Changing relationships: Acquired Brain Injury, family functioning and the experiences of significant others.

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Appendices:

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Thesis Portfolio Abstract

Purpose: Acquired Brain Injury (ABI) affects both patients and families. This thesis portfolio aims to increase knowledge exploring post-ABI family life, using contrasting methodologies. Two papers are presented; an exploration of the relationship between post-injury neurobehaviouiral (NB) presentation and family functioning (FF), followed by an analysis of subjective experiences for spouses and partners of ABI patients.

Design: A systematic review is presented exploring the relationship between NB change and FF. Broad search terms were applied across three databases, with fifteen studies reviewed. Data extraction and quality assessments are presented. In contrast, the empirical study adopted Interpretative Phenomenological Analysis (IPA). Nine women, whose significant other had experienced an ABI, took part in semi-structured interviews regarding their experience of realisation of change. Analysis was conducted both within and across accounts, with a reflective journal maintained for transparency.

Results: FF mediated the relationship between NB change and caregiver distress, meaning the distress potentially triggered through NB change can be explained through FF. Within NB, behaviour concerns were most predictive of FF, however the differing degrees of detail within the definition and measurement of "neurobehavioural change" are considered. The IPA derived four main themes; "pushed apart by brain injury", "bravery to face lingering awareness and emotions", "lost and trapped in an unsolvable maze" and "unfolding events leading to new perceptions". Each included two subthemes.

Conclusions: Post-ABI changes elicit a multitude of experiences, including relational disconnect and feeling trapped. Notably though, distress can also be

predicted by quantitative measurement. Clinical applications include keeping the whole family in mind when considering ABI sequelae and promoting longer-term support to couples. Further studies could address specific NB aspects to increase predictive accuracy, while extensions of the empirical study could explore underlying internal processes, potentially using Grounded Theory.

Introduction

The onset of health concerns affects the wellbeing of whole families, a phenomenon established across contexts and medical conditions (Mausbach et al., 2012; Romero-Moreno et al., 2011; Martire, Lustig, Miller, Schulz, 2004; Newby, 1996; Livingston, Brooks and Bond, 1985; Pless, Roughmann and Haggerty, 1972). Where the need for support is ongoing, family members may adopt caregiving roles which contrast with their previous relationship to their loved one, requiring substantive personal adjustment (Martire et al., 2004; Oddy and Herbert, 2003; Kahn, Baguley and Cameron, 2003). Following this, caregiver outcomes repeatedly include ongoing stress and meeting clinical thresholds for mental health diagnosis (Mausbach et al., 2012; Romero-Moreno et al., 2011; Gilliam and Steffen, 2006; Ergh, Hanks, Rapport and Coleman, 2003).

Acquired Brain Injury (ABI) refers to injury to the brain occurring after birth, via traumatic impact or medical condition (Headway, 2020), with potential cognitive, behavioural, emotional and physical implications (Marsh, Kersel, Havill and Sleigh, 2002). In this context, family relationships have been researched for around four decades (Brunsden, Kimele and Mullin, 2015; Oddy and Herbert, 2003; Brooks, Campsie, Symington, Beattie, McKinlay; 1986, Rosenbaum and Najenson, 1976), and family support is highly valued within rehabilitation services (Hart et al., 2003; Williams and Kay, 1991).

Understandably, the experience of ABI affects marital relationships (Rosenbaum and Najenson, 1976). Divorce rates are mixed however, with a range of 15-54% (Kreutzer, Marwitz, Hsu, Williams and Riddick, 2007). Conversely, Wood and Yurdakul (1997) and Kreutzer et al. (2007) found divorce and separation rates to be below general population levels, influenced by injury severity and pre-injury relationship length (positively and negatively correlated, respectively). Furthermore, Wood, Liossi and Wood (2005) found that mood changes within the injured person and unpredictable behaviour explained differences between couples who separated and those who stayed together. Spousal life satisfaction however, while "happy" for less than a third of couples (Eriksson, Tham and Fygl-Meyer, 2005), was not significantly different to other chronic illnesses (Haley, Roth, Hovater and Clay, 2015 cited in Arguello, 2013). Consequently, mixed findings generate difficulty determining whether relationship changes are specific to those affected by ABI, or reflect the influence of other factors.

Following ABI, personal recognition of reduced marital satisfaction is found to increase depressive symptoms (Blonder, Langer, Pettigrew and Garrity, 2007), and overarchingly negative mental health outcomes for family members are well documented (Sander, Maestas, Clark and Havins, 2013; Kreutzer, Ketchum, Marwitz and Menzel, 2009; Blonder et al., 2007; Verhaeghe, Defloor, Grypdonk, 2005; Rosenbaum and Najenson, 1976), often meeting clinical thresholds (Kreutzer et al., 2009; Clark, et al., 2004). Such outcomes can be seen within the context of the whole family systems (Verhaeghe et al., 2005), which hold wide diversity in their degree of enmeshment and problem management between family members (Olson, 2000; Epstein, Bishop and Levin, 1978). Family units are theorised to seek homeostasis in the face of change (Verhaeghe, et al. 2005), with researchers applying this to formulate adjustment following the ill health of one family member (Begun, 1996 cited in Degeneffe, Gagne and Tucker, 2013; Patterson and Garwick, 1994).

In exploring these patterns, several models of family functioning (FF) have been derived (Dai and Wang, 2015). Arguably the most widely recognised is the

McMaster Model of Family Functioning (MMFF) (Mansfield, Keitner and Dealey, 2015; Epstein et al., 1978), which proposes the interacting domains of problem-solving, communication, affective responsiveness and control (influence over others) in defining family system wellbeing (Epstein et al., 1978). Extremes of these dimensions indicate lower FF, as assessed through the valid and reliable Family Assessment Device (FAD) (Mansfield and Keitner, 2015; Miller, Epstein, Bishop and Keitner, 1985). The MMFF was extended to emphasise wider biopsychosocial goals and interactions between family members, assessed via the Family Assessment Measure (FAM) (Dai and Wang, 2015), forming the seven-dimension Process Model (Steinheiser, Santa-Barbara, Skinner, 1984). With specific application to ABI however, Clark (1999) applied the ABCX model (Hill, 1949 cited in Clark, 1999). The model proposes a "pile up" of demands derived from supporting the injured person (A), use of family resources (B) and attributed meanings (C), which contribute to family adaptation (X). Path analysis supported this model in predicting family adaption 12 months after injury (Clark, 1999).

FF models (Dai and Wang, 2015) support an understanding of the role of FF on patient, primary caregiver and family outcomes. Greater deficits in the social skills of the injured person were associated with reduced caregiver problem solving during interactions (Godfrey, Knight and Bishara, 1991), a pattern likely to influence FF (Epstein et al., 1978). Furthermore, "effective" FF prior to stroke was likely to fall to a degree impacting clinical outcomes for the injured individual (Bishop and Evans, 1995), while families with lower pre-injury FF were more likely to remain this way (Epstein, Bishop and Baldwin, 1982; Kabacoff, Miller, Epstein, Bishop and Keitner, 1990 cited in Bishop and Evans, 1995).

Some positive outcomes have also been indicated, although this is explored less frequently. Within siblings, Degeneffe et al. (2013) described a strengthened “bond”, and posttraumatic growth has been observed within family members supporting stroke survivors (Hallam and Morris, 2014). Understanding the predispositions, responses and strategies contributing to such outcomes is essential towards understanding the effect of ABI, and considering clinical applications. Relevant concepts here include meaning making (Park, 2010) and ambiguous loss (Boss, 2008), alongside consideration of perceived differences in participants awareness of their disability and how this is seen by relatives (Yeates, Gracey and Evans, 2007). Positive outcomes are further reported from family therapy (Yeates, Edwards, Murray, Creamer and Mahadevan, 2013: Kreutzer et al., 2009), where use of pre-existing strategies for managing emotions have aided relationship adaptation (Blas and Boisvert, 2005).

Alongside these outcomes, marital satisfaction has been linked to positive rehabilitation outcomes (Walsh, 2003 cited in Godwin, Chappell and Kreutzer, 2014; Carnwath and Johnson, 1987), however exploration of couples lacks presence within the ABI literature (Kreutzer, Sima, Marwitz and Lukow, 2016; Kreutzer et al., 2007). This is despite evidence suggesting spouses or partners of those with ABI experience greater distress than parents (Panting and Merry, 1970 cited in Verhaegue et al., 2005; Hall Karzmark, Stevens, Englander, O’Hare, Wright, 1994). Such concerns include intimacy and sexuality (Kitzmuller and Ervik, 2015), loss of social networks, personality changes and reduced emotional support (Bodley-Scott and Riley, 2015). Alongside this, the physical demands of care may be particularly challenging for caregivers in later life (Gosman-Hedström & Dahlin-Ivanoff, 2012).

The nature of how ABI affects an individual and family is also case specific. Pre-determined and generalised models, adopted by quantitative methodology, is likely to miss case-specific subtleties. Smith, Flowers and Larkin, (2009) highlight the importance of individual variability in experience. Within the context of ABI, all individuals involved in supporting an injury-affected family are perceiving them from a position influenced by their own experiences. Consequently, while the role of quantitative research in informing population-based policy and practice should not be overlooked (Noyes et al., 2019), the positivist assumptions underlying results may be questioned (Braun and Clarke, 2003). Qualitative studies provide an alternative perspective, exploring the subjective experiences of relationships affected by neurobehavioural sequalae (Whiffin et al., 2017; Bodley-Scott and Riley, 2015 for example).

In consideration of the above, this portfolio adopts a critical realist stance to consider the multiple forms of "truth" within the complexity of post-ABI life. A systematic review of quantitative studies addressing the relationship between post-ABI presentation and family functioning is presented (Chapter 1), followed by a bridging chapter (Chapter 2) and qualitative study (Chapter 3), which aimed to capture "deep" subjective accounts of family life following ABI. These contributions are followed by in-depth methodological consideration (Chapter 4), and further results from the qualitative study (Chapter 5) for additional transparency. Finally, the portfolio concludes with a critical review of the two papers (Chapter 6). It is hoped that this portfolio will not only contribute to knowledge and clinical practice, but also resonate with those affected by ABI.

Chapter 1.

Systematic review

Prepared for submission to: Neuropsychological Rehabilitation (Appendix A).

The relationship between Neurobehaviour and Family Functioning following Acquired Brain Injury (ABI): A Systematic Review.

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Abstract

Research has established how Acquired Brain Injuries (ABIs) elicit numerous outcomes both within the individual and wider family. Neurobehavioural (NB) sequelae require adjustments from individual family members with a ripple effect throughout the family system, diverging established family functioning (FF) patterns. A systematic review was conducted with fifteen studies addressing the relationship between post-injury NB presentation and FF, which included 1039 family members of ABI patients. Cross-sectional designs were prominent, with two studies taking longitudinal approaches. The majority of studies were of “fair” quality, and potential biases were considered.

Findings identified a negative association between NB and FF, with behavioural difficulties predicting less healthy FF. Many studies found FF mediated the relationship between NB impairments and caregivers’ psychological health, although results were mixed. Furthermore, reduced FF within the domain of family roles were predicted by NB impairments, although there was some variation across studies. Adopted measures and suggestions for future research were considered. Overall, behavioural difficulties following ABI predicts FF, and support for newfound family roles may promote positive outcomes.

Keywords: *Brain injury, stroke, family, behaviour, neuropsychology*

Introduction

The impact of potential long-term neuropsychological sequelae of Acquired Brain Injury (ABI) on psychological and physical health are well documented (Verberne, Spauwen, Heugten, 2019; Marsh, Kersel, Havill and Sleigh, 2002), with spouses or parents typically assuming caregiver roles (Livingston, Kennedy, Marwitz and Arango-lasprilla, 2010). Family caregivers' emotional needs are an increasingly recognised part of rehabilitation (Cameron, Cheung, Streiner, Coyte and Stewart, 2011), with numerous studies having identified the impact of ABI on close family members and caregivers in relation to experienced burden, life satisfaction, distress and mental health (Armstrong, Schupf, Grafman, Huey, 2013; Livingston et al., 2010; Epstein-Lubow, Beevers, Bishop and Miller, 2009; Kreutzer et al., 2009; Marsh et al. 2002; Machamer, Temkin and Dikmen, 2002; Wood and Yurdakul, 1997; Brooks, 1991; Rosenbaum and Najenson, 1976). Within this, caregiver quality of life is positively correlated with rehabilitation outcomes (Perrin et al., 2016; Cameron, Cheung et al., 2011; Verhaeghe, Defloor, Grypdonck., 2005; Sander, Caroselli, Becker, Neese and Scheibel, 2002), however the first two years following ABI reduces caregiver life satisfaction (Livingston et al., 2010), and is linked to significant long-term distress (Brooks and Campsie, 1986 cited in Verhaeghe et al., 2005).

Sander, Mastas, Clark and Havins (2013) reviewed 28 studies exploring predictors of emotional distress in caregivers following traumatic brain injury (TBI). Findings showed caregiver medical history and emotion-focussed coping "may possibly" (due to study quality) relate to emotional distress. Other significant factors have included gender, age and time demands, interpreted as impacting strain (Ain, Dar, Ahmad, Munzar, Yousfzai, 2014). This presents some of a complex range of factors potentially influencing caregiver wellbeing.

The definition of “neurobehavioural” (NB) has been described as impaired social functioning induced through cognitive and behavioural change (McMillan and Wood, 2000). Exploration of marital satisfaction following changes to the injured persons responsivity to others’ emotions has differentiated ABI from other conditions, such as chronic pain (Burridge, Williams, Yates, Harris and Ward, 2007). Additionally, Watanabe, Shiel, Asami, Taki and Tabuchi (2000) measured NB difficulty and caregiver mental health in 34 Japanese families affected by traumatic brain injury (TBI), and found a positive correlation between behavioural and cognitive challenges, and family member anxiety. Sander et al. (2013) concluded that both FF and NB change were considered “probable” risk factors for caregiver distress; based upon both prospective and retrospective studies with relatively low bias. In contrast, a logistic regression of factors explaining strain (Boycott, Yeoman and Vasey, 2013), did not find NB functioning to predict caregiver outcomes.

Cultural norms within some studies however (such as Watanabe et al., 2000) may influence trends in family adaptation, potentially limiting generalisability. Furthermore, differences between findings may reflect broadness in defining what is meant by “behaviour”. Nevertheless, overall research findings suggest that NB change may hold a prominent role for post-injury relationships and mental health.

Studies have also sought to determine the impact of ABI on family unity, with FF referring to the daily emotive and communicative structure of family life through multiple perspectives (Beavers and Hampson, 2000; Steinhauer, Santa-Barbara and Skinner, 1984). A variety of factors have been correlated with FF within the context of ABI (Epstein-Lubow, et al., 2009; Gan, Campbell, Gemeinhardt and McFadden, 2006; Clark and King, 2003), and identified a relationship between increased mental health concerns in family members and reduced FF.

Within this, NB changes may be particularly challenging to caregiver wellbeing and FF; increased emotional and behavioural needs alongside poorer caregiver mental health has been associated with greater family conflict (Clark and King, 2003). A recent literature review (Fisher, Bellon, Lawn and Lennon, 2019) also described behaviours of concern to be one of the most problematic aspects of ABI for families. Long-term FF has been predicted by caregivers' attributions around patient competency and received social support (Douglas and Spellacy, 1996), and studies employing path analysis suggest that FF mediates the relationship between ABI sequalae and caregiver outcome (Anderson, Simpson and Morey, 2013; Schönberger and Ponsford, 2010). Such results highlight the complex relationships between NB changes, thinking processes and FF.

The relationship between the consequences of ABI and FF have been reviewed within the paediatric TBI population (Rashid et al., 2014), with key results showing severe and sometimes moderate TBI to have the greatest impact on FF, in comparison to mild TBI and orthopaedic injury groups. Research exploring the relationship between ABI and FF in an adult ABI population has yet to undergo systematic review. Given the established correlation between FF and the wellbeing of those involved (Epstein-Lubow et al., 2009; Gan et al., 2006; Clark and King, 2003), this creates a gap in the literature which the current review seeks to address. Consequently, this review aims to answer the following question: Is there a relationship between NB change and FF outcomes within an adult ABI population?

Method

A systematic review exploring the relationship between NB changes and FF within an adult ABI population was conducted. Given the background research, this review will use the term “NB presentation” in reference to post-ABI behaviours for which family members seek ways to cope and manage. Consequently, specific neurological deficits assessed through psychometric assessments, physical disability and mental health diagnosis are not included in this definition. Furthermore, within the background literature and reviewed studies, NB measures are administered following ABI without access to a pre-ABI baseline. This means that perceiving these outcomes as a “change” attributable to injury is an inference rather than measured difference.

Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA, Moher, Tetziaff and Altman, 2009) (Appendix B) guidelines were followed, and a protocol was registered with PROSPERO (ID: CRD42018088907). A population, intervention, comparison and outcome (PICO) outline guided the search due to its recommended sensitivity (Methley, Campbell, Chew-Graham, McNally and Cheraghi-Sohi, 2014). This was adjusted to remove the comparison criterion and apply an “exposure” rather than intervention, due to the naturalistic nature of the topic.

The search was completed on 18th September 2019 and utilised three databases; Medline Complete, PsychInfo and CINAHL. Exposure terms were all variations of “neuropsychological”, “neurobehavioural” and “behavioural” (“behav*) within abstracts, combined via Boolean operators with the outcome terms; “care” (“car*”), “family”, “partner”, “marital” or “spouse”, which referred to the continued relationship within the family following ABI onset, and was searched for within whole articles. Searches were filtered to exclude “child” and “paediatric” terms. Population definitions were “stroke” and “brain injuries”, searched using all databases and as MeSH terms via Medline Complete, paired with the NB and outcome terms.

The following inclusion criteria were adopted:

- Written in English.
- Incorporated a measurement of NB presentation.
- Included a validated measure of FF. Studies may have used different terminology but included items relating to an established FF model.
- Adopted quantitative methodology.
- Included only an adult ABI population.
- Relationship between NB and FF must have been analysed, although this did not necessarily need to be the primary research question.

Given that research in families following ABI dates back several decades (such as Rosenbaum and Najenson, 1976), limiting the search by publication date could have neglected key studies.

The following exclusion criteria were applied during title and abstract screening:

- Topic did not directly relate to the review question.
- Only used measures relating to mental health, distress and/or coping e.g. Hospital Anxiety and Depression Scale (HADS).
- Child/paediatric ABI.
- NB defined as Activities of Daily Living or single domain without a global NB measure. For example, the Oxford Handicap Scale (in Rigby et al., 2009) as the independent variable (IV).

- Behaviour was the dependent variable (DV) rather than IV (unless both NB and FF are then correlated in the analysis).
- Adopted a qualitative method.
- Summarised literature but was not a systematic review.

Of the articles screened in full text form, 10.5% were also randomly selected and assessed for eligibility by an impartial colleague using the same criteria. While the majority of ratings matched, studies with opposing ratings were revisited for further consideration. Data extraction took place independently via the lead reviewer, under supervision from the research team.

Quality Assessment

To evaluate methodological quality, the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QATOCCS; National Heart, Lung and Blood Institute, NHLBI, 2014) was chosen due to its suitability for cross-sectional and observational approaches. The QATOCCS is formed of 14 questions (Appendix C), addressing the explicitness of the research question, population, sampling, assessor blindness and management of confounding variables. Reviewer responses include “cannot determine”, “not reported” and “not applicable” alongside “yes” or “no”. The ratings are then summarised with a “good”, “fair” or “poor” rating (Table 1).

Each assessment was made based on the report of the individual study, to prevent methodological assumptions being made about linked studies (such as Anderson, Parmenter and Mok, 2002; Anderson, Simpson, Morey, Gosling and Gillett, 2009 and Anderson et al., 2013). All studies were quality assessed by two reviewers, with five discrepancies revisited in detail regarding their ability to answer the review question, design and sample.

Results

Study Characteristics and Design

Figure 1 provides a search flowchart, which generated 9028 records for title and abstract screening and concluded with 15 studies for review (Table 1). Fourteen were from peer reviewed journals, with one (Chinnery, 2005) doctoral thesis. All were published between 1994 and 2013. Due to a range of measures and two study designs, narrative synthesis was used. Results were considered regarding ability to answer the research question, study design, measures, quality and overall findings. See Appendix D for screenshots of records attained.

Across all studies included, two were longitudinal (Schönberger, Ponsford, Olver and Ponsford 2010; Testa, Malec, Moessner and Brown, 2006) with the remainder using a cross-sectional design. Data was collected between 16 days (Carnes and Quinn, 2005) and 40 years (Groom, Shaw, O'Connor, Howard and Pickens, 1998) post-injury. Four studies collected data during hospitalisation of the injured patient (Carnes and Quinn, 2005; Douglas and Spellacy, 1996; Kreutzer, Gervasio and Camplair, 1994) or potentially shortly after admission (Testa et al., 2006), whereas six (Anderson et al., 2013; Ponsford and Schönberger, 2010; Schönberger er al., 2010; Anderson et al., 2009; Ponsford, Olver, Ponsford and Nelms, 2003; Anderson et al., 2002) collected information from those living in the community. A further three studies recruited through rehabilitation services (Ergh, Rapport, Coleman and Hanks, 2002; Nabors, Seacat and Rosenthal., 2002) or a mixture of these sources (Chinnery, 2005). For two studies this information was not reported (Groom et al., 1998; Kosciulek and Lustig, 1998).

In defining FF, one study explored family or caregiver burden (Nabors et al., 2002) and three were interested in family adaptation or adjustment (Carnes and

Quinn, 2005; Ponsford et al., 2003; Kosciulek and Lusting, 1998). FF was assessed as part of these definitions. One study was primarily interested in psychological distress (Chinnery, 2005), yet incorporated an FF measure. Ten studies (Anderson et al., 2013, Ponsford and Schönberger., 2010; Schönberger et al., 2010; Anderson et al., 2009; Testa et al., 2006; Anderson et al., 2002; Ergh et al., 2002; Groom et al., 1998; Douglas and Spellacy, 1996; Kreutzer et al., 1994) explored FF as the primary dependent variable. Within these ten studies, seven measured FF alongside psychological distress, caregiver functioning, perceived stress or mental health (Anderson et al., 2013; Ponsford and Schönberger, 2010; Schönberger et al., 2010; Anderson et al., 2009; Anderson et al., 2002; Ergh et al., 2002; Groom et al., 1998). The remaining three (Testa et al., 2006; Douglas and Spellacy 1996; Kreutzer et al., 1994) measured FF only, without the inclusion of mental health or distress.

