of the Chief Investigator's doctoral degree. Your personal data (address, telephone number etc.) will be kept for a year after the end of the study so that we are able to send you a summary of the findings. All other data (e.g. interview transcripts) will be kept for 10 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality.

Direct quotations from the interviews will only be published in academic reports, publications and presentations. The summary of findings sent to participants will not contain any quotations or information that would be able to identify you. No quotations will be presented at any presentations to other service users. In any publication, a pseudonym will be used so that you or your partner cannot be recognised and care will be taken to ensure that you cannot be identified from the quotations. Your name and contact details will remain confidential and will not be stored or reported with your research data.

You should be aware that if you disclose anything that raises concern about harm to yourself or to others (including disclosure of abuse) that the researcher may need to discuss these concerns with other members of the research team to decide whether any further actions are needed. One outcome of this might be a referral to social services. Where possible, this will be discussed with you first.

What will happen if I don't want to carry on with the study?
You are free to end your participation at any point in the study without consequence to the care you or your partner receives. At the end of each interview you will be asked if there are any comments you do not wish to be included in the analysis. In addition, at the end of the second interview, you will be reminded that you have up to a week to inform the researcher if you don't wish your data to be used in the analysis. Up to this point, if you choose to withdraw part or all of your data, it will not be transcribed and used in analysis. After this time, interviews will be transcribed and may still be used in analysis.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the Chief Investigator who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS

Complaints Procedure by contacting the Patient Advice and Liaison Service (PALS) on 0800 917 2885.

In the very unlikely event of a mishap as a result of taking part in the study there are no special arrangements for compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay your legal costs.

What support is available to me if I need it?

If your participation in the study highlights a need for support that has not previously been identified by services, with your consent, this will be discussed with <<Name of Local Collaborator>>. <<Name of Local Collaborator>> may then take action to enable you to access further support. Alternatively, you may wish to contact one of the following services who offer support for carers or would be able to signpost you to sources of further support:

Headway West Midlands   0121 457 7541
Headway Worcester   01905 729 729
The Carers Support Team   0121 466 4314
(Birmingham Community Healthcare NHS Trust)

What will happen to the results of the research study?

The results of the study will form part of a doctoral thesis and may be published in scientific journals and presented at scientific conferences. You will not be identified in any report or publication. You may request a summary of the findings at the end of the study by advising us of your wish during your interviews or by contacting us using the details below.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee. The scientific relevance of the study has also been reviewed by independent members of the University of Birmingham.

Contact Details

If you have any queries or would like further information about the study, please do not hesitate to contact us:

Dr Sarah Bodley Scott   Dr Gerry Riley
School of Psychology, University of School of Psychology, University of
Birmingham, Edgbaston, Birmingham, Birmingham, Edgbaston, Birmingham,
B15 2TT   B15 2TT

Appendix vi   **Participant Consent Form**

UNIVERSITYOF
BIRMINGHAM

Participant Identification Number:...............

CONSENT FORM
Title of Project: Traumatic Brain Injury & Personality Change
Researcher: Sarah Bodley Scott

Please initial each box

1. I confirm that I have understood the information sheet dated November 2012 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.

3. I give permission for the researcher to write to my GP to inform them of my participation.

4. I understand that the research interview will be audio-recorded

5. I understand that following the research interview I will have a one-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.

6. I understand that the data collected during this study will be looked at members of the research team at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. I understand that study documentation may also be looked at by authorised representatives of the University or regulatory authorities to check that the study is being carried out correctly.

7. I understand that parts of the data may also be made available to the clinical team responsible for me or my family member's care but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed. I understand that one outcome of this may be a referral to relevant authorities (e.g. social services).

8. I give permission for direct quotes from my interview to be published in any write-up of the data. I understand that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.