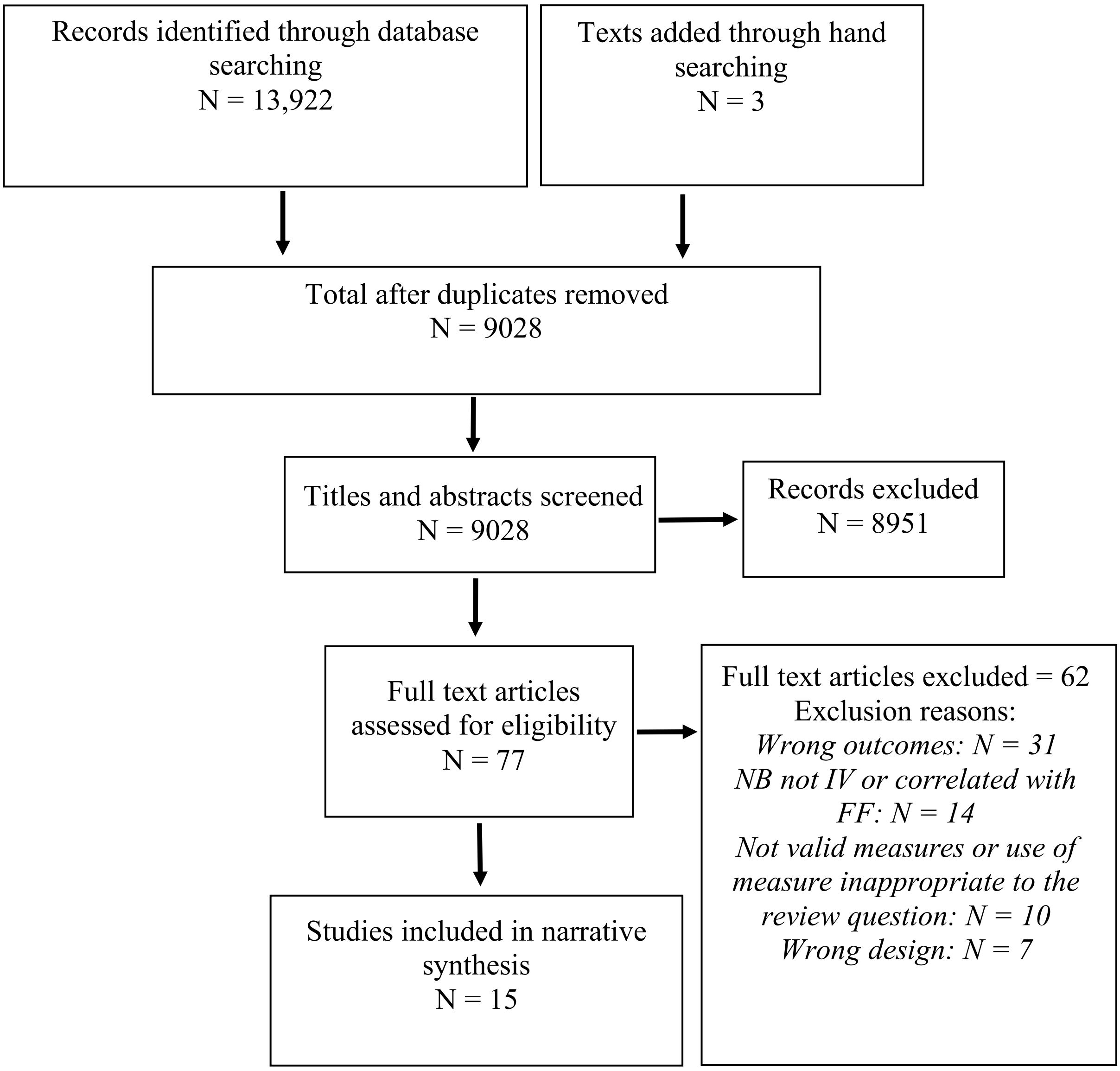


Figure 1: Flow diagram of records screened for eligibility

Synthesis of Included Studies

Participants.

The reviewed studies included 1039 family members of individuals with ABI. Within these, 253 were spouses or partners, while 189 were parents. The remainder (597) were either not defined within the reporting of the study or were a different relation, however two studies (Nabors et al., 2002 and Groom et al., 1998) grouped parents and spouses together. The studies also included 1070 individuals with ABI.

Three studies included participants with all ABIs (Carnes and Quinn, 2005; Ergh et al., 1998; Kreutzer et al., 1994), while the remainder used a TBI population. Interestingly, despite the word “stroke” being searched, no studies focusing solely on stroke met inclusion for review.

Four studies explored only severe ABI (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002; Douglas and Spellacy, 1996) and four incorporated both moderate and severe (Testa et al., 2006; Ergh et al., 2002; Nabors et al., 2002; Groom et al., 1998). A further five used mixed mild-severe samples (Ponsford and Schönberger, 2010; Schönberger et al., 2010; Carnes and Quinn, 2005; Ponsford et al., 2003; Kreutzer et al., 1994), while two did not report severity (Chinnery, 2005; Kosciulek and Lusting, 1998).

Measures

Measures of NB impairments

Measures tended to rely upon family member ratings for the injured individual, due to potential impairments in self-awareness (Ponsford and Schönberger, 2010). They included the Neurobehavioural Problem Checklist (NPC) from the General Health and History Questionnaire (GHHQ), which was utilised by four studies (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002; Kreutzer et al., 1994). The NPC consists of 105 items and a 4-point Likert scale to assess five domains; physical/somatic, cognition, behaviour, communication and social (Anderson et al., 2009; Kreutzer et al., 1994). Alternatively, the Structured Outcome Questionnaire (SOQ) was incorporated by three studies (Ponsford and Schönberger, 2010; Schönberger et al, 2010 and Ponsford et al., 2003), to address cognitive, behavioural, social and emotional changes (Ponsford and Schönberger, 2010).

Ergh et al. (2002) and Groom et al. (1998) utilised the Neuropsychology Behaviour and Affect Profile (NBAP), a 106-item questionnaire collecting data on indifference, inappropriateness, pragnosia, depression and mania (Nelson et al., 1987 cited in Groom et al., 1998). Critically, concern around user bias has been reported (Satz, Holston and Uchiyama, 1996; Nelson, Satz and Uchiyama, 1998), potentially limiting conclusions from these studies.

Carnes and Quinn (2005) used the Los Ranch Amigos Levels of Cognitive Functioning Scale (LOCF), consisting of a three-point Likert scale (BrainLine, 2012), alongside the Brain Injury Behaviour Scale (BIBS) to assess slowness, poor memory, anger and aggression. While the study correlated BIBS scores with the validated Memory and Behaviour Problems Checklist (MBPC), the BIBS itself was not a validated measure (Carnes and Quinn, 2005).

Differentiating from reliance on family ratings alone, a further three studies used the Problem Checklist (PCL), part of the New York Head Injury Interview/Head Injury Family Interview (HI-FI) (Kay, Cavallo, Ezrachi and Vavgiakis, 1995 cited in Chinnery, 2005; Nabors et al., 2002; Kosciulek and Lusting, 1998). The 43-item list assesses Cognitive, Affective/Behavioural and

Physical Dependency domains. Use of the full HI-FI collects data from both patient and family member (Nabors et al., 2002), reducing potential bias. Douglas and Spellacy (1996) adopted the examiner-rated and validated Neurobehavioural Rating Scale (NRS) (Levin et al., 1987) adding further robustness. The NRS consisted of 27 items on a seven-point scale focussing on behavioural challenges, patient observation and test performance (Levin et al., 1987).

Only Testa et al. (2006), used the Neurobehavioural Functioning Index (NFI), consisting of 70 items on a five-point Likert scale, addressing depression, somatic, memory/attention, communication, aggression and motor areas of functioning. This measure has been validated within a TBI population (Kreutzer, Marwitz, Seel and Serio, 1996). Across the studies, these measures form a potentially rigorous summary from multiple sources.

FF measures

Thirteen studies (Anderson et al., 2013; Ponsford and Schönberger, 2010; Schönberger et al, 2010; Anderson et al., 2009; Chinnery, 2005; Ponsford et al., 2003; Anderson et al., 2002; Eugh et al., 2002; Nabors et al., 2002; Groom et al., 1998; Kosciulek and Lusting, 1998) measured FF via the Family Assessment Device (FAD), or FAD General Functioning Index (FAD-GF); a summary measure (Schönberger et al., 2010; Nabors et al., 2002; Groom et al., 1998; Kosciulek and Lusting, 1998), based on the McMaster Model of FF (MMFF) (Epstein-Lubow et al., 2009; Epstein, Bishop and Levin, 1978). The FAD has 30 years of research demonstrating its' ability to differentiate FF between groups experiencing various stressors, such as ill health (Miller, Epstein, Bishop and Keitner, 1985; Mansfield, Keitner and Dealey, 2015). It is a 60-item questionnaire where respondents indicate their satisfaction with MMFF domains (Mansfield et al., 2015).

Douglas and Spellacy (1996) used the Family Environment Scale (FES); 90 true and false questions completed by both family caregiver and patient, measuring family relationships, personal growth and system maintenance via ten subscales. Adequate reliability and validity are reported (Douglas and Spellacy, 1996), yet not within brain injury populations (for example, Moos and Newborn, 1980 cited in Douglas and Spellacy, 1996). Furthermore, Carnes and Quinn (2005) used the Family Adaptation, Partnership, Affection and Resolve Scale (APGAR), which has adequate reliability and validity (Smilkstein, Ashworth and Montano, 1982 cited in Carnes and Quinn, 2005).

Table 1.

Evidence table with studies exploring the relationship between post-ABI Neurobehavioural presentation and Family Functioning.

Author	Study Design	Participants	Severity	Exposure and measure used	Outcome and measure used	Results	QATO Qualit rating
1. Anderson et al., 2013	Cross-sectional	Included respondents from Anderson et al. 2002 and Anderson et al. 2009 (122). Ninety-three included in analysis.	Severe to extremely severe	Interested in male/female caregiver comparison. Cognitive and behavioural presentation when living with a family member with TBI. Measure: NPC from GHHQ.	FF and psychological distress. Measures: FAD-GF; Brief Symptom Inventory for psychological distress.	Proposes model validated through structural equation modelling (SEM). Describes thinking and behaviour to have “significant, direct” effects on roles and FF. Behaviour had a significant correlation to FF using FAD-GF, but a non-significant relationship to the FAD role subscale. NPC thinking scale was significantly correlated with FAD role subscale, but not to the GF scale. NPC social scale was significant to FAD-GF. NCP thinking and FF had significant relationships to family member distress.	Fair

2.	Anderson et al., 2009	Cross-sectional	64 spouses from 2002 study combined with 58 sets of parents; totalling 122, who were carers for 93 people with TBI.	Severe to extremely severe	Caring for a relative with TBI. Measure: NPC.	FF and psychological distress. Measures: FAD and BSI.	SEM/path analysis. For spouses, the model infers that thinking and behaviour had "direct" effects on FF, which mediates psychological distress. For parents, NB was not related to FF or distress. FF had a moderate correlation with distress.	Fair
3.	Anderson et al., 2002	Cross-sectional	64 spouse caregivers of people who sustained TBI.	Severe	Having a spouse with a severe TBI. Measure: NPC from GHHQ.	FF and psychological distress. Measures: FAD, BSI.	SEM/path analysis. (Problematic) behaviour had an inferred significant adverse effect on FF. "Thinking" had only a small correlation with FF. FF was inferred to have the strongest direct effect on caregiver distress, followed by communication and social concerns. Implies FF may be a mediator between NB and caregiver distress.	Poor
4.	Carnes & Quinn; 2005	Cross-sectional	Questionnaires administered to 123 family members of 65 participants (convenience sample), who recently	Mixed	Having a family member with ABI. Measures: Rancho LOCF, Intergenerational Solidarity Scale (premorbid relationship	Family adaptation. Measures: APGAR, BSI.	BIBS and MBPC scores were not significantly correlated with FF. Both these scales were positively correlated with the psychological distress of family members. Social support, finances and premorbid relationship quality	Poor

			experienced ABI.		quality), BIBS, GCS, MBPC.		instead significantly correlated with FF. Additionally, factors theorised a “pile-up” of stressors on FF which correlate with psychological well-being.	
5.	Chinnery; 2005	Cross-sectional	45 married spouses of people with TBI.	Unknown	Being a spouse of someone with a TBI. Measures: PCL from HI-FI.	Psychological distress. Measures: BSI, FAD, Interpersonal Support Evaluation List.	FF found to be a strong mediator for the relationship between NB presentation and spouses’ psychological distress.	Poor
6.	Douglas & Spellacy, 1996	Cross-sectional	26 adults with TBI and their primary caregivers (14 wives, 11 mothers, 3 husbands and 2 fathers).	Severe	Having a family member with TBI. Measures: NRS, Index of recent Negative life events, Patient Competency Rating Scale (PCRS), Instrumental Social-Support Scale, Health and Daily Living form, Self-Rating Depression Scale.	FF. Measures: FES and FF composite variable (Expressiveness and Conflict scales); F-COPES.	Multiple regression found NB function to explain significant variance within FF (a further 0.14). Consequently, increased NB dysfunction predicted impaired FF.	Fair

7. Ergh et al., 2002	Cross-sectional	60 pairs of participants (couples) – one member of each couple had an ABI.	Moderate and severe	Neuropsychological presentation following ABI of one member of each pair. Measures: GCS. CAGE – screening for alcohol abuse, Neuropsyhcological tests, PCRS, NBAP, Social Provision Scale (SPS).	Caregiver and FF. Measures: BSI, FAD	Multiple regression found NBAP ratings were the most significant predictor of family dysfunction. Explaining a further 0.05% pf variance in the model.	Fair
8. Groom et al.,1998	Cross-sectional	153 family members (TBI patients). 86.3% were parents or spouses.	Moderate and severe	Neurobehavioural presentation following TBI of a family member. Measures: NBAP.	Family functioning, perceived stress. Measures: FAD-GF, Perceived Stress Scale.	Family members rated higher family dysfunction than the normative sample. All NBAP subscales were significantly correlated with FAD-GF; moderate strength relationships. Full Scale NBAP and FAD-GF correlation was 0.54. Inappropriateness alone accounted for 20% and indifference 0.8%. The remaining subscales accounted for 32% of the variance in FAD-GF scores.	Fair

9.	Kosciulek & Lusting, 1998	Cross-sectional	Ninety-two families with one member who had ABI; 97% reported as TBI. Participant was defined as primary caregiver.	Unknown	Being primary caregiver to a family member with ABI. Measures: Family Information Sheet (demographic information), PCL.	Family adaptation. Measure: FAD-GF	Stepwise multiple regression identified affective/behavioural factors to explain 20% of the variance in family adaptation (FAD-GF scores).	Poor
10.	Kreutzer et al., 1994	Cross-sectional	Sixty-two families of patients with injuries, ranged from 1.5-60 months postinjury.	Mixed	Having a family member with a brain injury. Measures: NPC, eight neuropsychological tests.	Family functioning. Measures: FAD, BSI.	NCP predicted the General Functioning, Communication and Roles subscale scores on FAD. Behaviour subscale score was the best predictor of family functioning, and most predictive of the role's subscale. No further scales of the NPC added predictive value.	Fair
11.	Nabors, et al., 2002	Cross-sectional	Forty-five caregivers of individuals with TBI. Patients had received either inpatient care or acute rehabilitation services.	Moderate to severe	Being primary caregiver to a family member with ABI. Measures: HI-FI.	Caregiver burden. Measures: Family Needs Questionnaire (FNQ) to assess perceived needs beyond family system,	Mixed results; a significant negative correlation between the affective/behavioural burden and ratings of needs being met on the FNQ, however FAD-GF was not significantly predicted by affective/behavioural burden.	Fair

					Personality Assessment Inventory, FAD-GF.		
12. Ponsford, et al., 2003	Cross-sectional	143 TBI rehabilitation patients attending follow-ups with a family member. Thirty-nine percent mothers, 26% wives, 11% siblings and 4% children. Forty-nine percent were primary carers.	Mixed (72% severe)	Living with TBI/ a family member with TBI. Measures: Leeds Scales for Self-Assessment of Anxiety and Depression, SOQ: Section on cognitive, behavioural and emotional changes, Craig Handicap Assessment and Reporting Technique (CHART), the Sickness Impact Profile.	Family adjustment. Measure: FAD	A mid-strength correlation was found between emotional and behavioural factors and FAD-GF scores. The strongest predictor of FAD-GF was the number of cognitive, behavioural and emotional changes reported by the family member. Other FAD sub-scales non-significant, although roles approached significance. Unhealthy FAD scores for family members were more likely where problems with concentration, impulsivity, initiative and depression were reported.	Fair

13. Ponsford & Schönberger; 2010	Cross-sectional	Three hundred and one individuals with TBI and their families; 266 at 5 year follow up, 98 of which were at both. TBI patients had received rehabilitation follow ups at 2 and 5 years post-TBI.	Majority moderate-severe	Having a family member experience TBI. SOQ, HADS, (patient completed), CHART. Westmead PTA scale (injury severity)	FF and relatives' emotional status. Measures: FAD, HADS	Path analysis identified relationships between anxiety and depression, FF and NB presentation. FF was related to the number of emotional, cognitive and behavioural challenges experienced by the individual with the TBI. FAD-GF scores were significantly predicted by both behavioural concerns and anxiety in the patient with TBI (2-year and 5-years post injury). FF communication and affective involvement were the highest two subscales.	Poor
14. Schönberger et al., 2010	Longitudinal	Sixty-six family members nominated by individuals with TBI.	Majority moderate-severe	Having a close family member with TBI. Measures: Westmead PTA scale, SOQ.	FF, family member anxiety and depression of the nominated family member. Measures: FAD-GF, HADS.	Significant coefficients via path analysis were present between behavioural concerns and FF at 2 years (greater behavioural concerns associated with poorer FF), but only significant when the model was corrected for collinearity. Cognitive and social presentation did not predict FF or mental health concerns in caregivers.	Good

15. Testa et al., 2006	Longitudinal	Seventy-five modetate/severe TBI, 47 with mild TBI and 44 with orthopaedic injury (OI).	Moderate and severe	NB presentation following TBI. NFI.	FF via FAD-GF.	A relationship was established between FAD-GF scores and all scales of NFI for severe/moderate group, but not for mild TBI. Consequently, depression, communication, aggression and memory/attention were significantly predictive of family dysfunction for families affected by severe/moderate TBI. No differences in FAD scores based on group (moderate, mild TBI and OI groups).	Good

Summary of Quality Assessment

Eight studies (Anderson et al., 2013; Anderson et al., 2009; Ponsford et al., 2003; Ergh et al., 2002; Nabors et al., 2002; Groom et al., 1998; Douglas and Spellacy, 1996; Kreutzer et al., 1994) were considered "fair" quality, whilst five (Ponsford and Schönberger, 2010; Carnes and Quinn, 2005; Chinnery, 2005; Anderson et al., 2002; Kosciulek and Lusting, 1998) received "poor" ratings. Two (Schönberger et al.; Testa et al., 2006) were considered "good" and both used longitudinal designs. Within these however, the follow up rates were either a loss of 20% of participants (Schönberger et al., 2010) or not reported (Testa et al., 2006), indicating potential bias despite the more robust design. Furthermore, only one study (Schönberger et al., 2010), provided a justification for sample size, discussion of effect size and power.

All but four studies (Anderson et al., 2009; Carnes and Quinn, 2005; Anderson et al., 2002; Kosciulek and Lusting, 1998) had well-defined research questions. Valid, reliable exposure measures were used for all but two studies (Carnes and Quinn, 2005; Ponsford and Schönberger, 2010), whereas all studies achieved this for outcome measures. Additionally, all but three studies (Anderson et al., 2002; Chinnery, 2005 and Kosciulek and Lusting, 1998) addressed confounding variables via statistical adjustment, for example through calculating the strength of relationships (such as Groom et al., 1998).

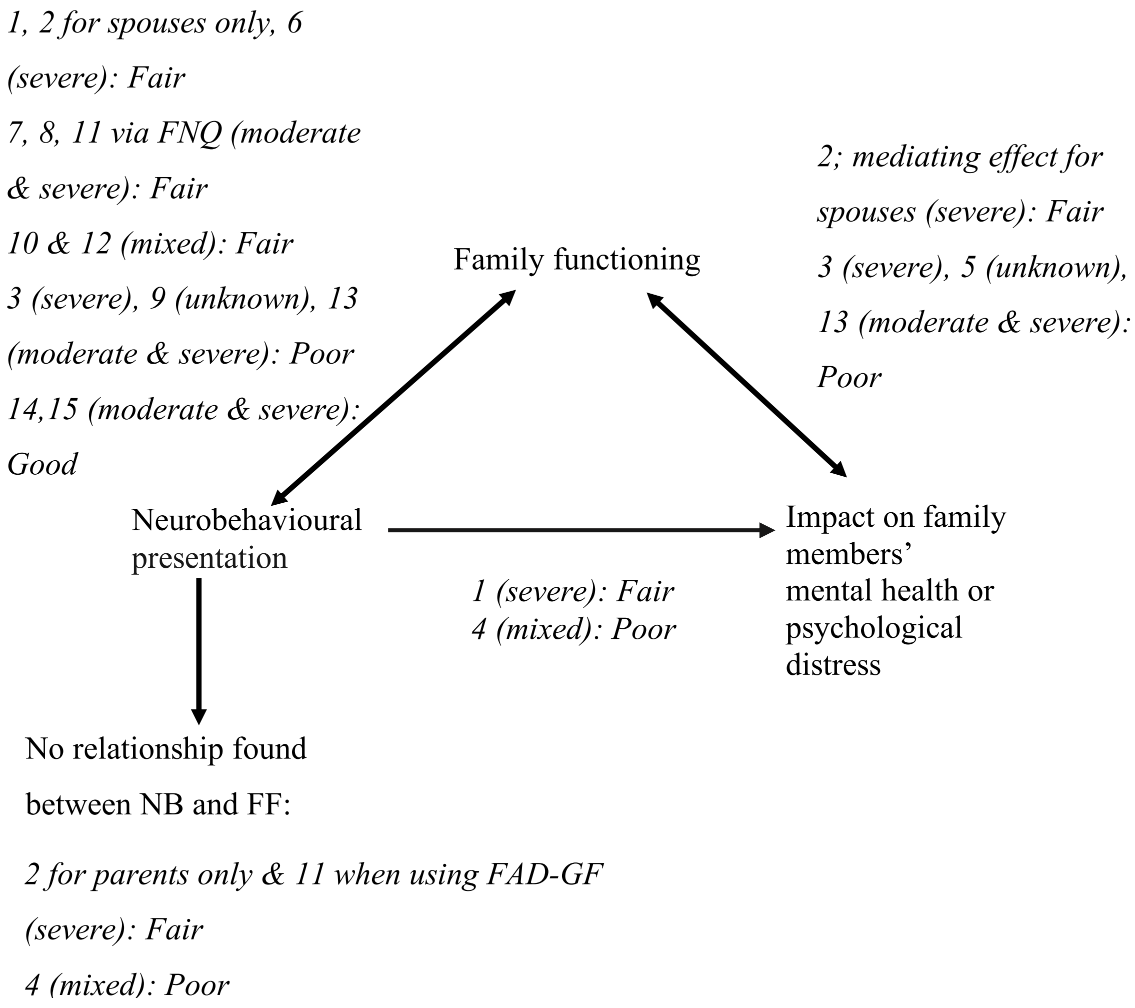
Concerningly, only five studies (Anderson et al., 2013; Anderson et al., 2002; Carnes and Quinn, 2005; Groom et al., 1998; Ponsford et al., 2003) reported a participation rate of 50% or higher, whilst eight clearly define inclusion and exclusion criteria (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002; Ergh et al., 2002; Douglas and Spellacy, 1996; Kosciulek and Lusting, 1998;

Nabors et al., 2002; Testa et al., 2006). Consequently, samples may be disproportionate representations of populations or have variable inclusion criteria, questioning generalisability. Wide variations (Carnes and Quinn, 2005; Groom et al., 1998) or lack of information (Carnes and Quinn, 2005; Kreutzer et al., 1994) regarding time since injury also contributed a challenge to drawing conclusions across results.

Overall, some studies showed methodological rigour by incorporating valid FF measures and addressing confounding variables (Appendix C). There were two “good” ratings however (Table 2 and Appendix C), and biases included difficulties determining causality, the confounding influence of time since injury and lack of reporting statistical power.

Study Findings

Table 1 summarises the results of studies evidencing the relationship between NB presentation and FF. Across studies, correlations, multiple regressions and Structural Equation Modelling (SEM) explored NB concerns in relation to FF. This relationship was acknowledged alongside mental health and psychological distress variables, discussed below. Figure 2 demonstrates these relationships.



Key: 0-15 = study identification numbers (see Table 1)
Good/fair/poor = quality ratings (Appendix C)
Severe/moderate & severe/mixed/unknown = injury severity

Figure 2. Diagram depicting study findings in explaining the relationships between NB, FF and mental health/distress, with quality ratings.

NB presentation **and family functioning.**

As demonstrated in Figure 2, all but one study (Carnes and Quinn, 2005) provided evidence observing bi-directional relationships between NB presentation and healthy FF, NB presentation and mental health/distress, and mental health/distress and FF. Carnes and Quinn (2005) had a “poor” quality rating however, primarily due to lack of clarity around time since the injury, lack of clear inclusion and exclusion criteria and using a non-validated measure (BIBS). Consequently, findings may not be rigorous enough to contradict results from higher quality research.

Across studies, FF and NB were moderately correlated (Nabors et al., 2002; Groom et al. 1998), with multiple regressions predicting FF via NB impairments (Ergh et al. 2002; Douglas and Spellacy, 1996; Kreutzer et al., 1994). Furthermore, SEM tested causal relationships, suggesting that NB impairments have a negative influence on FF (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002). Quality was predominantly fair (Anderson et al., 2013; Anderson et al., 2009; Eugh et al. 2002; Nabors et al., 2002; Groom et al. 1998; Douglas and Spellacy, 1996; Kreutzer et al., 1994), with common sources of bias (Appendix C) including lack of clarity around exposures being measured before outcomes, only assessing exposures once and lack of statistical reporting (Anderson et al., 2013; Anderson et al., 2009; Eugh et al., 2002; Nabors et al., 2002; Douglas and Spellacy, 1996; Kreutzer et al., 1994). A participation rate of only 15% was also of concern (Nabors et al., 2002), alongside an insufficient time frame since the injury (Kreutzer et al., 1994). One study was rated "poor" (Anderson et al., 2002), because significant relationships which did not fit the proposed model were perceived as trivial and removed (Anderson et al., 2002; Pedhazur, 1997 cited in Anderson et al., 2002). This may have excluded alternative perspectives.

Findings around specific NB impairments appear varied. Affective and behavioural problems held the strongest correlation to FF, accounting for 20% of the variance in two studies, of "fair" and "poor" quality (Groom et al. 1998 and Kosciulek and Lusting, 1998, respectively). The "poor" rating (Kosciulek and Lusting, 1998) was due to an unclear research question, lack of controlling for confounding variables and poor participation rate. Notably though, the results were supported by studies incorporating path analysis (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002; Ponsford et al. 2003; Ponsford and Schönberger, 2010; Schönberger et al., 2010). Such evidence was predominantly "fair", with one "good" quality rating (Schönberger et al., 2010).

There is both "good" and "fair" evidence that unhealthy FF is more likely when depression, communication, aggression, memory, impulsivity and initiation difficulties are reported (Testa et al. 2006; Ponsford et al., 2003 respectively). Aggression and impulsivity explained 53% and 45% of FF variance for male and female caregivers respectively (Anderson et al., 2013), and inappropriateness (Groom et al., 1998) was predictive of FF for up to 5 years post-injury (Ponsford and Schönberger, 2010; Schönberger et al., 2010; Ponsford et al., 2003). While predominantly "fair" in quality, Ponsford and Schönberger (2010) was deemed "poor" due to an unclear description for the population used and clarity around the validity of measures (Appendix C).

Extreme FAD roles subscale scores (indicating lower FF) were significantly predicted by NB presentation across multiple domains (Anderson et al., 2013; Chinnery; 2005; Kreutzer et al., 1994) with one study approaching significance (Ponsford et al., 2003). Kreutzer et al. (1994), provided "fair" evidence of FAD general functioning (general FF) and communication scores also being predicted by overall NB score. While this evidence is predominantly "fair", Chinnery (2005) was deemed "poor" quality due to lack of inclusion and exclusion criteria and potentially unreliable information around injury type.

Individual domains within the concepts of NB and FF also hold varied relationships to each other. "Fair" evidence for the model proposed by Anderson et al. (2013), extending the results from their previous two studies (Anderson et al., 2009; Anderson et al., 2002), showed a significant relationship between cognition and family member roles (FF roles), and behaviour to general FF (Anderson et al., 2013). Cognition and general FF were non-significant. Interestingly, this latter result has reached significance elsewhere (Groom et al., 1998; Kreutzer et al., 1994), suggesting mixed evidence, all of "fair" quality.

Alternatively, the number of NB problems across domains (cognitive, behavioural, emotional) may also predict FF (Ponsford and Schönberger., 2010; Ponsford et al., 2003.; Carnes and Quinn, 2005), however these studies are at risk of bias (Table 1 and Appendix C).

FF, NB presentation **and mental health/stress.**

Reviewed studies tended to explore FF alongside a measure of mental health (Ponsford et al., 2010; Schönberger et al., 2010) or distress (Anderson et al., 2013; Anderson et al., 2009; Chinnery, 2005; Anderson et al., 2002; Groom et al., 1998; Kreutzer et al., 1994). "Fair" evidence indicates that depression and inappropriateness within the injured family member accounted for 29% of FF variance together, and positively correlated with caregiver stress (Groom et al., 1998). This suggests that NB impairments may independently impact on both FF and mental health/distress variables. Notably, Ergh et al. (2002) reported the relationship between NB presentation and FF to be stronger than that between NB and caregiver distress. Alongside this, there is "good" evidence that caregiver anxiety and depression were predictive of FF at 2 and 5 year follow ups (Schönberger et al., 2010).

Evidence suggests that FF is a mediator for the relationship between NB and FF (Anderson et al., 2009; Anderson et al., 2002), with FF explaining a further 11%

of the variance in NB presentation and caregiver depression (Ponsford et al., 2003). Chinnery (2005) describe similar (yet “poor”, Table 1 and Appendix C) findings in spouses; removing the FF variable reduced the relationship between NB problems and stress to being non-significant. Consequently, FF may be tentatively inferred to contribute an underlying mechanism for relationship between NB and distress/mental health.

The influence of injury severity.

Families supporting those with moderate or severe injuries are those for whom FF is more likely to become challenging (Anderson et al., 2013; Anderson et al., 2009; Anderson et al., 2002; Douglas and Spellacy, 1996). Chinnery (2005) provides a negative correlation between severity and FF (Chinnery, 2005), however Groom et al. (1998) associated severity with indifference (NB) but not FF (“poor” and “fair” respectively). Ponsford et al., (2003) provide “fair” evidence that FAD-GF did not correlate significantly with injury severity, while Testa et al. (2006) found “good” evidence of a negative correlation between NB impairments and FF for moderate-severe TBI cases, but not mild cases. Consequently, higher-quality evidence indicates that severity plays a role in the NB and FF relationship, with moderate and severe ABI potentially inducing a greater quantity or intensity of NB presentation, negatively impacting FF. Studies using mixed or unknown severity (Carnes and Quinn, 2005; Chinnery, 2005; Ponsford et al., 2003; Nabors et al., 2002; Kosciulek and Lusting, 1998), are consequently difficult to generalise.

Discussion

There is a good quantity of evidence (13/15 studies) of the negative association between NB presentation and FF. Several studies found more problematic behaviour following injury to be negatively correlated with healthy FF (Ponsford et al., 2010; Schönberger et al., 2010; Ponsford et al. 2003; Groom et al. 1998 and Kosciulek and Lusting, 1998), and the functioning of family roles was predicted by the presence of NB presentation (Kreutzer et al., 1994). This could have impacted upon problem-solving, communication, affective responsiveness and control, according to the MMFF model, upon which the majority of reviewed studies were based (Epstein, Bishop and Levin, 1978). The severity of NB presentation, as well as the number of changes, were both predictive of FF (Ponsford and Schönberger, 2010; Kreutzer et al., 1994). In addition, some studies found a mediating effect from the relationship between NB and FF upon the association betweenNB and distress/mental health (Ponsford and Schönberger, 2010; Ergh et al., 1998; Groom et al., 1998). This supports the FF background literature (Clark and King, 2003; Epstein-Lubow et al., 2009).

Consistency Within the Literature

This review identified the role of FF in contributing to explaining the relationship between NB and mental health/caregiver distress. Results were mixed when “poor” quality studies are included (such as Chinnery et al., 2005; Ponsford et al., 2003). A number of reviewed studies were previously addressed by Sander et al. (2013) regarding emotional distress (Ponsford and Schönberger, 2010; Schönberger et al., 2010; Anderson et al., 2009; Ponsford et al., 2003; Anderson et al., 2002; Douglas and Spellacy; 2000; Ergh et al., 2002), emphasising the association between FF and mental health/distress. This review additionally considered the complexity of the relationship between NB, FF and mental health/distress. From both reviews, NB presentation may have impacted upon both family resources and individual caregiver distress, potentially leading to each of these variables mediating the relationship between the other and NB presentation.

Additionally, while executive functioning predicted caregiver distress (Sander et al., 2013), cognition was generally not found to be related to FF (Anderson et al., 2013; Anderson et al., 2002), suggesting that FF was only one of numerous possible variables contributing to the NB and caregiver distress/mental health relationship. Potentially, given the link between caregiver distress and neurorehabilitation outcomes (Verhaeghe et al., 2005), FF could hold a bi-directional relationship with rehabilitation outcomes as well, which future studies could consider.

Additional variables may explain further variance within FF, including demographics, pre-injury marital factors and individual family member perceptions (Ain et al., 2009; Burridge et al., 2009; Carnes and Quinn, 2005; Douglas and Spellacy, 1996), which were not addressed in this review. Cultural differences (Watanabe et al., 2000), also require consideration, as reviewed studies are all based within a first world, largely Western context. Measures such as the FAD are also derived from Western culture, although some models of FF have been applied cross-culturally (Keitner et al., 1990). Furthermore, the age of some of the studies (such as Kreutzer et al., 1994; Douglas and Spellay, 1996; Groom et al., 1998; Ergh et al., 1998) cannot accommodate modern developments in family norms. Consequently, conclusions have been drawn tentatively.

Three studies reduced the complexity of defining NB by measuring the quantity of problematic aspects of NB across domains (Ponsford and Schönberger., 2010; Carnes and Quinn, 2005; Ponsford et al., 2003). Despite quality concerns (Table 1) this approach provided an alternative way of assessing the intensity of NB presentation, which related directly to models of FF (Hill, 1949 cited in Clark, 1999), indicating that the "build up" of multiple NB challenges may negatively impact FF regardless of the NB domain.

Discussion of Measures

To assess NB presentation, all-encompassing assessments of interpersonal relationships, cognition, inhibition and communication commonly determine functional ability (Alderman, Williams, Knight and Wood, 2017; Alderman, Wood and Williams, 2011). Notably, NB impairments have been one of the last concepts of post-ABI presentation to be quantified (Wood, Alderman and Williams, 2008; Grant and Alves, 1987 cited in Groom et al., 1998) and there is an acknowledged lack of validated measures (Carnes and Quinn; 2005). This was accounted for within the inclusion criteria, where the validity, reliability and consistency of administration of NB measures considered as part of the quality assessment (Appendix C). Only two studies used validated NB measures however (Testa et al., 2006; Douglas and Spellacy, 1996), and other validated measures, such as the clinically-applied SASNOS (Alderman et al., 2017; Alderman et al., 2011), were not observed in the reviewed studies.

Concerns around inconsistent variables measured within the definition of NB may also be considered. Schönberger et al. (2010) indicated concerns around collinearity, suggesting that social, cognitive and behavioural variables were not discrete. Within the reviewed studies, some separated mental health outcomes for the injured person from NB measures (Douglas and Spellacy, 1996) whilst others used an NB measure incorporating emotion scores (Ponsford and Schönberger, 2010;

Groom et al., 1998). Lack of specific behavioural descriptions contributed to this, particularly where small sample sizes were used (Nabors et al., 1998). Interestingly, Ponsford and Schönberger's (2010) use of measuring the quantity of NB challenges could negate the need to over-focus on NB domains, as potentially any NB aspect could have a relationship to FF. Nevertheless, there is a possible gap in the literature to explore which behaviours, for example aggression or withdrawal, relate to which specific domains of FF.

The majority of studies measured FF using the FAD; based upon the MMFF (Epstein et al., 1978). While this model is well supported in other populations (Mansfield et al., 2015), research has provided extensions to the MMFF (Steinhauer, 2011), so studies may be considered over-reliant on this model. Interestingly, the ABCX model (Hill, 1949 cited in Clark, 1999) has been applied within the context of ABI (Clark, 1999) yet was not utilised by the reviewed studies. Given the wide-ranging possibilities of NB presentation (Alderman et al., 2011), such reliance on the MMFF and FAD may limit alternative ways of perceiving FF following ABI.

Within MMFF orientated studies, several used the FAD-GF scale alone (Anderson et al., 2013; Schönberger et al., 2010; Nabors et al., 2002; Groom et al., 1998; Kosciulek and Lusting, 1998). The FAD-GF cannot determine which MMFF domains are affected by NB, limiting detail. Studies using the full FAD were able to define the NB presentation and FF relationship with more detail (such as Kreutzer et al., 1994), with potentially greater clinical implications. Despite over-reliance on the MMFF within the literature, a double-bind exists where studies that did not use the FAD (Carnes and Quinn, 2005; Douglas and Spellacy, 1996), could be critiqued for not utilising more robust measures. Consequently, there may be a balance between continuing to develop the concept of FF, and the need to further knowledge in the areas models and measures are applied to.

Critique of the Current Review

While the search results used inclusive terms and screened a high quantity of studies, the inclusion criteria were lenient due to including studies without explicitly validated NB measures (Appendix C). This may have led to lower quality studies being included, however excluding this research would have overly limited the studies available for review.

While the inclusion/exclusion criteria allowed for grey literature, the databases predominantly included peer reviewed journals. Only one unpublished thesis was included (Chinnery, 2005). Consequently, publication bias is only partially addressed and a ProQuest search may have rectified this. Notably though, Chinnery (2005) was rated “poor” in quality, potentially questioning the benefit of including studies which have not received peer review. Other potential in the selection criteria include accessing studies only written in English, alongside only using three databases. Plausibly, additional terms for ABI’s could have been incorporated, for example “cerebrovascular accident”, however they were not considered to add additional results during the early design stages of this review. Additionally, only 10.5% of the studies at full text assessment (Figure 1) were checked by a second reviewer, and increasing this proportion would add methodological rigour. A strength of this review is the use of a second reviewer for all quality assessments and thoroughness of search terms.

Some studies could have been conducted at higher quality than rated here, yet failed to report details which pertained to the QATOCCS. In particular, when exploring papers by Ponsford and Schönberger (2010; rated “poor”) and

Schönberger et al. (2010; rated "good"), it is plausible that both studies shared the same sample and potentially design, yet both aspects are unclear. The paper by Ponsford and Schönberger (2010) does not clearly specify a longitudinal method and lacks the details included in Schönberger et al. (2010), so a higher rating was unable to be applied. To have treated these studies as related would have risked relying on assumptions and potentially favour biased results.

While the term "stroke" was included in the search, no studies using a specific stroke sample were returned. Within stroke literature, a wealth of research has covered a broad array of family and caregiver experiences (for example Kinney, Stephens, Franks and Norris, 1995; Grant, Weaver, Elliott, Bartolucci and Giger, 2004; Gillespie and Campbell, 2011), and within the scope of this review it is unclear why studies have not progressed in the direction of this topic. Stroke sufferers are likely to have been included in studies using an ABI sample (Carnes and Quinn, 2005; Ergh et al., 1998; Kreutzer et al., 1994), generating a literature gap as to whether the relationship between NB and FF is different depending on the origin of the injury.

Only one study separated mild and moderate/severe TBI (Testa et al., 2006), yet four have unknown or mixed severity (Kosciulek and Lusting, 1998; Carnes and Quinn, 2005; Chinnery, 2005; Kreutzer et al., 1998). Those managing milder impairments are concluded to be better able to adjust the family system (Verhaeghe et al., 2005), whereas logically those with more severe conditions may face greater challenges (Testa et al., 2006). Where this was considered (Testa et al., 2006; Groom et al., 1998) it was not overtly related to NB and FF. An alternative explanation is that the relationship between injury severity and FF is mediated by another variable (for example mental health), leading to multiple small yet non-significant relationships, particularly where sample sizes are small or where studies have struggled to recruit over 50% of eligible participants. More stringent inclusion criteria around variables contributing to the NB and FF relationship may have generated clearer conclusions.

Regarding analysis, SEM was utilised to derive causal effects (Anderson et al., 2013; Schönberger et al., 2010), however the nature of many study designs may not lend themselves to a conclusion of causation. Nevertheless, such sophisticated statistics may infer possible causality. While this does not remove the limitations of the designs of reviewed studies, it may generate clinically useful data, develop theory and drive future research.

In critiquing the method, narrative synthesis offers a standardised way to bring results together where study designs are too varied for meta-analysis (Ryan, 2013; Popay et al., 2006). Some commonalities were observed across designs, however. Table 1 shows all reviewed studies used either SEM or path analysis, multiple regression or correlation. Should a greater number of studies using one statistical approach be identified in the future, meta-analysis may become feasible (Borenstien, Hedges, Higgins and Rothstein, 2009) and add statistical rigour to an update of this review. Generally, narrative synthesis risks reviewer bias when summarising study results however, and could conflate results in a misleading manner (Andrews and Harlen, 2006). The results for this review were checked by a supervisory team and each study was considered in relation to its quality assessment and ability to answer the research question.

Conversely, by only including quantitative studies, any inferences around NB and FF which may be drawn from qualitative findings were excluded. Bayesian theory has been suggested as a way of combining methodological approaches for reviews (Gorard, Roberts and Taylor, 2004 cited in Andrews and Harlen, 2006), and some reviews have included both a narrative synthesis and thematic synthesis to avoid exclusion of qualitative results (Lucas, Baird, Arai, Law and Roberts, 2007), which could be a considered for future exploration. Consequently, methodological extensions of this review could take one of two directions; adding objective rigour via meta-analysis or including subjective experiences to summarise findings across paradigms.

Summary and Conclusions

The results of this review demonstrated predominantly "fair" evidence supporting a negative association between NB presentation and FF. Results have suggested that NB impacts FF, and FF mediates the relationship between NB and mental health/distress. This may indicate bi-directional relationships where NB challenges reduce FF, and reduced FF contributes to explaining the relationship between NB presentation and mental health/distress. Given the correlations between FF and mental health/distress, NB presentation may contribute to possible deterioration in both FF and mental health/distress.

Within established domains of NB, behavioural difficulties were found to be the most predictive variable of FF, however studies incorporated a mixture of measures and some "poor" quality evidence was present. Only two longitudinal studies were considered "good" quality. Within FF, the impact upon family roles and general FF were most commonly identified, however this was mixed, with others showing effects across many FF domains or only utilising a generalised measure. While this review was inclusive of a large quantity of studies during the search, some bias has been considered including the contribution of grey literature and those from non-Western cultures. Nevertheless, future research may benefit from defining specific behaviours explored as part of NB presentation, using validated NB measures and exploring of a range of FF models with detailed measures.

Declaration of interest statement

The authors report no conflict of interest.

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Chapter 2.

Bridging Chapter

Bridging chapter

The systematic review identified quantitative research exploring the relationship between neurobehavioural presentation following Acquired Brain Injury (ABI) and family functioning (FF). The majority of studies used a cross-sectional design, limiting conclusions around cause and effect, and were predominantly rated "fair" in quality. Variation of outcome measures was observed, with some using general FF scales whilst others incorporated more detailed varieties. Within the systematic review, "neurobehaviour" measures included cognitive, behavioural and emotional domains, suggestive of complexity. There is a need for studies to be able to contribute to specific predictions about changes to family life, which could inform systemic formulations in clinical practice (Bowen, Yeates and Palmer, 2010).

Furthermore, given that quantitative research seeks to summarise psychological phenomena numerically, broad measures such as the Family Assessment Device-General Functioning scale (Mansfield, Keitner and Dealey, 2015) summarised across large samples, misses information on what it is about family functioning that has adjusted. While models of FF (Steinheiser, Santa-Barbara and Skinner, 1984; Epstein, Bishop and Levin, 1978), go some way to alleviate this, they also impose assumptions taken form a large sample onto individual cases, potentially missing detail within individual accounts, which could otherwise be captured through qualitative means. Consequently, since the nature of ABI combined with family histories and dynamics is unique, only a superficial account is captured through quantitative means.