9. I agree to take part in the above study.

....
Name of participant   Date   Signature

....
Name of researcher   Date   Signature

Appendix vii   **Flow Diagram of Recruitment Process**

Participant
Identification &
Approach

| Local collaborator identifies potential participant based on inclusion/exclusion criteria |

| Local collaborator approaches potential participant. Obtains consent to pass contact details to Chief Investigator |

Informed
Consent & Data
Collection

| Chief Investigator contacts participant to arrange information session. |

| Information Session
Chief Investigator meets with participant
Participant given copy of Participant Information Sheet and Participant Consent Form |

| Telephone Call
Chief Investigator rings participant to confirm participation and to arrange first interview. |

| First Interview
Chief Investigator obtains written consent before interview |

| Second Interview |

| Telephone Call
Chief Investigator rings participant to confirm continued consent to use data in analyses (one week after second interview). |

Appendix viii   Interview Schedule

<u>First Interview</u>
Background
1. Could you tell me what happened to your partner?
   Prompts: Cause of injury? When the injury happened? Sense of severity of injury and disability (e.g. length of hospitalization, current care needs of partners and services partner is in receipt of)?

2. How long have you been together?
   Prompts: Any children? How they met?

The Person
3. How would you describe <<name of partner>> before the injury?
   Prompts: Five words to describe partner? Things they liked and disliked about them?

4. How would you describe them now?
   Prompts: Five words to describe partner?

5. Would you say that their personality has changed? How?

6. In what ways is <<name of partner>> still the same?

The Relationship
7. How would you describe your relationship before the injury?
   Prompts: Closeness? Roles in relationship?

8. How would you describe it now?
   Prompts: Closeness? Roles in relationship?

9. Would they say that their relationship has changed? How?

10. In what ways is their relationship still the same?

<u>Interview 2</u>

<< Précis of first interview>>
Questions followed up and explored the concerns of participants arising in their first interview

1. You mentioned in the first interview that << name of partner>> was now <<some personality change>>, how has this affected you?
   Prompts: As a person? Feelings about <<name of partner>>? Your relationship?

2. You mentioned in the first interview that <<some change in the relationship>>, how has this affected you?
   Prompts: As a person? Feelings about <<name of partner>>? Your relationship as a whole?

3. You have spoken about a number of changes you have observed in your partner; other family members of people with brain injury also report other changes that you have not mentioned. I would now like to ask you about a few of these just to see if you have noticed any of these in your partner.
   Have you noticed <<Personality change not previously mentioned*>> in <<name of partner>>?
   If yes, has this affected you/your relationship? In what ways?

4. Out of all the changes, what has been the most difficult?
   Prompts: For you to cope with? To accept? For your relationship?

5. Have you learnt anything positive over the last <<time since injury>>
   Prompts: about your partner? about your self? about your relationship?

6. Is there anything I haven't asked about that you would like to add?

*Personality changes identified from the literature from which participants' transcripts were cross-referenced with to identify changes they had not mentioned

   More easily loses their temper/verbally or physically aggressive/more argumentative/more irritable/ impatient
   Experiences mood swings, is unpredictable
   Inflexible in behaviour and/or thinking/Obsessed with ideas and interests
   Is Irresponsible/impulsive/lacking in self-control
   Is socially inappropriate or tactless
   Lacks self-awareness or insight into their behaviour and/or difficulties
   Is insensitive to needs/feelings of others/Is self-centred and unappreciative of others/Lacks empathy
   Is lacking in affection/intimacy
   Lacks motivation/Lacks interest in things/Lacks initiative and drive
   Is anxious/less outgoing/low in mood/Has lost confidence
   Is withdrawn and less sociable

561	INT:	So how would you describe him now as a person?
562	Anita:	Horrible, horrible, nasty, evil. Some of the things that
563		come out of his mouth. He's just disgusting. He told me
564		to go and "f*****g" die the one day when I was driving the
565		car and I just – "How dare you?" I said, "Your six year old
566		kid is in that car with me." "Well f*****g do it on your
567		way back then." Just as cold as that. It's just horrible. I
568		would not tolerate a person like that ever. Not even as a
569		friend. Not even to talk to. Because I would not put up
570		with anybody like that. But now I have to. It's either that
571		or I split up with him. Kick him out and he's got nowhere
572		to go then and I can't do that. You know, I can't do that