Qualitative studies seek to provide detailed accounts from a small number of participants, which may compliment or provide an alternative perspective to quantitative domains. Case-by-case accounts could also have transferability to readers who have also experienced the topic of interest, (Lincoln and Guba, 1985, cited in Braun and Clarke, 2013), alongside contributing to extending knowledge on the phenomenon (Braun and Clarke, 2003). While the systematic review provides an overarching population perspective, the qualitative study aims to provide a unique and “deep” account of what this experience is like for those facing it (Smith, Flowers and Larkin, 2009). Supporting literature has also established variation within how different family members experience change following ABI (Verhaeghe, Defloor and Grypdonck, 2005), meaning that understanding both family systems and individuals would help meet gaps in knowledge around post-injury family experiences. Consequently, it may be helpful to further explore individual subjective accounts using a qualitative approach, which is the focus of the next chapter.

Chapter 3.

Empirical Study

Prepared for submission to Neuropsychological Rehabilitation (Appendix A).

The experiences of wives following acquired brain injury (ABI). A qualitative analysis exploring realisations of change following the ABI of a "loved one".

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Abstract

The experiences of family members following Acquired Brain Injury (ABI) are well established, with spouses in particular facing a multitude of personal and relational changes. Qualitative studies have explored accounts pertaining to a range of sequalae, however “change” itself had yet to be addressed. This study explored the experiences of realisation of change for married women living with their husbands following ABI. Nine participants took part in semi-structured interviews focussing on becoming aware of changes in both their spouse and themselves post-injury. An Interpretative Phenomenological Analysis (IPA) was completed, arriving four main themes; “pushed apart by brain injury”, “bravery to face lingering awareness and emotions”, “lost and trapped in an unsolvable maze” and “unfolding events leading to new perceptions”. Participants generally experienced realisation of change gradually, in some cases finding strategies to control their exposure to distress. They often referred to “acceptance”, which held varied meanings, and metaphors appeared to aid personal meaning making. Relationship changes generated dilemmas or feelings of being trapped. Clinical applications and potential further research are discussed.

Keywords: *Stroke, brain injury, family, marriage, couple, qualitative*

Introduction

Acquired Brain Injury (ABI) affects approximately 1.4 million people per year (National Institute for Health and Care Excellence, 2014). Sequalae include emotional, cognitive, behavioural and physical health impairments, often associated with mental health concerns (Finset & Andersson, 2000). Family members regularly take on caregiver roles and support rehabilitation (Gagnon, Lin and Stergiou-Kita, 2016), and an association exists between healthy family relationships and positive rehabilitation outcomes (Carnwath and Johnson, 1987). Adapting to post-injury life involves facing common changes to emotional health, lifestyle choices and relationships (Jackson, Turner-Stokes, Murray, Leese and McPherson, 2009), leading to personal challenges.

Background Research

Family members of ABI patients experience double the population prevalence for long-term depression, somatic symptoms and anxiety (Kreutzer, Ketchum, Marwitz & Menzel, 2009; Hall, Karzmark, Stevens, Englander, O'Hare, Wright, 1994; Brooks, Campsie, Symington, Beattie and McKinlay, 1986). Several models endeavour to understand this.

The Y-shaped model (Gracey, Evans and Malley, 2009), proposes that post-injury identity is experienced as contrasting with the idealised pre-injury self. The personal meanings attached to post-injury changes may be perceived as a "threat to self", eliciting efforts to reduce incongruence. Strategies to achieve this might be unhelpful in the long-term however, maintaining these discrepancies. For example, the idealised feeling of what a spouse "should do" may lead to actions that feel "right" (such as becoming a carer) yet generate personal costs (distress), increasing discrepant feelings. Interventions using the model promote healthy resolution of these discrepancies through developing therapeutic safety, orientation towards goals and addressing the personal meanings behind post-injury life (Gracey et al., 2009).

Within families however, members concurrently seeking to resolve discrepancies may lead to negative interactional patterns, systemically maintaining them (Bowen, Yeates and Palmer, 2010). Family patterns require homeostatic adaptation to achieve maintenance in the face of change (Verhaegue, Defloor & Grypdonck, 2005), which may be particularly challenging following ABI. This generates a dilemma between the emotional safety of sameness versus the potential permanency of post-injury changes (Yeates, Edwards, Murray, Creamer and Mahadevan, 2013), generating anxiety. Systemic therapies address negative interactional patterns, focusing on de-escalating conflict through externalising shared challenges, and adjusting interactions to promote secure attachment (Yeates et al., 2013).

The meanings attached to personal and relational changes also reflect shifting beliefs about the world, and one's purpose within it (Park, 2010). Adjusting strongly held beliefs can take time, reflection and support, as assumed by established clinical models (Beck, 1979). Consequently, interventions may help address how people make sense of demanding circumstances, supporting beliefs to change.

Making sense of traumatic events around the ABI has been expressed through narrative analysis of individual and family interviews (Whiffin, Bailey, Ellis-Hill, Jarrett and Hutchinson, 2015). Perception of change was prominent, sometimes contrasting with parallel awareness of objective progress. This provided insight into the potentially muddled or dilemma-laden experiences of post-ABI change. Participants also focused on comparing the past and present, including aspects of relationships previously taken for granted. Such tendencies provide an insight into how narratives may reflect a strategy for making sense of personal change.

Spouses and partners of ABI patients may experience specific areas of challenge. Experiences include changes in intimacy and sexuality (Kitzmuller and Ervik, 2015; Rosenbaum and Najenson, 1976), difficulties with the physical demands of care (Gosman- Hedström & Dahlin-Ivanoff, 2012), loss of social networks, personality changes and reduced emotional support (Bodley-Scott and Riley, 2015). Where the injured partner expresses unpredictable mood swings, a "Jeckyll and Hyde" experience is reported, with uninjured spouses feeling "married to a stranger" (Wood, 2005 cited in Yeates et al., 2013).

Mixed methods research explored the experiences of women (Gosling and Oddy, 1999), following their husbands' ABIs. Marital roles had changed towards a parental nature, and some couples had responded aggressively towards each other (Gosling and Oddy, 1999). Notably, the specific qualitative methodology was unclear, and a focussed phenomenon could have increased study quality.

Specific qualitative research used grounded theory to explore marriage after stroke (Anderson, Keating and Wilson, 2017). Patterns around reconstructing the marriage included feeling overwhelmed, resolving conflict and perceiving continued value in their relationship. Other studies used Interpretative Phenomenological Analysis (IPA) to explore detailed accounts of individual experiences contributing towards such processes. Bodley-Scott and Riley (2015), analysed the experiences of five partners of Traumatic Brain Injury (TBI) patients and found that making sense of personality change was linked to how participants explained change to themselves, for example perceiving control over behaviour. In an exploration of women in later-life, themes included feelings around the injured spouse being another man and living in fear of another stroke (Gosman- Hedström & Dahlin-Ivanoff, 2012). Additional key research analysed accounts of six male partners, highlighting four main themes; encompassing the unknown "world" of ABI, feeling imprisoned, having compassion without self-compassion and holding on to hope (Brunsden, Kiemle and Mullin, 2017).

In exploring post-ABI relationships, change represents one potential phenomenon of interest. Responses to change within whole families are identified by Whiffin, Bailey, Ellis-Hill, Jarrett and Hutchinson (2015) with narratives expressing continuity when facing potential change (Whiffin, Ellis-Hill, Bailey, Jarrett and Hutchinson, 2017). "Change" was described as a dynamic and ever-developing concept; at risk of limitation through rigid descriptions, for example seeing post-ABI experiences this in terms of overall loss. This contributes to a gap in the literature around how change is experienced for families of those affected by ABI.

The Current Study

Qualitative studies highlight the importance of understanding individual experiences related to established spouse and partner outcomes. Realisation of change, the point at which a spouse notices and subjectively makes sense of changes following the ABI of their significant other, will aid this understanding. Here, "change" refers to both the immediate differences resulting from ABI sequelae and longer-term implications triggered by this event.

This study explored how the wives of men affected by ABI experience realisations of change, and the personal meanings drawn from them. Participants were either attending a support group or receiving contact through specialist ABI services when recruited. Alongside building upon prior phenomenological research, this study aimed to provide a reflective account for others experiencing similar circumstances, and inform services supporting families following ABI.

Method

Methodology and Design

To elicit in-depth accounts of experience, a qualitative approach using IPA was adopted. IPA is idiographic; focussing on the particular and seeking to generate case-by-case results with rich detail, followed by an interpretation across accounts (Smith, Flowers and Larkin, 2009; Braun and Clarke, 2013). IPA is based upon phenomenology; capturing the nature of experience and how participants have made sense of, or attached a personal meaning to it (Smith et al., 2009). The double hermeneutic is also acknowledged. This refers to data collection and analysis depicting the participants expression of their interpretation of events, which is then interpreted reflexively by the researcher (Smith et al., 2009).

The data was collected by the lead researcher via semi-structured interviews, using a topic guide (Appendix E). The guide was developed alongside the Public and Patient Involvement (PPI) member of the research team, to generate meaningful interview questions for those with lived experience.

Participants

Nine participants were recruited via purposive sampling through local ABI support services. Inclusion criteria were:

- The onset of their significant others' ABI occurred at least one year prior to recruitment.
- They had a continued couple relationship with the injured person.
- Appropriate fluency in English due to the reliance on expression of language for the analysis.

Exclusion criteria were any circumstances potentially impairing capacity to consent or take part in a detailed, potentially emotional interview.

Twelve participants were approached by the lead researcher, and nine were recruited. Of the three who declined participation, one did not wish to discuss the interview content, one was too busy and one cancelled their interview due to illness.

All interviewees were female, white British and married. The age range was between 50 and 73, and the length of spousal relationships ranged from 13 to 52 years. Eight had late teenage or adult children. As this study focussed upon meaning making, participants were asked directly about the nature of the ABI their spouse experienced, summarised in Table 2. All injuries were adult-onset and all participants had a relationship with their significant other prior to the injury of interest. The sample also included a range of time scales since the injury, presented in Table 2 with pseudonyms applied.

Table 2.

Time scales and described impairments since injury

Pseudonym	Time since husband's injury (years)	Participant’s descriptions of their husband’s injury and resulting impairments
Debbie	5.5	Stroke: Less tolerant and understanding, finds it difficult to process things.
Maureen	6	“A bleed on the brain”: Aphasia and depression
Sheila	4	“Brain an.", sudden “bump”/fall, surgery “brain drain” (shunt), unconscious for 7 weeks: Short-term memory & mobility impaired
Tina	10	Car accident (TBI): Memory, change in personality, lack of empathy and patience
Iris	1.25	Fell off a ladder and suffered skull fracture: Mood and anger changes, deaf in one ear.
Alice	4	Ischaemic stroke and haemorrhage: Fatigue, mood swings, cognitive impairment, left hand side weakness, cannot follow rules/tasks (unclear writing).
Hazel	10	Stroke: Right-sided weakness and memory problems
Florence	3	Hydrocephalus (diagnosed late), right side of body collapsed, surgery (shunt) then “two bleeds in his head”: Loss of movement/bodily control, memory loss
Grace	6	Stroke: No feeling on one side, sensory and speech, difficulty walking

Table 2 highlights 1.25 to ten year range since injury onset, pre-empting variations within the data. A summary is provided of participant descriptions of their spouses’ injury type and impairments, highlighting a range of physical, cognitive and personality sequelae.

Procedure

Ethical approval was provided through the Social Care REC, London (Appendix F) and the Health Research Authority (Appendix G). General Data Protection Regulation (UK Government, 2018) and the Data Protection Act (1998) were adhered to. Confidentiality, and the boundaries of this, were outlined to participants in the Participant Information Sheet (Appendix H) prior to providing consent. For three participants, a relationship with prospective participants was gained through attending support groups and discussing the study face to face. Six participants were initially approached by familiar service staff and a relationship with the lead researcher was initiated over the phone. These introductions communicated the study purpose and interviewer training level. Upon consent (Appendix I), participants provided demographic information (Appendix J) and were asked about what it was like to realise that both their lives were changing, whether there had been moments where they perceived themselves differently and what the changes meant for them, with prompting questions to elicit detail (Appendix E). Interviews lasted around an hour of the 90-minute appointment, which ended with a debriefing and handout (Appendix K) to address any potential distress and advice on avenues of support. Field notes were taken by the researcher for the purpose of returning to key areas mentioned by the participant, however they were not used for analysis. Eight interviews took place at the participant’s home, with one taking place at a local community day service. Only the researcher and participant were present in the interview. No interviews were repeated.

Analysis

Audio recordings of four interviews were transcribed using a transcription service, and five by the lead researcher. Transcripts were then entered into

Microsoft Excel to support the coding process. Analysis involved reading and re-reading transcripts to ensure immersion and familiarity (Smith et al., 2009). Once familiar with an interview, linguistic, descriptive or conceptual notes were generated (Smith et al., 2009) (Appendix L), which often raised questions and led to revisiting interview segments.

IPA emphasises the importance of reflexivity, referring to the self-awareness of one's own experiences and assumptions, and acknowledging and bracketing their potential influence throughout the IPA process (Smith et al., 2009). The lead researcher was a female, Trainee Clinical Psychologist studying at doctoral level with ten years' experience working with vulnerable populations. Workshops and supervision were attained throughout the study. A reflective journal was also maintained, aiding the hermeneutic process emphasised for IPA (Wagstaff, Jeong, Nolan, Wilson and Tweedie, 2014), alongside noting initial thoughts and non-verbal reflections after interviews. Reflections aided acknowledgment of tendencies to automatically apply psychological models, due to the nature of Clinical Psychology training. The journal also enabled awareness of salient emerging themes (such as those relating to women's roles), which helped bracket assumptions for subsequent interviews and recognise the double hermeneutic.

Following initial noting, emergent themes were drawn from individual transcripts, then clustered to generate superordinate (overarching) themes (Appendix L). This involved consideration of common experiences among emergent themes, supporting the derived superordinate themes (Smith et al., 2009). Reflections continued to be logged alongside this (Appendix L).

Interviews were analysed independently and then explored across accounts (Appendix M-O). Table 3 outlines the analytic process for the development of one main theme derived from an individual transcript, through the initial quotes and coding (derived via initial notes). Superordinate themes for each case were explored as to whether there were similar or related experiences within every other case (Appendix M).

Table 3.

Example of analytic process from one transcript to a main theme.

Quote	Coding	Reflection	Emergent theme	Subtheme	Main theme
"Quite frightening, erm, because you wonder what you've done wrong and you can't think of a single thing that you've done…if you can't think of something that you've done wrong then there's no way that you cannot do it again"	Powerlessness to prevent anger as she can never predict the trigger. Sense of being able to get managing moods right "there's no way"; perhaps trying not to upset spouse is experienced as an unachievable task?	Researcher sense of confusion, powerlessness and non-direction when listening, recognising that this would have been anxiety-provoking. Impression of "what do I do now?"	Confusion and powerlessness in response to newly observed anger	Balancing dilemmas within muddled challenges	Lost and trapped in an unsolvable maze

Across all cases, 40 superordinate themes were identified. If present within five or more interviews (over half the accounts), they were considered potential cross-cutting themes (Appendix M). Together, they were considered in relation to common aspects of experience and grouped through subsumption; where a superordinate theme for an individual participant became a main theme, due to reflecting similar experiences across accounts (Smith et al., 2009). This generated subthemes across accounts which were then grouped through commonalities into main themes (Appendix N-O).

Once complete, the results were discussed with the PPI team member, to determine whether someone with lived experience related to the emerging themes. Participants were then provided a summary of the findings (Appendix P). Feedback was received from one participant who felt that the results closely emulated their experience, supporting the intention to keep themes closely embedded within accounts (Smith et al., 2009).

Results

Four main themes were derived across accounts, presented in Table 4 alongside the accompanying subthemes. The below paragraphs address key aspects of each main theme. "In the moment" experiences of realisation are presented within the first two main themes, while the second two refer to realisations of longer-term change and reflections over time.

Table 4. Main themes and subthemes.

Main theme	Subtheme
Pushed apart by brain injury	Navigating a changed marriage
	Being alone in a partnership
Bravery to face lingering awareness and emotions	Facing the boundaries of being a wife
	Holding the emotion of unexpected change
Lost and trapped in an unsolvable maze	Trapped and isolated from the life that once was
	Balancing dilemmas within muddled challenges
Unfolding events leading to new perceptions	A realisation of personal acceptance
	A gradual shift in perception of self and other

Pushed Apart by Brain Injury

This theme aimed to capture participants' realisation of changed emotional connection; present within seven accounts. Participants reported realising they were no longer able to rely on their partner, an experience of being both married and alone:

> You have to deal with anger and well almost a tantrum….it's a lonely existence…you can't feel secure anywhere (Tina).

Tina's emphasis on "tantrums", a phrase commonly used for young children, may reflect a role change towards feeling like a parent, with infantilising language suggesting disconnection. Her feelings of insecurity may reflect forced distancing from a former partnership. Within this, others reported the feeling of their marriage having ended:

> That is like, the marriage has ended….the whole axis has changed, I'm now his carer, and he's like a dependent, that's not a partnership anymore. (Hazel).

Through her spouse's dependency, Hazel expresses a transition from wife to carer, which contradicted expectations of how marriage "should" be experienced, enhancing emotional separation. The role of "carer" removed the reciprocity that was previously in their relationship. This is highlighted further through seemingly small, habitual interactions being lost:

> I miss it a lot….somebody just saying, putting their arm around you and saying ‘cor that was a lovely meal’, you know a few little things really that, have gone. (Florence).

Subtheme: Navigating a changed marriage.

Participants were placed in a position of finding ways to continue a changing marriage:

> I used to go and say goodnight to him and there was nothing there....now I’ll say to him…can I have a hug and he sort of giggles (Sheila).

Sheila describes a potentially lonely and unexpected experience, however her continued attempts to encourage a response from her spouse shows determination and hope for the pre-injury life to return. She also described working against being pushed apart, possibly reflecting an urge to problem-solve when facing disconnection:

> I still felt that I was striving towards getting him better and we’d have a future (Sheila).

The demands of providing physical support contributed to realisations of permanent change to their marital lifestyle. At times, this was evaded, with realisation being both described as something “that creeps up” (Hazel) yet may be experienced with emotional intensity:

> Just suddenly something hit me and I just went into overload I mean there was no nothing in particular that seemed to trigger it there was it was just natural progression....I'd been pushing myself too hard (Sheila).

Interestingly, one theme contrasted with the experiences of the majority; one couple formed a closer relationship following ABI. For Alice, relief and acceptance were prominent, alongside focusing upon what remained the same post-injury:

> If this is as good as it gets that's good enough for me….the essence, the essential [name] is still here, he might be impaired… but…he's still managing to make me laugh.... (Alice).

Recognition of past memories may contribute to finding acceptance, emphasising historical relationship commitment, which could make the potential to be "pushed apart" appear manageable. Alongside this, Florence uses her positive shared history with her spouse in a way that appears to find a sense of peace.

> All of the lovely things we have done is great, and if we never do anything again that's fine (Florence).

Subtheme: Being alone in a partnership.

Participants experienced a realisation of being both with and without a partnership. Some years after injury, they became aware of what may benefit self-care, yet this was affected by no longer feeling like a "typical" couple. This realisation was one of reduced social support and personal isolation:

> It's very lonely and you know but I've got to be careful who I say it to because not everybody understands and they all think I'm being very selfish (Sheila).

The above quote emphasises beliefs around how a caregiving wife "should" appear, placing boundaries upon confidence and expression. Participants questioned their next step to finding personal fulfilment, yet recognised the need to do so. The quote below represents this dilemma regarding socialising independently:

> …I was humming and harring about it, and then I thought, no I really would like to go, erm, that was so nice, I mean when I go to [place name] that was lovely, to just pull up at a restaurant and get out and go in, without worrying are there steps, where's the toilet, is it accessible, erm, all the things you have to work out. (Hazel).

Bravery to Face Lingering Awareness and Emotions

Within seven accounts, participants described bringing realisations on the periphery of awareness into acknowledgement; an emotionally evocative undertaking. In the following quote, Maureen describes how she was able to consider leaving her husband post-injury:

> My sister….she said you know you just you don't need to live like this you know you know you don't deserve it really….I wouldn't say I enjoyed my

> life but I wasn't thinking of leaving him….I think I felt quite empowered I think it was a very brave decision and I think I felt good daring to think it. (Maureen).

Maureen's recognition that she wasn't enjoying her life suggested that she may have been holding back from a potentially life-changing realisation. Her feeling of "empowerment" and "daring" elicit a sense of bravery through facing avoided thoughts, potentially enabled through receiving empathy.

Subtheme: Facing the boundaries of being a wife.

Radical change following injury left participants few options but to persist with their new roles, perhaps prior to acknowledging the emotional repercussions. This elicits a sense of comprehending each change "in the moment", and persisting nonetheless:

> You're like a duck on the water and legs are going mad underneath and you've got to keep like a calm serene top half going (Tina).

The feeling of being settled within a married role was also overturned upon realisation. For some, this led them to notice boundaries within the definition of being a wife:

> I'm the home maker…when I realised that maybe he might leave me or subsequently did I not want to stay….what a fool I was to have bought into that sort of married life…..women get a bum deal (Maureen).

Here, beliefs and values of marriage are challenged alongside an experience of disempowerment and self-criticism (“fool”). Her prior commitment to marriage may have elicited an experience of feeling trapped, and that supporting a spouse as a woman may intensify post-injury life.

For others, the security of "wifehood” is challenged. Participants frequently reported challenges with taking on household roles previously completed by their spouse, but for some this generated a sense of lonely and isolated self-reliance; an uncomfortable experience:

> It's down to me all the responsibility and every decision is down to me and I get very tired of it....I’ve never lived on my own.....I went from home I worked at [place name] which was where I met [name] and then we got married. (Sheila).

Subtheme: Holding the emotion of unexpected change.

Participants experienced a demand on them to tolerate emotions connected to their spouse’s injury. Iris described the “feeling of unbelief” regarding the early stages of injury; a twist on language summarising non-readiness to attend to realisation of change. To face realisation, she described revisiting a strategy from a previous bereavement:

> It’s almost like you go up to the pain and you pat it, and then you run away like mad, and then when you are feeling a bit stronger, you go back and you do it again and very, very gradually over time, that, you learn to live with

> it....you know you recoil from it, w-what it, you're sort of acclimatising yourself to it, you know, you can't deal with all that in one go, you'll go crazy. (Iris)

"Recoiling" from pain emphasises the enormity and personal control around facing distress associated with realisation of changes. The physicality of Iris' description emphasises the fear of the emotion being overwhelming; that this is an entity that needs to be approached with care and a potential fast escape. There is great personal resilience from "acclimatising" oneself to the pain and being ready to do so, which may be accompanied by curiosity or responsibility regarding feeling the need to approach realisation.

A bereavement-like experience remained particularly prominent for participants, reiterating the paradox of experiencing both the loss and presence of her spouse:

> Well it's on-going it's well it's all the things that you would feel had somebody have died and nothing, in the same way as if somebody has died there's nothing you can do to bring them back. (Tina).

Repetition of "if somebody had died..." may further reflect the confusion of this paradox. For Tina, this realisation was repeated with events that linked to the injury, leading her to once again sit with her initial bereavement.

> We were told....see what he's like in a year see what he's like in two years and so you reach these milestones and although you do see some

> improvements....you're never going to get back the person that you had and that's the hardest thing. (Tina).

Lost and Trapped in an Unsolvable Maze

In realising the implications of change, six participants reported struggling to make sense of a feeling of permanency and being trapped. Expressing this appeared challenging at times, and elicited use of metaphor:

> It's a vicious circle although it's not actually a circle.... (Tina).

Here, Tina seeks to express re-lived realisations as a harsh yet predictable pattern, yet notices that life is not this predictable, evoking a sense of insecurity. Participants also described hope for further recovery, yet were stifled by the realities of their spouses' injuries:

> Whilst there's hope, there's also a fear, fears a bit of a strong word but there's also a thought that nothing's going to change (Florence).

The fear Florence mentioned evoked a sense of powerless and sense of an unsolvable personal, tentative position between hope and fear.

Subtheme: Trapped and isolated from the life that once was.

Participants reported a realisation that they had become stuck in an adjusted lifestyle to accommodate post-injury life. Grace expressed the frustration of this as like looking out at the world rather than being in it:

> I feel like a goldfish swimming round in a medical bowl....there's never no release you know... (Grace).

This was accompanied by a sense of relentlessness, later described as a "regime". Within this, participants also established commitment to their spouses, perceiving the boundaries of the "maze" as a personal choice:

> You still make that decision to stay, you're putting yourself back in the trap (Tina).

Potentially, participants' attempts to define their "trap" through metaphor aided their sense making of this experience.

> You have a hole like a…waste paper bin or something of screwed up pieces of paper which are all the rubbish that you've had to deal with and sooner or later it gets it's overflowing and you can't you get lost underneath the piles and piles of paper and you you're not there anymore the person you were before has completely changed. (Tina)

Tina's metaphor expresses a sense of how her day to day life creates a build-up of unwanted tension, described like rubbish, which spills over and swamps her sense of identity. It captures the confusion of struggling to find a predictable pattern in post-injury life, and losing personal identity through persistence with a potentially endless, insurmountable personal load. Potentially, difficulties finding predictability may add to a sense of confusion and repetitiveness of realisation of change.

Subtheme: Balancing dilemmas within muddled changes.

Participants described opposing expressions indicating a dilemma or internal swing between positions:

> Accept that appointments don’t always work, shunts don’t always work, umm, yes there’s hassle in life....we’re lucky to be here (Florence).

This quote describes acceptance of emotionally difficult realities, however maintaining these views long term may be feared or personally damaging. Florence balances this with a sense of luck, perhaps to counteract the challenges on the opposing side of this dilemma.

Other participants also experienced uncertainty between two positions of being hopeful for further recovery yet aware that this may be unlikely, and adopted a stance in-between these:

> To be honest at that point you daren’t think too much because you don’t want to have two and two making five and, you’re overthinking it and thinking it’s worse than it is… you don’t know whether or not it’s going to change, you just don’t know (Iris).

Here, the unknown is less threatening than overthinking, yet tolerating uncertainty is uncomfortable. There is an underlying awareness of needing to face the “truth”, yet fearing the personal consequences of realisation. Overall, accounts reflect conflict in manage the dilemma between the feared “truth” and the unknown as post-ABI changes emerge.

Unfolding Events Leading to New Perceptions

Within six accounts, participants expressed a gradual or “unfolding” experience of realisation of change, generated through multiple experiences:

> That sort of dawn on you (Hazel).

They continued to experience realisations of change over time, with different attached meanings:

> As time has gone on...he’s improved, er and you’ve seen him being perfectly okay with somebody else, then that, ‘he can’t help it he’s got a brain injury’ becomes, wears a bit thin... (Iris).

Here, Iris highlights a personal change towards seeing ABI as explaining all her spouses’ actions; the personal meaning adjusting to the realisation of his self-control.

Subtheme: Discovering acceptance

“Acceptance” was prominent across accounts and seemed to accompany the emotional impact of realisations of change, but held subtly different meanings for individual participants. For some, acceptance meant determination to cope with distressing emotions from realisation of change:

> I never thought oh what's he doing to my life, I just accepted that we're together as a couple and whatever come, have gotta be faced (Grace).

Others reported acceptance to mean finding a new life together alongside injury sequalae:

> I have to remember that, that the times when I get things wrong, I'm not doing it on purpose, just as [name] not doing it on purpose erm, it just is what it is and we just have to muddle through (Alice).

There was a sense of powerlessness however, where acceptance appeared the only option:

> I told myself if you fight it, that's not going to change, just going to make life worse for both of us and that's not going to alter anything, we're still going to be in this situation (Grace).

In a similar way, finding acceptance also seemed to enable a new perception of normality:

> What was normal before, is gone, this is the new normal, it's not necessarily the only normal, but as things improve which hopefully they will continue to do, another normal will come, and then hopefully another one after that, but in the meantime, this is the normal that you got. (Iris).

Iris' "new normal" indicates a perception towards continuity within the context of change, and that finding their "normal" created sense of peace with the present whilst allowing for further change. Having found this perspective, future realisations may be experienced differently to those nearer the onset of injury.

Subtheme: A gradual shift in perception of self and other

Over time, participants reported a change in their perception of both themselves and how they relate to others:

> I surprised myself most I, suddenly I could assert myself more, you know, because when you're fighting someone else's corner sometimes that's necessary, you do it for them perhaps where you wouldn't have done it for yourself (Grace).

Alongside this, Grace described an initial self-critical feeling when realising her own assertiveness with the services supporting her husband. She attributed this to the role of caregiver, aiding acceptance. Further accounts report realisation of the self in terms of changes to perceived resilience:

> I don't think I perceive myself as anything really….they also say stupid stuff like you know what doesn't kill you makes you stronger I don't actually agree with that I think sometimes what doesn't kill you makes you weaker.... (Tina).

In contrast, Maureen described:

> I am quite an independent person and I think it was it was very hard to be under the control so it was connecting a bit with yes with myself a really you know feeling empowered (Maureen).

From these two quotes, the self can be seen as “weaker” (Tina) or “empowered” (Maureen). While taking differing directions, both reflect recognition of a changed sense of identity, evoking a drive to move forward (Maureen) or sense of weakness and exhaustion from trying to make sense of post-injury experiences (Tina).

Returning to a former parental role, with associated challenges, was also recognised:

> It’s like a twenty stone two-year-old having a tantrum sometimes (Hazel).

Conversely, this familiarity may have elicited a sense of amusement or light heartedness:

> I probably laughed at the time (laugh) thought oh I’m a mum again (Grace).

Furthermore, strategies taken from parenthood may have been applied to post-injury life, potentially providing participants with a response to managing the unknown:

> When they’re babies, they’re totally dependent on you, and erm, you gradually give them back to themselves as they grow up….I sort of did that

> with [name] (Iris).

Overlapping subthemes

While subthemes were grouped depending on their subjective connections to each other, alongside quotes and researcher reflections, some subthemes may be considered to overlap across these groups, as demonstrated in Figure 3.

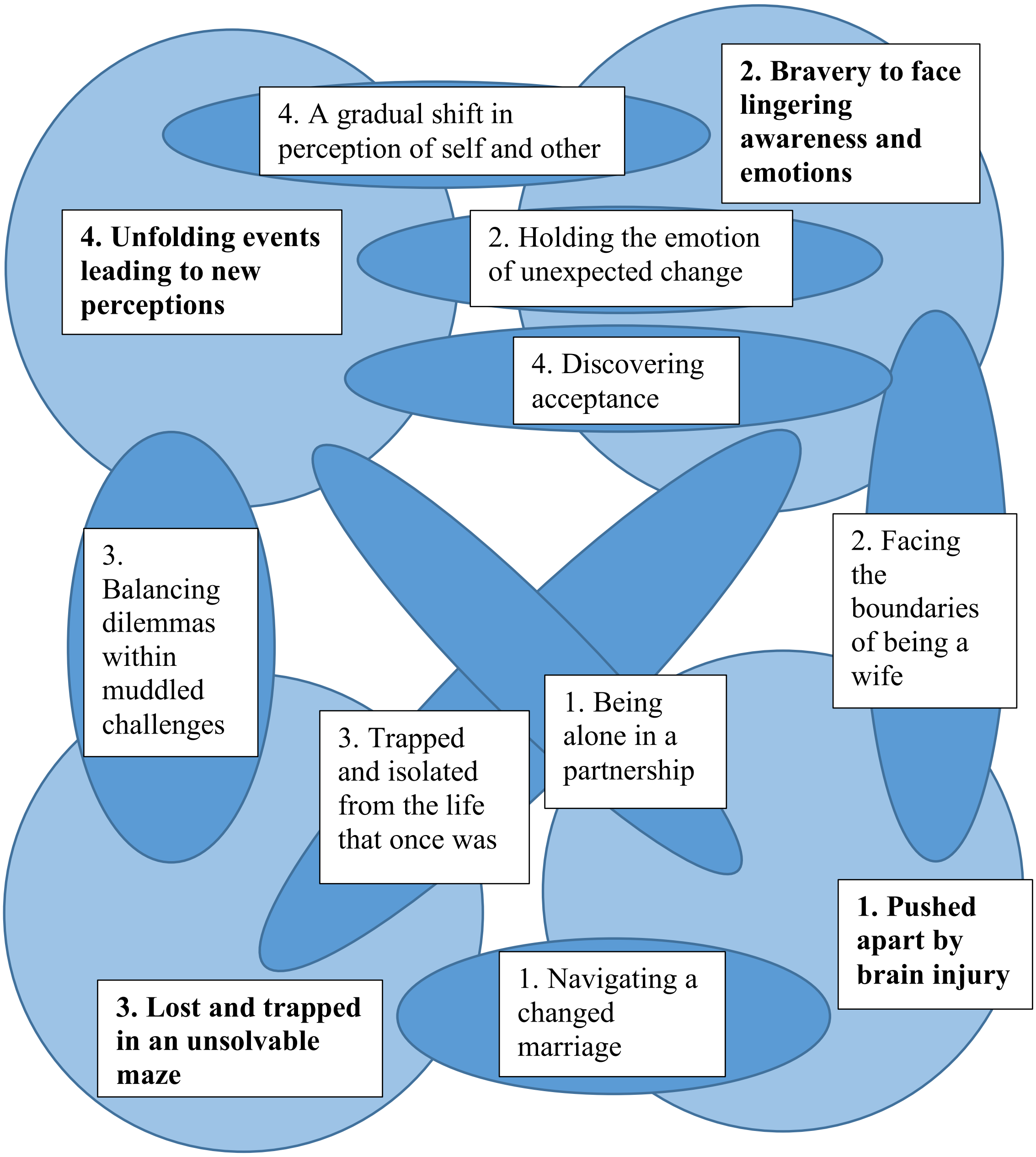

Figure 3. Thematic map to illustrate the four main themes with subthemes, alongside plausible overlaps between subthemes and main themes for which they were not originally grouped.

Figure 3 highlights the interlinking nature of the subthemes, which while part of one main theme may share smaller connections with others. For example, the feeling of being “pushed apart by brain injury” may bring awareness to the "boundaries of being a wife" and the need to face boundaries that appear unpleasant but were not recognised or experienced different pre-injury. Similarly, facing the feeling of being trapped may be likely to require the experience of "bravery". While the four main themes separate different aspects of experience, "bravery to face lingering emotions" can be seen to hold the most overlap of subthemes from other main themes. Plausibly, this theme could be perceived as a particularly prominent result of this study.

Conclusion of results

Multiple experiences of change were seen to instigate ongoing realisations for years following ABI. For some, there was a point of feeling "built up" prior to making sense of post-injury experiences. Participants experienced parallels with previous experiences of bereavement alongside a gradual unfolding of experiences generating different realisations, which may be interlinking, relived or changeable. These included realisations of change around marital roles and feeling trapped within post-injury life, experienced as a monotonous "regime" for some yet lacking the safety of certain predictabilities for others. Changes within the self and relating to others were also prominent, alongside returning to approaches used to manage historical realisations.

Participants appeared to try and find a balance between tensions, uncertainty and dilemmas. These included hope and fear, their own needs and that of their spouses, a sense of duty whilst feeling trapped, and striving for change yet acknowledging personal acceptance. Participants also felt alone in a partnership, yet maintained persistence and hopefulness for further change.

The four main themes emphasised experiences of disconnection, concurring with recognition of role change and a loss of partnership. Notably, roles mirroring parenthood could be challenging yet were not always experienced negatively, whilst realisation of aspects that had remained following ABI contributed to a closer romantic relationship.

Participants also experienced unsolvable boundaries within post-injury marriage; they tried to solve “in the moment” challenges whilst personally managing their sense of permanency. This internal and endless dilemma could be difficult to make sense of and some participants used metaphors to help communicate this.

Bravery was important in allowing participants to realise changes; a prominent main theme which drew some connections across other subthemes (Figure 3). The emotionally laden nature of this included disbelief, reliving realisations and “daring” to realise personally aversive aspects of change. Newfound questioning occurred around marriage, with accompanying feelings of personal boundaries imposed through their perceived duty and responsibility as wives. Furthermore, holding realisation at bay until feeling personally ready may allow some meaning making strategies to be developed, for example through metaphors or recognising similarities to previous experiences.

Discussion

This study sought a “deep”, subjective interpretation of the personal meanings related to wives’ experiences of realisations of change, adding to the literature by taking a specific, previously unexplored focus. The main themes were “pushed apart by brain injury”, “bravery to face lingering awareness and emotions”, “lost and trapped in an unsolvable maze” and “unfolding events leading to new perceptions”. Commonalities across accounts captured the nature of how realisations come to pass, often involving an “unfolding” of multiple experiences over time. A multitude of personal tensions and dilemmas was also acknowledged, such as anticipation of impending realisation and tolerating the unknown.

Thematic similarities exist across studies. Bodley-Scott and Riley’s (2015), recognition of the role of perception of injured spouses’ personal control could form part of the “unfolding” experience of realisation, especially where non-injured spouses notice newfound areas of control. Furthermore, relationship changes emulating a parental role rather than spousal partnership mirrors the findings of Gosling and Oddy (1999).

Brunsden et al. (2017) include a main theme of imprisonment, similar to the finding “lost and trapped in an unsolvable maze”, with further thematic overlaps relating to hope and experiencing the unknown. Brunsden et al. (2017) report a male sample with injured wives, suggesting experiential commonalities across gender. Questioning marital roles however, remains specific to this study’s sample of women, with sociocultural context potentially contributing to women’s roles within the lifeworld. Additionally, the theme “compassion without self-compassion” (Brunsden et al., 2017) indicates subtly different experiences to the themes of this study, potentially reflecting gender differences. Given the non-comparative nature of IPA however, only tentative suggestions may be drawn.

Within this study, accounts referred to finding “acceptance”, a “new normal” and noticing personality traits that have remained post-injury. While these lie within the context of change, they indicate a striving for continuity previously noted by Whiffin et al. (2017). Realisation of remaining aspects of pre-injury life add another dynamic to experiencing realisation of change, and whether there are experienced similarly when noticed alongside recognised continuity could be considered. Here, change went beyond ABI impairments alone, for example through participants’ questioning marriage and observing self-change. This avoids yet reiterates the potential limitations of imposing change as a phenomenon (Whiffin et al., 2017), if applied in a binary way.

Participants’ experiences portray multiple interpersonal and intrapersonal experiences of discrepancies including realisation of changed interactions within their pre and post-injury relationship, of sitting between two opposing positions of knowing a potentially difficult truth or sitting with the unknown, and between concepts of the self (wife as an equal partner and wife as carer). This is consistent with a systemic application of the Y-shaped model (Gracey et al., 2009). These may be managed in unsustainable ways, such as continuously striving for recovery or avoiding realisation of feared potential change. The meanings held by those struggling to come to terms with post-injury demands may be that such adjustments are personally unacceptable, preventing integration into potential personal beliefs or an experience of resolution.

Interestingly, the current study also demonstrates a light heartedness to some realisations of change, along with one couple being brought closer together. It is therefore important that researcher expectation from prior results do not hinder the recognition of the possibility of optimistic outcomes and the experiences or strategies leading to these. This has been reflected in traumatic growth research (Hallam and Morris, 2014).

Methodological Considerations

Quality checks included Yardley's (2000) characteristics of "good" qualitative research, which are considered useful principles, albeit practically non-specific (Smith, 2003). The design demonstrated alignment between the underlying epistemology, research question and method, while the results conveyed unique subjectivity and commonalities of experience which may have clinical applicability. Sociocultural factors such as gender were also noticed. The reflective journal aided transparency around these aspects, whilst analysis accumulated these interpretations across accounts. Furthermore, a member of the research team had lived experience of their spouse surviving ABI, and provided PPI support in generating generate a meaningful topic guide and providing agreement between the main themes and lived experience, supporting consideration that analysis was successful and relatable.

Given the quantity of data over three months of analysis, it is difficult to definitively conclude data saturation. O'Riley and Parker (2010) however, note that saturation is an inappropriate quality marker for many qualitative studies, supporting consideration that the current results are of sufficient quality. Furthermore, upon completion it was perceived unlikely that any uncovered themes would be prominent enough to change themes across accounts. The COREQ (Tong, Sainsbury and Craig, 2007) was followed to ensure reporting quality (Appendix Q), due to providing a consolidation of established checklists for qualitative research publication.

In considering limitations, the COREQ (Tong et al., 2007) indicates that returning transcripts to participants for checking may have increased interview clarity prior to analysis. Piloting the topic guide may have also helped achieve this, but would have led to a legitimate account being excluded from analysis, losing available data.

Another limitation regards participants descriptions were relied upon to gather information on injury type and the resulting impairments, which cannot provide an objective, standardised account. While IPA does not aim for generalisability (Smith et al., 2009), having further medical details may have eased clinical application. Nevertheless, the recruitment process accessed those who had experienced injuries significant enough to seek ongoing, whilst Table 2 suggests that all could be perceived to have long-term consequences of ABI.

A 23-year age range was present within the sample, reflecting different stages in the family life cycle (Rolland, 1987), and indicating some heterogeneity (Smith et al., 2009). Research has also focussed on later life separately from middle-age (Gosman- Hedström & Dahlin-Ivanoff, 2012), suggesting age-specific experiences and potentially explaining observed variation during analysis. Notably though, given that realisation of change has not been explored before, broad, mixed gender inclusion criteria was applied, however only married women opted in. While this improved homogeneity and the analysis allowed for each participant to be seen as unique (Smith et al., 2009), male experiences remain unrepresented (Brunsden et al., 2017). Furthermore, the recruitment strategy meant that all participants were seeking help when they took part. This may have contributed to the expression of losses and challenges within the results, as they may have been seeking support for these. Consequently, the experiences of wives who are not seeking or receiving professional involvement were not collected.

Implications

Experiences of realisation of change within the self are identified as part of the “ripple” effect following ABI, including the questioning of marriage and their relationship. This study explored beyond specific ABI-related changes to consider self-change within the non-injured spouse, questioning relationship roles and dilemmas around facing difficult realisations. This relates to family systems theories, in considering that parts of a system will adjust in response to each other in a homeostatic manner (Verhaegue et al., 2005), however within the context of brain injury, this may be extremely challenging (such as in Yeates et al., 2013), leading to the need to develop a “new normal”. The idea of a “new normal”, a direct participant quote here, has been previously considered in a thematic analysis exploring multigroup family therapy following ABI (Couchman, McMahon, Kelly and Ponsford, 2014), demonstrating further prominence across accounts. The groups led to a sense of connectedness, identity and increased knowledge for families, supporting their definition of a “new normal”.

In the current study, the “new normal” summarised the experience of one family member, rather than a group. In further considering the Y-shaped model, achieving a “new normal” as a family group may help prevent several family members trying to resolve personal discrepancies in different ways, potentially exacerbating them (Bowen et al., 2010; Gracey et al., 2009). This has clinical implications around engaging key family members in considering what is “normal” for them post-injury and separating this from the expectations of pre-injury life. Park’s (2010) model of meaning making is also relevant here, where addressing personal beliefs (such as the belief that they need to strive to re-achieve pre-injury life) could aid a sense of acceptance.

Further links to applied models include changes to attachment due to negative interactional patterns (Yeates et al., 2013) potentially having a two-way relationship with the experience of realisation of change, such as being “pushed apart by brain injury” and feeling trapped. Spouses may cope with these experiences by adopting a more withdrawn position within their relationship (Yeates et al., 2013), due to being unable to express themselves as they did pre-injury.

Furthermore, participant experiences suggest that realisations are changeable and occur continuously over time, suggesting a need to revisit assessments potentially years on from ABI onset. Initial realisations, experienced changes and perceived wellbeing at the point of service contact is likely to be a temporary perspective, developing over time.

Suggestions for Future Research

In addition to the gap around male experiences, prior research has focused on specific changes within the injured person, rather than the wider implications of lifestyle change for a family impacted by ABI. Given the experiences of realisation of self-change, further qualitative research focussing on this area may extend the current study. Furthermore, given suggestion that younger families are more vulnerable (Verhaegue, 2005), the age range of the current sample and many background studies (Gosman- Hedström & Dahlin-Ivanoff, 2012; Gosling and Oddy, 1999) have not included younger adult participants; another gap for future research.

Notably, the reviewed literature (Anderson et al., 2017; Brunsden et al., 2017; Whiffin et al., 2017; Gosman- Hedström & Dahlin-Ivanoff, 2012; Brody-Scott and Riley, 2015; Goodwin et al., 2014; Whiffin et al., 2014; Gosling and Oddy,

1999) and current results identify themes pertaining to the experiences of spouses following ABI with a multitude of themes that both diverge and overlap. An important next step would be an in-depth review using qualitative synthesis. Additionally, this study has suggested a gradual nature to experiencing realisation as singular events unfold. This may indicate an underlying process, and a longitudinal, potentially constructionist (Charmaz, 2008) Grounded Theory approach could generate a clearer perspective of this from similar data.