Annotations:
- and his ... (blame – brought on them by him –)
- Negative feeling toward partner
- verbal abuse
- Lack of feeling in abuse – horrible
- Having to tolerate – no choice
- Feeling responsible for him
- Can't finish relationship – not his fault – accident – ndao up like this
- (16)

573		because at the end of the day, none of this is his fault,
574		none of it. He had an accident and he's woke up like this
575		and he's suffering. He's suffering big time. He doesn't
576		want to treat us like this. He doesn't want to be like this.
577		He can't eat very well. You know, everything tastes
578		disgusting to him. He's gagging on his food. He's lost his
579		eyesight. He's lost his job. He's lost his driving licence.
580		You know, he's very down. They're going to put him on
581		anti-depressants. So life for him is vile as well. You know
582		– but ... I haven't just got him to think about, I've got my
583		children. And the little one copes with it so well. It just
584		goes over his head. [laughs] He just answers his dad back
585		and goes, "God mum, he's starting on me again." But the
586		girls it affects, really hurts them. It's how long can I keep
587		protecting everybody, you know, just - How strong do I
588		need to be? I don't know, only time will tell. I don't
589		know. I don't know where we're going to be in the future,
590		I really don't.
591	INT:	In what ways is he still the same as he was before?
592	Anita:	As before erm ... that's difficult. I suppose the only way

Annotations:
- He's suffering too + Not just them
- uncertainty of being – he doesn't want to treat them like that
- Empathy for him + what he is going through – what he has lost
- Torn between caring for him + caring for children – needing to do best for everyone
- Affect on children
- Having to be responsible for everyone – hard
- uncertainty about future + ability to continue coping

Appendix x   Extract of an Annotated Interview Transcript (later in analysis)

Post-injury person (He's) horrible, nasty, evil Disgusted by things he says Verbal abuse Lack of feeling in abuse - hurtful No choice but to tolerate Responsible for him –can't leave Not his fault - He's suffering too – does not want to be like this, treat us like this - ? making it harder to leave Empathy for what he is going through and what he has lost Torn between responsibility for him and responsibility for children Weight of responsibilities for protecting everyone Uncertainty about future	INT: So how would you describe him now as a person? Anita: Horrible, horrible, nasty, evil. Some of the things that come out of his mouth. He's just disgusting. He told me to go and "f*****g" die the one day when I was driving the car and I just – "How dare you?" I said, "Your six year old kid is in that car with me." "Well f*****g do it on your way back then." Just as cold as that. It's just horrible. I would not tolerate a person like that ever. Not even as a friend. Not even to talk to. Because I would not put up with anybody like that. But now I have to. It's either that or I split up with him. Kick him out and he's got nowhere to go then and I can't do that. You know, I can't do that because at the end of the day, none of this is his fault, none of it. He had an accident and he's woke up like this and he's suffering. He's suffering big time. He doesn't want to treat us like this. He doesn't want to be like this. He can't eat very well. You know, everything tastes disgusting to him. He's gagging on his food. He's lost his eyesight. He's lost his job. He's lost his driving licence. You know, he's very down. They're going to put him on anti-depressants. So life for him is vile as well. You know – but ... I haven't just got him to think about, I've got my children. And the little one copes with it so well. It just goes over his head. [laughs] He just answers his dad back and goes, "God mum, he's starting on me again." But the girls it affects, really hurts them. It's how long can I keep protecting everybody, you know, just - How strong do I need to be? I don't know, only time will tell. I don't know. I don't know where we're going to be in the future. I really don't.	Negative feelings towards partner Behaviour change (Verbal abuse) Managing behaviour Sense of behaviour: Ambivalence about relationship/Torn feelings Impact on children Emotional toll Uncertainty