Summary

In exploring realisations of change, participants experienced an emotional separation from their husbands, leading to questioning beliefs around their marriage and relationship. Participants reported feeling trapped in their post-ABI lifestyle, and experienced dilemmas around the permanency of this and working towards further improvements. Realisation of change required great bravely to acknowledge feared and challenging emotions. There were also shared experiences of gradual realisation across multiple events, continuing long after the onset of ABI. Future projects could extend this study, potentially using a process-orientated approach such as Grounded Theory. Awareness of the potential for similar experiences within clinical settings may help assess and support the wellbeing of non-injured spouses. Overall, it is hoped that this study provided an interpretation that resonates with those experiencing similar circumstances.

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Declaration of interest

The authors report no conflict of interest.

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Chapter 4.

Extended Methodology

Chapter 4

Extended Methodology

This chapter provides further consideration of the methodological approaches to conducting the systematic review and empirical study. For the systematic review (Chapter 1), definitions and search terms are considered. For the empirical study (Chapter 3), the philosophical underpinnings; ontology and epistemology, are defined, alongside further details of the procedure and outcomes. Recognising and owning researcher position is considered an important quality marker within qualitative research (Biggerstaff and Thompson, 2008), and a reflective journal was maintained throughout all parts of the study. Extracts from the reflective journal are included to demonstrate this process.

Systematic Review

Definition of "Neurobehavioural" (NB).

McMillan and Wood (2000) define the term "neurobehavioural" to be the "constellation" of long-term cognitive and behavioural changes following ABI, leading to impaired social functioning. It could refer to any neurological change impacting behaviour, yet may be difficult to define within a family context. Family members are likely to be responding to the interpersonal aspects of NB change, linked-to yet distinct from the results of psychometric assessments. Some studies have used this term in such a manner (Douglas and Spellacy, 1996; Ergh, Rapport, Coleman and Hanks, 2002 for example). Consequently, the systematic review focussed on the overt changes within the injured person, which would be directly experienced by family members (rather than psychometric test scores). This aimed to narrow the broad inclusion of all possible NB variables, which would have generated difficulties comparing studies.

Search Considerations

A PICO format without the comparison criterion was used, due to the relationship of interest being between two variables within one group (NB and FF within a sample of families affected by ABI). Consequently, the research question and designs of available studies negated use of the most rigorous application of the Preferred Reporting Items for Systematic Review (PRISMA) guidelines (Mother, Liberati, Tetzlaff and Altman, 2009) (Appendix B).

Searches were provided by EBSCO and used a Boolean model. Population terms were set to be included in the abstracts of articles retrieved for "stroke" and "brain injury", due to retrieving an extremely high quantity of non-related studies when whole articles (rather than abstracts) were selected (see Chapter 1). Exposure terms were searched throughout whole articles as some studies may have measured this aspect as part of a wider assessment.

Quality Assessment

The following criteria aimed to ensure consistency across reviewers:

- Studies were considered "fair" quality if they used a cross-sectional design and scored "yes" for six or more items of the Quality Assessment Tool for Observational and Cross-Sectional Studies (QATOCCS) (National Lung, Heart and Blood Institute, 2014). Six represented at least half of relevant items for most studies (items 12 and 13 had limited applicability to those with cross-sectional designs).
- Studies were considered "poor" if they scored five or less "yes" ratings.
- Studies were considered "poor" if they appeared to have severe methodological concerns despite six or more "yes" scores.

- Only studies using a longitudinal design with more than six “yes” scores received a “good” rating.
- Studies were rated “no” for item 5 (Appendix C) unless power and sample size justification had been addressed, however it was recognised that multiple regression and correlational analysis would also indicate effect size, as requested by the QATOCCS.

Furthermore, lack of validated measures for NB impairments is well recognised (Groom, Shaw, O’Connor, Howard and Pickens, 1998; Carnes and Quinn, 2005). Consequently, studies were rated a “yes” on item 9 (Appendix C) if they have used an established measure and acknowledged reliability (for example the GHHQ, Anderson, Simpson and Morey, 2013). This approach differentiated between “poor” studies relative to all research reviewed, rather than repeatedly identifying a well-acknowledged measurement difficulty.

Empirical Study

Philosophical Considerations

Ontology refers to the definition of knowledge, and its perception relative to human awareness (Braun and Clarke, 2013). On a continuum, “realism” perceives “truth” as an observable phenomenon separate from observer experience, and an assumption of quantitative enquiry (Avis, 2005; Mandill, Jordan and Shirley, 2000). Alternatively, “relativism” refers to the subjective construction of knowledge, ever-changing across contexts (Cromby and Nightingale, 1999 cited in Braun and Clarke, 2013) and suited to qualitative exploration. Typically, Interpretative Phenomenological Analysis (IPA) adopts critical realism (CR), allowing the presence of “true” reality yet acknowledging that this is experienced through subjective perception (Braun and Clarke, 2013). CR brought a biopsychosocial perspective into qualitative research, perceiving the body as being an objective "truth" which is subjectively experienced in relation to the individual and social self (Williams, 1999). By incorporating embodiment (Van Manen, 1990), this makes CR particularly appropriate for use in research exploring disability.

Epistemology provides positions of what can be considered scientific knowledge (Braun and Clarke, 2013). Along a similar continuum to ontology, quantitative methods take a positivist stance (Avis, 2005), whilst constructionism perceives knowledge to be generated through the complexities of specific contexts (Braun and Clarke, 2013). Contextualism, on the other hand, continues to seek the truth in a context dependent manner (Mandill et al., 1999), without assuming a single reality or method (Tebes, 2005 cited in Braun and Clarke, 2013).

CR is sometimes seen as overarching both ontological and epistemological positions (Fletcher, 2014). It is assumed that "reality" would occur regardless of researcher perception, whilst recognising causal mechanisms leading to interpreted observations (Fletcher, 2014). The application of this to research method forms the contribution of CR to epistemology (Fletcher, 2014).

Differing philosophical positions makes methodologies difficult to compare due to researchers' perceiving knowledge as different concepts (Braun and Clarke, 2006). ABI research generates a dilemma, where medical interpretation of the injury will be explained within positivist stance, whereas relational aspects, while influenced by neurological change, lend themselves to social constructionist interpretation. Consequently, CR provides a balanced perspective. By focussing on "in the moment" experience, IPA may capture where these realities intersect; the neurological changes resulting from ABI, and the impact on the individual and family making sense of this within a sociocultural context.

Interpretative Phenomenological Analysis (IPA)

The research question (Chapter 3) defines exploration of experience, lending itself to phenomenological philosophy and potentially touching on several dimensions of the lifeworld (Van Manen, 1990). Consequently, IPA was applied.

IPA was developed in the mid-1990's (Biggerstaff and Thompson, 2008) and interprets lived experience using an idiographic focus to phenomenological enquiry, alongside acknowledging hermeneutic processes (Wagstaff, Jeong, Nolan, Wilson and Tweedie, 2014). "Idiographic" refers to the particular, in contrast to population-based exploration (Pietiewicz and Smith, 2012; Smith, Flowers and Larkin, 2009). This involves studying a small sample and comparing the analysis of individual accounts (Pietiewicz and Smith; 2012). Phenomenological research seeks to capture the "lifeworld", the lived world of different human experiences (Van Manen, 1990). Four lifeworld themes theorised as common across human experiences include lived space, body, time and human relations (Van Manen, 1990), with a multitude of personal dimensions adding further connection with the world (Galvin and Todres, 2013; Shaw, Smith and Hiles, 2018). Furthermore, the "lifeworld" is conceptually seen as both beyond the limits of perceiving the body as an objective "thing", and accumulated through the experiences of others as well as the self (Landgrebe, 1973).

Phenomenology aims to capture the distinct ways experience is consciously acknowledged by an individual (Pietkiewicz and Smith, 2012). Early transcendental phenomenology is described by Husserl as the study of "being", identifying the structures of individual experience (Larkin and Thompson, 2011), yet may reflect conscious awareness of the perceived experience, rather than accessing the experience itself (Landgrebe, 1973). Husserl's phenomenology has been considered too abstract to apply to a research method (Avis, 2005), and IPA has drawn upon the definitions of phenomenology by Heidegger and Merleau-Ponty, who perceive people as continuously embedded in “lived time” (Smith et al., 2009). Such expressions cannot be separated from personal embodiment however, holding phenomenological findings within their derived context (Larkin and Thompson, 2011).

Hermeneutics is held in mind throughout IPA. This refers to researchers attempts to understand another person’s experience through active involvement (Pietkiewicz and Smith, 2012), for example coming into the study from a particular profession or background (Van Manen, 1990). Consequently, participant’s “lifeworlds” are interpreted by the individual and expressed through language; first order meaning making (Smith et al., 2009). The researcher then interprets their explanation of this; second order meaning making. This two-step process is known as the double hermeneutic (Smith and Osborn, 2003 cited in Smith et al., 2009). Despite awareness of this, researcher preconceptions may only be realised during analysis (Gadamer, 1990 cited in Smith et al., 2009). Consequently, a continuous reflexive process is required though reflection, engagement and bracketing (Finlay, 2008 cited in Finlay, 2011; Smith et al., 2009), emphasising the active role of the researcher throughout the IPA process. The double hermeneutic was considered within the empirical study (Chapter 3), through the reflective journal and supervision with the research team.

This study also incorporated Patient and Public Involvement (PPI), as a member of the research team had lived experience of the phenomenon. This brought increased awareness as to what would form a meaningful study design and presentation of results. Following analysis, discussion with the PPI team member inferred a pathway through the experience of realisation of change, yet considered that participants may have experienced several themes at once. Consequently, considering themes in isolation represents a simplified summary, which tries to "tease apart" fluid and interchanging experiences (Figure 3).

Researcher Background and Position

In considering transparency to maintain the quality of qualitative research reports, the CORE-Q (Tong, Sainsbury and Craig, 2007) recommends explicit stating of researcher positions. This is presented here.

My own background has involved quantitative research incorporating realist ontology (Williams, 1999). In considering the ontological continuum, undertaking qualitative research required adjusting my perspective towards relativism. To acknowledge this I have approached both projects (Chapter 1 and Chapter 3) through CR. For Chapter 3, this brought the double-hermeneutic (Smith et al., 2009) to the forefront. Below is a reflective journal extract demonstrating the double hermeneutic:

> Interview took place 15 months post-injury. The incident causing TBI was told in a story-like form, with emotionally evocative imagery derived from the detail, and was communicated in a "matter of fact" manner. The interview enabled exploration of coping with realisation during early stages post-TBI, which seemed to involve finding ways not to experience realisation at times when this would not have been helpful; a surprising finding. The appointment was felt to be particularly intense when the participant realised in the interview that the experience of loss was similar to a historical, traumatic loss. (Reflective journal).

The above extract highlights my own experience of unexpected findings and emotional intensity when listening to the interview, alongside the participant interpreting their life events in relation to their own personal history.

Epistemologically, a contextual approach is adopted, acknowledging the role of context on acquired knowledge within IPA results (Mandill et al., 1999). Consequently, the applicability of findings depends on the nature of the ABI, family dynamics and participants' personal tendencies contributing to their interpretation of events. Whilst there are commonalities across experience, this underpins the purpose of IPA to understand subjective experience rather than seek generalisable conclusions (Smith et al., 2009).

Regarding the phenomenon of interest, I have personally experienced a relative acquire a brain injury. This generated pre-existing assumptions around service experiences and noticing change, which I maintained awareness of throughout the study. I also worked with vulnerable populations for a decade prior to the study, leading me to value unique experience, both contradicting and informing knowledge from formal education. As a trainee psychologist, I have supported those experiencing ongoing distress and adapted theory to work for them. Prior to the study, I perceived research as a separate aspect of a psychologist's role, and taking on a qualitative study has combined both empirical rigour alongside attempting to understand the self and other; drawing parallels to clinical work. This was captured in the reflective journal:

> Generally, I have noticed a tendency to apply research to a clinical setting whilst reading, which is likely indicative of my own clinical background and possibly familial experiences also. To some degree,

> this can make evaluating the methodology of research more challenging. (Reflective journal).

The above extract relates to the “coming together” of clinical and research experiences, aiding awareness of my tendency to apply theory rather than question it. Consequently, this aided consideration of the appropriateness of applying relevant models to the study results.

Potential Alternative Approaches.

In considering the appropriateness of IPA, the following methods were also considered:

Thematic analysis (TA).

TA identifies patterns pertaining to a topic within individual or small group accounts, leading to overarching main themes and subthemes (Braun and Clarke, 2013). Despite practical similarities to IPA, it is less adherent to philosophical concepts (Braun and Clarke, 2006). The flexibility of TA in this regard can be considered a benefit, as this can be applied to a wider variety of research questions than IPA’s focus on experience (Smith et al., 2009). Typically though, TA is considered less rigorous than other qualitative methods (Braun and Clarke, 2006). Additionally, TA encourages holding previous research in mind, to avoid unnecessary duplication (Joffe, 2012 cited in Harper and Thompson, 2012), whereas IPA would seek to bracket such knowledge (Smith et al., 2009). Given the research questions (Chapter 3), it was felt that a clear philosophical and methodological underpinning would best meet study aims.

Grounded Theory (GT).

GT emphasises social process and aims to generate a theory from the data itself (Glaser and Strauss, 1967 cited in Braun and Clarke, 2013). It can be flexible to philosophical underpinning with researchers adopting different positions within the same research design (Heath and Cowley, 2004; Charmaz, 2008; Fletcher, 2014). GT offers both flexibility and innovation, with constructionist GT tending to answer "what" and "how" questions, and more positivist stances answering "why" questions (Charmaz, 2008). Consequently, GT enables a number of further perspectives to fit researcher preference (Heath and Cowley, 2004).

When generating the research questions however, realisations of change were considered to potentially be a static moment, or set of moments pertaining to a specific event. Adopting a process-orientated approach like GT at this stage would have imposed further assumptions on the data itself, unlike IPA.

Narrative analysis (NA).

NA explores the stories people tell about themselves and tends to take relativist and social constructionist philosophical positions (Whiffin, Bailey, Ellis-Hill, Jarrett and Hutchinson, 2014). The results can resonate the meanings attached to narratives, which are maintained in full throughout the analytic process (Braun and Clarke, 2013). It was felt that the abstract nature of the phenomenon of interest may have been difficult for participants to tell in a narrative manner. Furthermore, given the range of possible experiences, exploring smaller sections of interviews meant IPA likely allowed a greater "depth" of analysis across accounts. Keeping accounts intact for NA would have risked focussing on trajectories in the data, potentially limiting interpretations in relation to the research question.

Discourse analysis (DA).

Discourse analysis explores the function of language in constructing knowledge and social processes, such as exploring sentence structure, yet includes multiple techniques depending on the research question (Glyos, Howarth, Norval, Speed, 2009).

Given the potential clinical implications for exploring meanings linked to spouse outcomes, IPA remained better suited to study aims. Smith et al. (2009) advise the initial notation of descriptive, linguistic and conceptual ideas for IPA analysis, and language was sometimes considered in relation to participant sense-making, for example list-like sentence structures. This provided further insight into experiences that were potentially difficult to articulate, aiding deeper analysis, alongside conceptual ideas. DA alone however, would have been unlikely to capture the required "depth" for the research question and aims.

Additional Methodological Considerations

Research ethics.

To address participants' right to withdraw and anonymisation of interviews, appointments provided a further opportunity to ask questions during completion of the consent form (Appendix I). Participants were allocated an identification number to quote should they wish to withdraw from the study after the interview appointment, further aiding anonymisation. Participants were given two weeks to withdraw, due to the potential for their interview to be integrated into the analysis after that time. No participants withdrew their interview. All transcripts and reports used pseudonyms.

Interviews were considered potentially emotive and participants were gently offered to take a break from the interview if they appeared distressed. They were also offered to rearrange the remainder of their interview for a different day and reminded of their withdrawal rights. While the majority of the participants were tearful at some point during the interview, all chose to continue. Appropriate clinical skills were applied to encourage participants to seek support or self-care following the appointment, where appropriate. If a physical or mental health problem was indicated, participants were advised to contact their GP. Concerns relating to safeguarding or clinical risk were shared with the recruiting service, with the participant informed. Following interviews, each participant was debriefed and provided information with the researchers details and services that may be able to provide further support (Appendix K).

Despite the above protocol, some participants may have experienced realisations of change within the interviews themselves. This was interpreted through the emotional responses of participants and sudden quantity of information in response to prompting questions (Appendix E). Potentially, this reflects how realisations of change may not be readily reflected upon without the opportunity to do so.

Recruitment.

Participants were approached by either a member of staff from one of the recruitment services or by the lead researcher through their local support group (Appendix R). Posters (Appendix S) were also used to encourage potential participants to approach staff. Participants received a Participant Information Sheet and completed a “consent to contact” form (Appendices J and T respectively). Potential participants were then contacted via telephone or e-mail to provide the option to take part and address any questions.

Participants were recruited a minimum of one year since injury. This attempted to ensure that participants had long enough to process and witness changes resulting from ABI and would be more likely to feel emotionally prepared to talk about this. In retrospect, there was a wide range of time scales (between 15 months and ten years) in the sample, which contributed to many different events from which realisations were described; both the onset of injury and experiences years later.

When initially approaching potential participants, some reported feeling they would be “betraying” their spouse if they took part. Discrepancies between internal feelings and what they feel they “should” do could have contributed to this, linking to the Y-shaped model (Gracey, Evans and Malley, 2009). This observation could also fit alongside the main themes. For example, these potential participants may have felt unable to face lingering thoughts and emotions incongruent with expectations. Consequently, those who participated may have already “faced” their thoughts and emotions enough to undergo the interview. Future studies could explore reasons why people choose not to participate in qualitative research, to broaden the voices heard through this means.

Given that realisation of change had not previously been explored, the study sought to find a general interpretation of the phenomenology of participants (Elliot, Fischer and Rennie, 1999). Elliot et al. (1999) described this as requiring a range of participants from varied backgrounds. This contrasts with the recommendation for IPA to have a “relatively” homogenous sample, to avoid difficulties drawing meaning from comparisons across accounts (Miller, Chan and Farmer, 2018; Smith et al., 2009). Other sources indicate that some variation could be useful, adding to subtle aspects contributing to a “rich” interpretation (Dahlberg, 2006). Further consideration indicates that sample homogeneity may be met along many dimensions (such as demographic or psychological) as fitting study circumstances (Robinson, 2014). The sample provided demographic homogeneity in terms of ethnic background and gender, and crucially, life-history homogeneity was attained (having their spouse experience an ABI). This phenomenon was often experienced in different ways however, due to the nature of the injury and personal factors, plausibly adding subtle variation (Dahlberg, 2006). Positively, the robustness of the analysis is supported by participant feedback (see Chapter 3).

Possible reasons why zero men participated were also considered. This could have been due to using support groups for recruitment, given evidence of gender differences in how services are accessed (Mackenzie, Gekoski and Knox, 2006).

Data collection.

The interviews themselves aimed to "flow" as a conversation, moulding to participant direction and preferences (Smith et al., 2009). This aimed to prevent the potential challenges of imposing researcher questions upon participants, which may not resonate with them. Throughout the interviews, the topic guide was modified depending on participant response. On reflection, the topic guide may have benefitted from further streamlining and reduced length to aid interview pace. Some interviews became longer than the hour recommended (Smith et al., 2009) and due to their emotive nature an ethically appropriate ending was required, possibly at the expense of deeper exploration of the phenomenon.

Some participants appeared to struggle with interview questions, yet remained creative and committed to participating, at times using metaphors to aid clarity. Participants sometimes talked about the experiences of living with change, rather than their "realisation" of it, which may have been more unusual to consider. They consequently came to the end of what they could say about their experience, even though questions to elicit further depth were being asked. Subtle adjustments to the wording of questions seemed to help. This may link to the limitations of expression of knowledge through language, acknowledged within phenomenological research (Heron, 1996).

The term “realisation” was also important, the study interpreted realisation to mean the experience of awareness, appreciation and understanding of these circumstances, which was prompted within interviews and contributed to interpreted themes.

Bracketing.

IPA encourages “bracketing” of the assumptions and position of the researcher (Marshall and Rossman, 2011), as part of maintaining continued awareness of beliefs and preventing them overtly leading the analysis. Husserl first described this as the process of placing the phenomenon of interest outside of one’s own pre-existing knowledge of it (Husserl, 1970 cited in Van Manen, 1990). Notably, it is also considered that researcher assumptions cannot be removed completely, and within a critical realist paradigm, the truth can only ever be seen within the boundaries of subjective perception (Fletcher, 2014). Van Manen (1990) recognises that trying to forget knowledge may lead to assumptions reappearing without awareness, and emphasises explicitness of assumptions in order to accept their presence and “hold them at bay.” Consequently, to fully recognise the double hermeneutic, the researcher needs to reflect on both the participants’ and their own subjectivity, requiring reflexivity and transparency which may enable greater access to the participants’ accounts (Brocki and Wearden, 2014).

Interestingly, there is some inconsistency around what should be bracketed. Ashworth (1996, cited in Finlay, 2011) recommends bracketing theories known from previous research, any known validity around participant claims and personal experiences. These guidelines may be best met through Van Manen’s (1990) recommendation around explicitness, since attempting to partial out personal experiences may be at risk of contradicting the realist or critical realist ontology regularly underpinning IPA (Braun and Clarke, 2013). Furthermore, Smith et al. (2009) advise considering existing theory in generating themes for IPA data. Colaizzi (1973 cited in Finlay, 2011) also recognise the importance of self-reflection as part of the generation of research findings, supporting the idea that bracketing in a rigid way could be limiting to achieving a description of the "essence" (Van Manen, 1990) of experience. Ashworth further recognises that shared social meanings within talking about a topic are unlikely to be bracketed (Ashworth, 1996 cited in Finlay, 2011), reiterating the subjective nature of this approach.

Within the empirical study, the following reflective journal extract provides an example of researcher assumptions, which were identified and bracketed. As discussed above, bracketing involved transparency of assumptions and awareness of the potential influence of this both within interviews and the analysis:

> In considering the impact of change upon relationships, I noticed how resistant to change I can be in my own relationships. Consequently, my assumption is that change is a negative, if unavoidable thing, meaning I am more likely to anticipate unexpected change to be particularly difficult for others. This leads me to anticipate participants being at the extreme end of distress rather than potentially embracing new roles and challenges. In some ways, it is uncomfortable to comprehend an alternative, in-case this is misinterpreted as dismissive during the interview process. There is a distinct possibility however, that people could also feel quite fulfilled stepping into a

> ‘caregiver’ role following spouse change. (Reflective journal).

The above extract demonstrates awareness of researcher assumptions around the phenomenon of unexpected change, leading to increased openness to participants’ presenting alternative views within the interviews and analysis.

Notes on the Analysis and Results

The analytic process.

Interviews transcribed professionally were read and re-read for an additional four hours compared to those transcribed by hand, to ensure that the lead researcher was immersed in the content of all interviews, as required for IPA (Smith et al., 2009).

Abstraction, subsumption and polarisation refer to three of the techniques presented by Smith et al. (2009) to derive overarching themes from emergent or subordinate ones across the analysis. Abstraction refers to the generation of a new theme to summarise existing ones, while subsumption refers to a theme achieving an overarching status through being able to summarise a number of other thematic aspects (Smith et al. 2009). Polarisation refers to the presence of "lower level" themes that may contrast with the experiences shared by the majority. In the current study, the four main themes were derived through subsumption, whilst underlying these includes some examples of polarisation and the potential experiences underlying these different outcomes are explored. The four main themes are chosen for their breadth as well as content, they are able to plausibly incorporate a range of lower-level themes, both across accounts and within individual interviews (Figure 3 and Appendices L-O).

Themes varied widely, with some remaining largely at a descriptive level, bearing immediate connection with the phenomenon of interest, while others led to more conceptual ideas regarding their meaning to the phenomenon. This was partly due to some themes bearing connection with broader areas of life in relation to realisation of change, an aspect this study intended to capture. Emergent themes were then clustered based on superordinate themes drawn out by the researcher.

This involved consideration of a facet of experience that appeared common across the emergent themes.

Analysis also interpreted common themes across accounts. While Smith et al. (2009) explain that there is no specific rule for deciding whether a theme is repeated, consistency was maintained by applying the following criteria across accounts:

- Evidence for potential main themes were present within the context of specific quotes or could be interpreted across multiple quotes. This holds even if other information originally adjusted the interpretation of the theme when analysing the specific case. In some cases, the raw data was revisited to cross reference this.
- A subjective interpretation could be made on what the participant was focussing on during the interview. For example, where trends across an interview demonstrated a focus on emotional responses to change as opposed to where participants showed a tendency to describe their spouses' impairments.
- Themes were considered present even if there were polarised (Smith et al., 2009) examples.

Additionally, themes were not considered present if they could not be overtly evidenced within the transcript. For example, "acceptance" was frequently spoken about during interviews, yet held subtly different meanings between participants, pertaining to different themes.

Often, an interview would result in approximately 8 or more emergent themes, accompanied by key quotes. Reflections were recorded throughout to track the double hermeneutic process, and awareness that the researchers' own perception of the phenomenon inevitably contributed to whether emergent themes were retained, discarded or combined. Below is an extract from the reflective journal providing an example of this thinking process during analysis:

> The interview started by drawing out quite descriptive themes, and went on to consider the interpretation of feelings during the experience of realisation. This led me to query my own perception of what is meant by "experience," as the interview questions tended to draw out thoughts, emotions, decisions and coping strategies referring to acknowledging information that may or may not have been hovering on awareness before. Coping strategies appeared particularly prominent, providing concrete examples yet drawing away from potentially more difficult areas such as thoughts and feelings. (Reflective journal).

In the above example, the researcher's anticipation around gathering data on "experience" is considered, given that a number of emergent themes had initially focused on specific thoughts and feelings. This related to aspects forming the lifeworld (Van Manen, 1990; Finlay, 2011), yet also became present within the main themes, which refer to recognition of realisations "hovering on awareness". Noticing the structure of where different subjects presented during the interview contributed to the concept of "bravery" as a superordinate, and later main, theme.

Results and IPA theory.

Smith et al. (2009) acknowledge that with more transcripts included in the IPA analysis, the less detailed they tend to be. It was felt that analysis had been completed to a "deep" level on the sections considered most relevant to the phenomenon, whilst maintaining awareness of bracketed assumptions. Given the quantity of the data however, greater saturation may have been achieved within many more months of analysis. Overall, the upon completion of analysis it was considered that the research questions had been addressed.

The dimensions forming the "lifeworld" (Landgrebe, 1973; Van Manen, 1990) were identified through the analysis. Relatedness (spending time with friends outside of being a couple) and spatiality (the metaphor of feeling like a "goldfish in a bowl") eluded to individual "lifeworlds". The entity of lived body (Van Manen, 1990) was also noted, where one participant referred to realisation as her body no longer being able to continue her current coping strategy. In particular, the main theme "unfolding events leading to new perceptions" is derived through participants experiences of temporality (Finlay, 2011), with perceptions of the past, present and future (Van Manen, 1990) contributing to how realisations of change are experienced. This may reflect a gradual change with the experience of time passing, and how this is noticed. Prominently, the results also relate to lived other (Van Manen, 1990) through the experience of changed social reciprocity.

Metaphors emphasised the double hermeneutic due to the researcher needing to interpret the intended meaning, which could be considered a more elusive expression of experience compared to direct description. Van Manen (1990) describes metaphor as pushing the capture of the "essence" of experience "beyond" its's original form. The analysis further developed these metaphors to interpret difficult-to-describe experiences. For example, the metaphor "like a goldfish in a bowl" was used in close succession to talking about a "regime", and was interpreted as an experience of looking out at aspects of an old lifestyle. While supported within the data, researcher associations with the metaphor, while reflected upon, may have contributed to the interpretation, through leading the researcher into certain avenues of thought. Furthermore, the researcher experienced realisations about the phenomenon throughout both data collection and the analytic process. Consequently, while the participant reflected upon experiences of realisation or potentially experienced new ones within the interview itself, the researcher also experienced realisations around the phenomenon alongside them.

Notably, taking part in an interview further embeds the realities of participant's realisations of change to recorded language, influencing expression of the "lifeworld". This links to the main theme "bravery to change…." due to the interview process potentially bringing "lingering" thoughts and feelings into awareness and language. Schleiermacher (1998 cited in Smith et al., 2009) and Heidegger (Smith et al., 2009) both discuss the role of language in interpreting experience, emphasising how experience is unable to be directly expressed without first order meaning making (Smith et al., 2009).

Summary

This chapter provided additional considerations regarding the search and interpretation of results for the systematic review (Chapter 1), and focuses on the underpinning theory and process of conducting an IPA study (Chapter 3). IPA methodology and philosophical paradigms were discussed; the study perceives knowledge from a CR perspective and takes an idiographic approach to exploring phenomenology (Smith et al., 2009), acknowledging the double hermeneutic through maintaining a reflective journal. Areas of further thought and reflection were discussed, including considerations around bracketing and language as a medium. It is hoped that the empirical study (Chapter 3) provides a reflective and theoretically adherent exploration of realisations of change for those with spouses affected by ABI.

Chapter 5.

Additional results

Chapter 5

Additional results

The following chapter intends to elaborate the results summarised in the empirical study (Chapter 3). Additional themes derived through analysis of individual interviews are described. For a demonstration of analytic process, see Appendices L-O.

Results per Case: Two Examples

Participants provided unique, detailed and reflective accounts of their experiences. While all participants had experienced realisation of change, this was articulated in unique ways. Two examples are outlined below:

Grace.

Grace was a lady in her late sixties, whose spouse had serious physical disabilities following a stroke six years prior. Grace described her own caring nature, which came across through her demeanour in the interview. At times, she described her caregiving duties in a list-like way, reflecting a lifestyle of holding multiple responsibilities in mind. She described an overnight change in her husband; his strong character diminished into dependency and passivity. This generated an experience of powerlessness and heartache:

> Although he's there, he's still your husband…there is nothing, there's nothing, and I think what hurt me the most is that he can't do anything (Grace).

Alongside the "hurt", "acceptance" was important to Grace; she realised the need for this soon after the injury, and had possibly pushed herself through realisations of change to thrive in new circumstances. The experience of waiting for change, followed by the realisation of permanency, was explicit:

> As time went by and there's no progress only, you know, you realise that even more, this is life, this is my husband this is how he is (Grace).

Additionally, Grace's realisation of changes within herself seemed more challenging to accept than those of her husband. Grace described having always been more like her father, yet post-injury life led her to act assertively, akin to her mother or brother. Through identifying with familiar others, she had been able to accept this new, assertive identity as necessary in supporting her spouse.

Iris.

Iris was a lady in her late sixties, whose spouse had experienced a TBI fifteen months prior. Iris was observed to use metaphors to express realisations of change, which may have otherwise been difficult to articulate. She experienced trepidation of her own imagination and the fear this could evoke. Nevertheless, and she held a sense of pragmatic optimism:

> Give him a bit of time and if you're really lucky they'll get a lot better (Iris).

Iris approached realisation of change tentatively, indicating a sense of knowing yet keeping the self-distanced from realising the emotional impact of change. This was further indicated by language typically used to advise another person ("if you're really lucky…"), potentially reflecting emotional overwhelm, control and management.

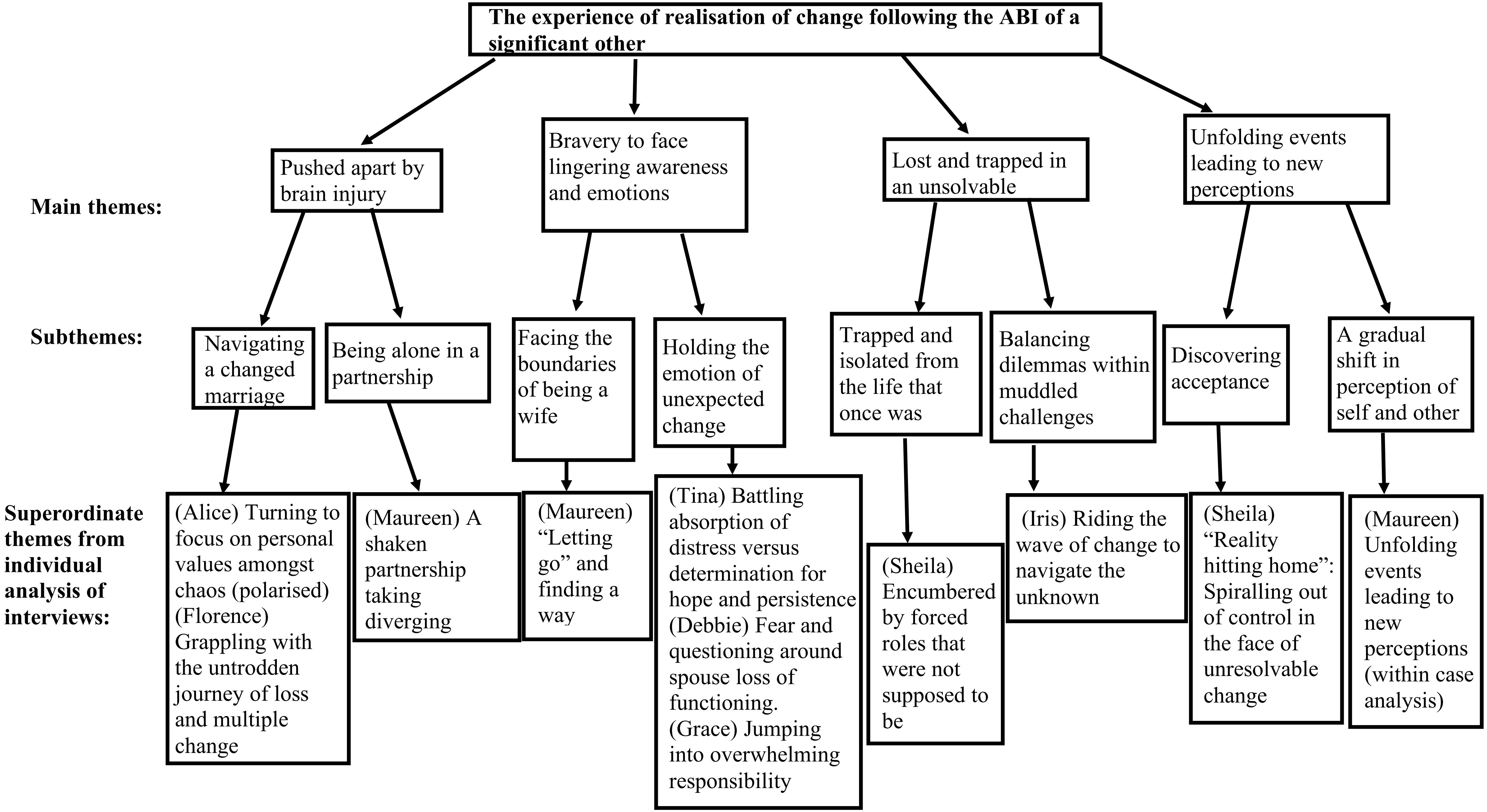

Figure 4. Diagram depicting analytic path from main themes through to prominent superordinate themes from individual case analysis.

Figure 4 shows the subthemes and main themes derived across accounts, as derived from superordinate themes from the analysis of individual interviews. Per-case superordinate themes for each main theme across accounts are described below:

Pushed Apart by Brain Injury: Case-specific Themes

Turning to focus on personal values amongst chaos.

Alice was a lady in her early fifties whose spouse had experienced two strokes, one three decades ago, and the other three years prior. The interview focussed upon change following the second stroke, which induced mood changes, memory and language comprehension difficulties and fatigue. The injury brought the couple closer together however, and they had gotten married since this event.

While contrasting with other accounts, Alice's experience continues to reflect a change in "togetherness". Following realisation of the potential severity her spouse's injury, she prioritised personal values, endeavoured to prevent potential regret:

> The thing that really hit me was....thinking oh my god if he dies….I'm going to really regret is the fact that we didn't get married (Alice).

For Alice, the realisation of her partner's mortality evoked increased commitment to the relationship. Within the continuum of feeling pushed apart or brought together, this quote emphasises how personal meanings contribute to the experience of these relational dynamics. Potentially, Alice's focus on personal values may have helped prevent her feeling as "pushed apart" as she may have otherwise.

Grappling with the untrodden journey of loss and multiple change.

Florence was a lady in her early seventies whose spouse had experienced hydrocephalus three years prior, leading to extreme fatigue and physical care needs. Florence described witnessing change within the context of an initial incorrect diagnosis, and struggling to know what to do upon realisation:

> Knowing that the different doctors we've seen at [hospital name] weren't really coming up with anything, tablet changing that wasn't working......there was a certain amount of frustration that we weren't getting anywhere (Florence).

The couple's experiences with medical care elicited a sense of disappointment and frustration, alongside discomfort with taking her spouse's roles away:

> He would have done cars and garden....I think at the beginning, he felt I was taking over, and I'm sure any man would feel like that (Florence).

She describes herself getting emotionally "hurt" when taking on more tasks while her spouse was adjusting to less, leading to her being criticised. This may reflect a "grappling" between additional responsibilities and was possibly linked to her husband's loss. Describing his response as normal may increase a sense of safety in such circumstances. This theme also indicated that realisation of change may be elicited where the injured person's response to change evokes realisation of the significance of this change in the uninjured spouse.

A Shaken Partnership Leading to Different Trajectories

Maureen was a lady in her early sixties whose spouse experienced a “bleed on the brain” six years previously, which lead to aphasia and contributed to depression within her spouse. She reflected their diverging trajectories as a couple:

> We were going through life together really and then it felt like yes we weren’t any more so yes it was difficult (Maureen).

This quote reflects a disconnect from previously shared values and personal connection. Contributing to this, Maureen also referred to an intrusive experience of change within her spouse:

> Two people I’m living with…I try to keep the status quo rather than you know antagonise the less nice aspect of his personality to come through (Maureen).

Perceiving her spouse as “two people” may reflect a way of comprehending more challenging changes to her spouse’s personality since injury, increasing a sense of being “pushed apart”.

Bravery to Face Lingering Awareness and Emotions: Case-specific Themes

"Letting go" and finding a way forward.

Maureen reflected on her financial reliance on her spouse, leading to post-injury questioning of personal beliefs around marital roles (see Chapter 3). When considering her own sense of personal "duty", Maureen experienced a feeling of "letting go" of pressure and responsibility. She made an empowered choice to support her spouse and accept the possibility of initiating change herself:

> I thought I'm actually going to give it a year…life just has to be better than this….letting go and accepting that maybe I would…live apart, I think that actually that released quite a lot you know I stopped trying so hard (Maureen).

Here, Maureen faced the possibility of living separately and broke free from the perceived boundaries of marriage. This held a balance between the dilemma of sitting with a feeling of marital unfairness and making an empowered choice to remain.

Battling absorption of distress versus determination for hope and persistence.

Tina was a lady in her mid-fifties whose spouse had experienced a Traumatic Brain Injury (TBI) ten years prior, presenting with personality changes affecting mood and empathy. This theme referred to emotionally "taking on" the emotions evoked through changes to daily interactions with her spouse:

> You just absorb it all (Tina).

Other strands of the interview indicated persistence; holding on to hope that further improvements could occur. Tina's experience of realising that nothing is going to change further was a struggle to share with her spouse, she undertook all responsibilities including ongoing perseverance for post-injury challenges:

> You have to…try and work out what you can do better to help stop that kind of thing happening again (Tina).

This quote presents a dilemma between the positions of "just keep going and hope..." versus awareness that "nothing is going to change". Focussing on one or the other may have aided coping, whereas the experience of dilemma (sitting between the two positions) could have evoked emotional discomfort; hope being met with disappointment. Consequently, she was swinging between both viewpoints.

Fear and questioning around spouse loss of functioning.

Debbie was a participant in her late sixties whose spouse had a stroke around six years prior, leading to language impairments:

> ....Scared really scared because I thought you know is he ever going to get his language back and how is he going to function as a person again (Debbie).

This directly captures Debbie's fear around long-term implications. Her spouse's ability to communicate was tied to her perception of personhood, and the potential loss of him rather than words alone. This fear was expressed as questioning, perhaps demonstrating discomfort with the unknown.

Jumping into overwhelming responsibility.

Grace described acknowledging caregiving responsibilities, while expressing a pressure around navigating the unknown. Consistent with other accounts (such as Iris, see Chapter 3 and Debbie, above), the unknown was an experience of discomfort:

> The first day they sent him home and I had him in the bath and was washing him and he was (sigh) just like a limp rag you know and I thought, you know, oh my god I got a zombie, they were the feelings I had then, you know I just thought that was sheer weakness I didn't realise exactly why (Grace).

Grace expressed her experience of realisation of change through language pertaining to feelings of shock and overwhelm. There was a raw contrast between her pre and post-injury perceptions of her spouse; describing him in outgoing terms previously in the interview, and experiencing him as a "limp rag" and "zombie". She emphasised the unexpected nature of personal responsibility following brain injury:

> Overwhelming, really, you can say overwhelming, because, you know, suddenly you think here am I and you got, you got all this responsibility (Grace).

This emphasised the unexpected nature of personal responsibility, and the pressure to control feelings of being overwhelmed. Potentially, the practical aspects of such responsibility may have left little room for emotional self-care.

Lost and Trapped in an Unsolvable Maze: Case-specific Themes

Encumbered by forced roles that were not supposed to be.

Sheila was a lady in her early seventies whose spouse experienced a ruptured aneurism four years prior, resulting in physical care needs and passivity. One of Sheila's realisations of change was the onset of responsibility for tasks previously undertaken by her spouse. When referring to managing these, Sheila reported:

> I hate it I don't know how else to describe how I feel it's just I'm angry that I'm having to do it but I've no choice (Sheila).

The powerlessness expressed through this expression highlighted the sense of burden and confusion, forming feeling trapped. Needing to figure out a new, potentially permanent situation (for example, with ongoing physical care needs), may evoke frustration and elicits a sense of being in a maze. Sheila also continued striving for improvement, even upon realisation of her spouse's diminishing "drive". This this perceived as problematic, yet again co-exists with the knowledge that further recovery may be limited, met with a feeling of relentlessly working towards this regardless of plausible outcome:

> I still felt that I was striving towards getting him better and we'd have a future (Sheila).

Riding the wave of change to navigate the unknown.

This theme aimed to capture Iris' realisation of change without pre-emptive knowledge of how to respond. Iris described continuously adjusting her expectations to manage feelings of shock as she witnessed changes unfolding, whilst recognising her own limitations and knowledge:

> I had no idea what constituted a bad head injury um, and I always thought people who were unconscious could just lie in there like a log and this is probably not true (Iris).

This quote reflects a feeling of having no other option but to "go with" the ever-changing condition of her spouse and find a way through experienced emotions; a journey of continuous realisation. The unpredictable nature of change during the early days post-TBI lead to the metaphor of "riding a wave". This added to an impression of finding ways to navigate through the "maze":

> Give him a bit of time and he might get a bit better, give him a bit of time and if you're really lucky they'll get a lot better, um, if you're really really lucky then they'll get completely better (Iris).

Iris' emphasis on luck brings out an experience of being out of control, yet "unknowns" within both quotes may have been approached as a feeling that "should" to happen. This may have somewhat alleviated the potential to feel "lost or trapped", identified within other accounts and potentially easily evoked through Iris' descriptions.

Unfolding Events Leading to New Perceptions: Case-specific Themes

"Reality hitting home": Spiralling out of control in the face of unresolvable change.

Sheila reported experiencing an emotional breakdown when she realised that life with her spouse was unlikely to improve further.

> It was suddenly something that hit me and I went into overload….it was just a natural progression…I'd been pushing myself too hard and my body just said hang on a minute no more (Sheila).

Sheila indicates a build-up of post-injury life triggering "sudden" realisation, physically halting her established coping strategy. This suggests disconnect between the self and embodied lifeworld; carrying on physically despite of realised realities. Notably, realisation is both "sudden" and a "natural progression" for Sheila, a contrast potentially suggestive of her own sense of overwhelm, along with challenges discerning realisation as a specific "moment". It may also reiterate that the experience of "realisation" can be difficult to articulate.

Superordinate theme: Unfolding events leading to new perceptions (within case analysis).

Maureen's account reflected on acknowledging the presence of "taboo" thoughts, describing realisation of these as something she had "dared" to think. Furthermore, she noticed socially imposed responsibility, particularly in regards to her spouse's suicide attempt.

> …people automatically think well what could I have done you know to have stopped him. (Maureen).

Emphasis on “people” may reflect a changed relationship between the self and others within the context of her spouse’s mental health concerns, associated with ABI. Furthermore, she made use of her own resources to cope with the emotions evoked by continuing to support her spouse.

> (The) hardest thing it’s, it feels like a huge weight on me when he’s home and he’s in that mood….I’ve got my own room upstairs. (Maureen).

The “weight” Maureen describes indicates a personal pressure, overlapping with her previous sense of “letting go” (discussed above). Potentially, realisation of this “weight” promotes personal care through ensuring her own space (a room upstairs). Consequently, realisations of change may initiate motivation towards protecting one’s own wellbeing.

Conclusions

The above results describe the superordinate themes derived from the analysis of each account (Figure 4). Similar to the overarching themes in Chapter 3 (Figure 3), plausible overlap may be seen where some superordinate themes could be allocated within more than one subtheme or main theme. For example, “grappling with the untrodden journey of loss and multiple change” could potentially fit within both “pushed apart by brain injury” and “bravery to face lingering awareness and emotions”.

One main theme is metaphorical; “lost and trapped in a maze”. While not a direct quote from an interview, it reflected some of the linguistic patterns observed, also indicative of experience. Overall, the four main themes pull together varied experiences reflecting realisation of change, with case-specific themes presented directly from individual interviews; holding the richest content of individual experience. In particular, participants interpretation of realisation of change may influence actions taken to protect wellbeing.

Participants struggled between practically “taking on” newfound responsibilities, and striving forward with hope for recovery. Furthermore, awareness of change may lead to considerable fear and questioning around how to manage immediate or imagined challenges. Participants may have aimed to get through each day whilst struggling to feel that they had made sense of witnessed changes. Across themes, participants were often managing the positions of thoughts evoking motivation to work towards further improvements, and acceptance of the permanent nature of the injury. Where awareness of both positions potentially evoked discomfort, participants found themselves switching between one or the other.

Results also reflected continuous realisations of change, with the unfolding of further changes and consequential realisations over time. This means that realisation is not a “static” experience pinpointed to single moments, and may highlight aspects of life previously held at an internal distance from personal awareness. For example, their own perception of marriage. Consequently, realisations of change require great personal bravery in facing those internal responses perceived as personally unacceptable, or emotionally painful, to experience.

Chapter 6

Critical Evaluation

Chapter 6

Critical Evaluation

This portfolio contributed two projects to the existing knowledge of family member experiences following ABI. The paragraphs below emphasise the methodology and key findings of each paper, and relate this to the background literature. Additional strengths and limitations of the papers are identified, alongside potential future research and clinical work. Both papers address the impact of Acquired Brain Injury (ABI) on family members, yet incorporate different perspectives. A further aim of this chapter is to bring the findings of both papers together across methodologies.

Bringing the Results Together

The systematic review (Chapter 1) highlighted the role of family functioning (FF) in mediating the relationship between neurobehavioural (NB) presentation and family member distress/mental health. In contrast, the empirical study (Chapter 3) contributed in-depth analysis of the experience of realisation of change following brain injury. The systematic review perceived the impact on family members in terms of an overall “system” (Begun, 1996 cited in Degeneffe, Gagne and Tucker, 2013) or FF, whereas the empirical study explored the internal “lifeworld” (Van Manen, 1990) of specific individuals within a family system. Such differences may be brought together through perceiving these as different angles of reality, as defined by critical realism (Fletcher, 2014; Braun and Clarke, 2003). Consequently, the systematic review and empirical study could be seen to form two “levels” of exploration, with varying levels of detail. The empirical study explores the rich detail of an individual’s experience and perception of “truth” (Fletcher, 2014), whereas the systematic review provides a “birds-eye” view through seeing phenomenon as measurable, objective variables.

Notably though, the variables explored within the systematic review impose pre-existing definitions on experiences otherwise demonstrated to be both complex and unique in the empirical study. Alongside this, the definition of NB and FF could still represent researcher interpretation of the participants perception of measures. This highlights how quantitative studies may provide a population-based (Noyes et al., 2019) heuristic of experience, yet may still be partial to the double-hermeneutic (Smith et al., 2009). Steinhauer, Santa-Barbara and Skinner’s (1984) Process Model acknowledges that FF exists within values and norms, and that formulating a family requires an understanding of this. Consequently, model dimensions do not directly determine problematic or healthy family functioning (Steinhauer et al., 1984), highlighting how individual experience to be embedded within representations of objective “truth”.

In considering the nature of adopting a caregiving role, themes from the empirical study may be inferred to contribute to the two-way process between post-ABI presentation and caregiver functioning, and caregiver functioning and neurorehabilitation outcomes (Walsh, 2003 cited in Godwin, Chappell and Kreutzer, 2014; Carnwath and Johnson, 1987). The captured experiences represent a snapshot of this process, where participants reflected upon both overt neuropsychological changes and changes within themselves. Furthermore, realisation of change reflects internal thinking underlying psychosocial and wider change following the injury. Here, the relationship between research formed of discrete variables, and unique individual experiences may be brought together. More directly, some studies included in the systematic review, using path analysis (Anderson, Simpson and

Morey, 2013; Schönberger and Ponsford, 2010) identify the strength of association overarching these relationships, which exist due to subjective experiences. For example, the theme "unfolding events leading to new perceptions" may underlie perceived NB changes, leading to interacting with the injured person differently and influencing domains of FF, such as affective involvement and communication (Epstein, Bishop and Levin, 1978). Consequently, the results of both papers interlink through explaining established outcomes. Furthermore, experiences of realisations of change may overlap with the diagnostic criteria forming mental health diagnosis; a variable mediated by FF in the systematic review. Essentially, the results of the empirical study add a "lived" reality to the links between variables explored within the systematic review.

Background Literature and Future Research

Research pertaining to both papers has been applied within healthcare settings, with positive outcomes found for family interventions (Kreutzer, Ketchum, Marwitz and Menzel, 2009; Martire, Lustig, Miller, Schulz, 2004; Pless, Roughmann and Haggerty, 1972). Research into the effects of ABI on family members often included individuals alongside family groups (Verhaeghe Defloor, Grypdonck., 2005), exploring an overall picture of the "ripple effect" across individuals and systems.

The results of the empirical study (Chapter 3) identified the theme "pushed apart by brain injury" which may provide subjective insight and detail to some quantitative outcomes. For example, lowered relationship and life satisfaction (Burridge, Williams, Yates, Harris and Ward, 2007 and Eriksson Tham and Fygl-Meyer, 2005 respectively), may reflect this experience of disconnection. Facing one's own internal experience alongside perceived dilemmas and feelings of being trapped could also contribute to the distress/mental health outcomes already established (Sander, Maestas, Clark and Havins, 2013; Kreutzer, Ketchum, Marwitz and Menzel, 2009). Notably though, differences in strategies to manage realisation, such as internally holding realisation “at bay” until personally manageable, supports the importance of raising awareness of pre-existing personal resources (Blas and Boisvert, 2005).

The finding that realisations of change are experienced as gradual and indefinite shifts in awareness, holds similarities to findings of long-term distress following injury onset (Verharghe et al., 2005). For some, their relationships changed with the experience of realisation, indicating a need for future research to generate more “in depth” accounts regarding temporality. An extension may incorporate Grounded Theory, exploring the idea of a “pathway”, as suggested by the PPI member of the research team, and consider changing experiences over time to potentially develop a process-based model (Braun and Clarke, 2003).

The McMaster Model of Family Functioning (MMFF) (Epstein et al., 1978) was commonly used throughout the studies reviewed in the systematic review. Without this, there may have been greater variation in FF definitions. The MMFF may also depict reductions in FF which may not be subjectively experienced as a concern, or that families may not be aware of (such as reflections on affective responsiveness). Consequently, it is questionable whether this creates a meaningful account or how it would translate clinically. Furthermore, other models appeared underused despite building upon the MMFF (Steinhauer et al., 1984 for example), indicating theoretical bias within the literature.

The systematic review in particular is directed towards the negative outcomes on families following ABI, as is prominent within the background research (see

Introduction). Within the included studies, this may only have been considered if no relationship had been found between NB presentation and FF. The results define anticipated family outcomes following ABI, yet are unable to provide information on the internal processes leading to better (or less negative) outcomes, aside from a reduction in the predictor variable. In contrast, the empirical study has drawn out themes relating to hopeful experiences, contributing to understanding internal experiences that may generate better outcomes.

Additional Strengths and Limitations

Initial SR search results identified over 9000 results after duplicates were removed (Figure 1), demonstrating difficulties finding focussed search terms. It would not have been appropriate to remove “behav*” or “car*”, since this could have missed important results despite generating high numbers of irrelevant records. Additionally, given that NB can refer to emotional challenges, and the link between FF and mental health/distress, some studies excluded on the basis of mental health alone may have added to the results. This could be addressed in a further systematic review; exploring post-ABI emotional experiences on FF and caregiver mental health.

In attempting to capture the “truth”, studies within the systematic review tended to define NB broadly; incorporating a large number of domains that overlap with mental health, behavioural and cognitive difficulties (Table 1). Studies may be unable to fully address overall “NB” when defining this concept so broadly. While it was not within the capacity of the systematic review to fully address this, the issue requires consideration within future research. Furthermore, while each study defined NB, the reviewer then interpreted these relative to the research question and eligibility criteria. This highlights how research that aims to be “objective” is still reliant upon researchers applying concepts consistently. Should a different ontological and epistemological paradigm be adopted, such realities could be seen as constructed (Braun and Clarke, 2013), and a range of definitions would be expected. Consequently, qualitative exploration of post-injury experience may be more conclusive than trying to further define “NB” as an objective variable, at present.

Within the empirical study, participant descriptions of the nature of the ABI were collected to maintain epistemological consistency. This attained vaguer descriptions than anticipated however, for example “stroke” without further detail, however collecting information on the impairments themselves alleviated some unknown aspects. Nevertheless, the purpose of collecting this information in IPA is generally to ensure homogeneity (Pietkiewicz and Smith, 2014), which was already established through other demographic and experiential aspects (Robinson, 2014). From the analysis, PPI discussion and participant feedback, it may be deemed unlikely that including further “objective” information about the nature of ABI would have added to the results.

Of further consideration, one participant reported their spouse to have experienced a stroke, yet they had recently received a diagnosis of vascular dementia. While they continued to meet the inclusion criteria, the interview focussed on experiences since the initial stroke to target the initial brain injury. It would have been inappropriate not to have included the participant on this basis, as the experiences were still equally able to answer the research question. Such cases indicate a merging of research areas however, which in themselves impose diagnostic labels onto experience, and depend on the inclusion criteria of the specific study. Consequently, such participants could easily be excluded from many studies. From this perspective the broad inclusion criteria are a strength; giving a voice to those sitting between diagnostic definitions. This fits well within the underpinning theory of IPA by emphasising the value of individual experience (Smith et al., 2009).

The phenomenon of realisation of change was sometimes difficult to identify. In particular, during interviews there was an assumption that both participant and researcher shared an understanding of the questions. Different participant interpretations of the questions generated a lot of surplus data, which required decision-making around what was “relevant” for analysis. Whole transcripts were focussed upon at the initial noting and emergent theme stage, giving a chance for all data to lead to superordinate themes. This dual process was across nine interviews was time-consuming, since participants occasionally used the interviews to express their frustrations, generating tangents. Limiting this would have been unethical, since recruitment promoted the opportunity to talk and interviews may have held some therapeutic function. Nevertheless, greater focus may have led to smoother analytic processes. Notably, consideration of language structures allowed for deeper interpretation using the “surplus” data, which helped to contextualise participant’s descriptions of realisations of change. This was further reiterated through feedback from the PPI member of the research team.

Application of Findings

Clinical applications.

The empirical study supports the continued inclusion of spouses within the rehabilitation process and promotes access to services for longer-term support. The systematic review highlights consideration of the wider family, and FF could also be considered as part of clinical assessment and monitoring of mental health and wellbeing.

The empirical study exposed a sense of “double bind” where participants continued to strive towards further change, such as rehabilitation outcomes, contrasting attempts to accept their “new normal” alongside this. This contrasts with the theme of “the new normal”, since some individual meanings of “acceptance” were not interpreted to acknowledge the permanency of post-ABI life. This interpretative process reflected upon the researchers’ own ideas of what “acceptance” means, which assumed that “normality” may be experienced when a phenomenon is truly accepted. While bracketed, this interpretation was derived through the researcher’s own perception of “acceptance”, as expected through a critical realist paradigm (Fletcher, 2014).

The above assumptions may have been generated from knowledge of psychological models. The Y shaped model (Gracey, Evans and Malley, 2009) might see acceptance as being able to sit with discrepancies long enough to become familiar with them, and opening up the possibility of meaning making without reacting to the content of the event itself. Therapeutic models, such as Acceptance and Commitment Therapy, would see “acceptance” as allowing all thoughts and feelings to be experienced, regardless of preference for them, and without using them to direct valued living (Hayes, Luoma, Bond, Masula and Lillis, 2006). Given the prominence of “acceptance” within the data, and the personal meanings attached to it, this interpretation may support the use of ACT and the Y-shaped model in clinical settings.

IPA results inform possible inferences made through clinical experience; the finding that spouses may relive realisations and that new realisations continue to occur years after injury suggests that anticipating full acknowledgment of impending changes at an earlier stage may be counter-productive. Prominently, spouses would benefit from long-term, open ended support, with case-specific strategies potentially leading to better outcomes.

Valuing qualitative knowledge within services could also build a mindset akin to the Power Threat Meaning Framework (Johnstone and Boyle, 2018), asking those experiencing difficulty about their sense making around experiences as an alternative to fitting diagnostic labels. Within this, experiences around power imbalances (such as feeling disempowered as a wife or within a caregiving role) generating personal threat could also be considered (Johnstone and Boyle, 2018). Given this, the results may contribute to a useful understanding of psychological wellbeing for those involved. Notably though, IPA is a robust research method which increases knowledge in an inductive manner, rather than seeking to inform clinical interventions (Smith, 2018).

Additional research applications.

From the systematic review, future research could explore relationships between mental health, FF and specific behaviours of concern. Furthermore, only a few studies specified particular domains of FF, with many studies using a general measure (Chapter 1, Table 1). Future research could explore the relationships between established dimensions of FF to specific areas of NB presentation. Additionally, models building upon the MMFF (Dai and Wang, 2015) could be incorporated.

To incorporate the empirical study, realisation of change could also be explored within a family group context, providing insight into the experience of FF following ABI. This would support the results of the systematic review whilst addressing areas that quantitative research is otherwise unable to.

Additional relevant research has revisited qualitative data using different approaches. Shaw, Smith and Hiles (2018) provide an extension to their IPA exploring the experience living with Parkinson's Disease, for both patients and spouses. They proposed an "abductive approach" forming a two-way balance between drawing theory from the data and applying theory to best address the research question (Pierce, 1903 cited in Shaw et al., 2018). IPA data was revisited using Narrative Orientated Inquiry to explore structural features of participants' stories, uncovering how participants re-lived experiences through narrative features where key IPA findings were prominent. Critically though, IPA allows for structural commenting during early stages of analysis (Smith et al., 2009), so a saturated analysis could negate the need for further exploration, however this may be questioned within the orientation of a different method. Conversely, Shaw et al. (2018) note that taking a pluralist approach (Frost et al., 2010 cited in Shaw et al., 2018) adds robustness to qualitative findings, as human experience may exceed the capacity of a singular approach. With this and other pluralist literature acknowledged (Coyle, 2010; Goodbody, 2011), revisiting data from the empirical study from another perspective may be tentatively considered.

Dissemination.

A summary of the research findings (Appendix P) was shared with participants and services supporting recruitment, in February 2019. Feedback was attained from one participant who described the results as representative of her experience. Further feedback was also attained from the main service of recruitment, identifying the results as reflecting the experiences of spouses engaging with the service.

Further dissemination will be the submission of both papers to Neuropsychological Rehabilitation for publication, and potential presentation at conferences.

Conclusions from Whole Portfolio

The results of the systematic review identified a relationship between NB presentation and FF, with FF mediating the relationship between NB and caregiver mental health/distress. Study quality tended to be “fair”, and biases were discussed. The results of the empirical study may form part of the experiences generating mental health concerns and the FF changes established within the systematic review. Consideration of the definition of variables and over reliance on one model were key considerations for further research. Both papers were consistent with the background literature, however only the empirical study was able to identify possible positive outcomes as well as the distress experienced by participants.

The empirical study primarily aimed to provide a meaningful account for readers who have experienced similar circumstances and inform those supporting them, alongside increasing knowledge of subjective experiences following the ABI of a loved one. Participants tended to experience gradual realisations, leading them to question the nature of their connection with their spouse. This included experiences of feeling both with and without a partner and/or that their partner was a different person in comparison to pre-injury life. Participants also experienced a range of emotional responses and uncertainty whilst often living within a predictable “regime”. Initial realisations, such as bereavement, could be re-experienced in response to repeated witnessing of post-injury change.

Alongside these challenges however, participants recognised the importance of finding personal acceptance, enabling a sense of normality. Noticing a continuation of personal values post-injury also supported commitment and hope. Additionally, participants showed great bravery and determination in facing the unknown nature of post-injury life. A particular strength of the study was PPI input, and initial participant feedback was positive. It is hoped that the results provide a meaningful account that resonates with those affected by ABI, and the professionals supporting post-injury family life. Clinical applications include long-term monitoring and support for spouses and the wider family system, with potential further research using Grounded Theory to consider a process existing alongside these experiences.

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Appendices

Appendix A. Author instructions for submission to Neuropsychological Rehabilitation

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Appendix B. PRISMA checklist for systematic review (Chapter 1)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	14
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	15
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	18
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	18
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	19
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	19-20
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	19-20
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	19-20

Section/topic	**#**	**Checklist item**	**Reported on page #**
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	19-20
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	21
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	19
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	21
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A – narrative synthesis
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	22
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	21
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A - narrative synthesis
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	24

Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	22-23
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	36-37
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	37-42
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	36-37
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	43
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	47-50
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	50-51
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A – part of ClinPsyD

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**

Appendix C. Quality assessment tables

Table 1: Per item ratings for the quality assessment of each study, using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart, Lung and Blood Institute (2014).

QATOCCS criteria	Anderson et al. 2013	Anderson et al., 2009	Anderson et al., 2002
1. Was the research question or objective in this paper clearly stated?	Yes	No	No
2. Was the study population clearly specified and defined?	Yes	Yes	Yes
3. Was the participation rate of eligible persons at least 50%?	Yes	Yes	Yes
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Yes	Yes	Yes
5. Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No	No	No
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	Yes	Yes	Yes
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Yes	Yes	Yes
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes
10. Was the exposure(s) assessed more than once over time?	No	No	No
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A
13. Was loss to follow-up after baseline 20% or less?	N/A	N/A	NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes	Yes	No

QATOCCS criteria	Carnes & Quinn, 2005	Chinnery, 2005	Douglas & Spellacy, 1996	Ergh et al. 2002
1. Was the research question or objective in this paper clearly stated?	No	Yes	Yes	Yes
2. Was the study population clearly specified and defined?	Yes	No	Yes	Yes
3. Was the participation rate of eligible persons at least 50%?	Yes	No	N/R	N/R
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	N/R	No	Yes	Yes
5. Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No	No	C/D	
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	No	Yes	Yes	Yes
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Yes	Yes	Yes	Yes
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	No	Yes	Yes	Yes
10. Was the exposure(s) assessed more than once over time?	No	No	No	No
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A
13. Was loss to follow-up after baseline 20% or less?	N/A	N/A	N/A	N/A
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes	No	Yes	Yes

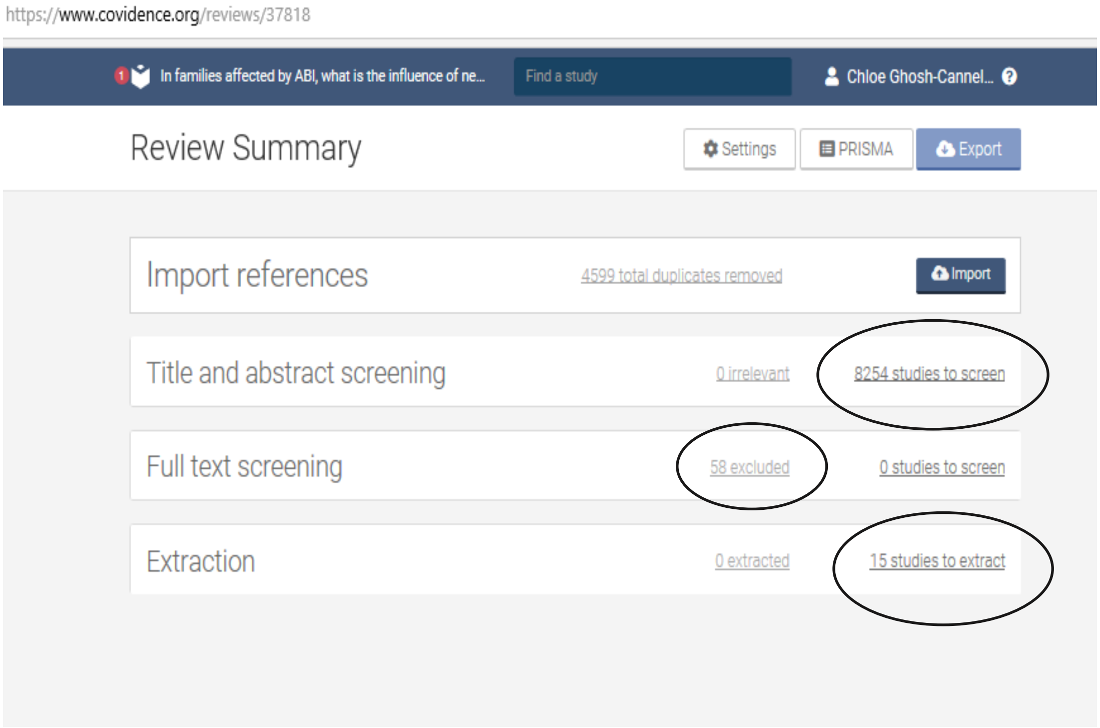
QATOCCS criteria	Groom et al., 1998	Kosciulek, Lusting, 1998	Kreutzer et al., 1994	Nabors et al., 2002
1. Was the research question or objective in this paper clearly stated?	Yes	No	Yes	Yes
2. Was the study population clearly specified and defined?	Yes	Yes	Yes	Yes
3. Was the participation rate of eligible persons at least 50%?	Yes	No	N/R	No
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	No	Yes	No	Yes
5. Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No	No	No	No
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	No	Yes	No	N/R
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Yes	No	Yes	Yes
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes	Yes
10. Was the exposure(s) assessed more than once over time?	No	No	No	No
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A
13. Was loss to follow-up after baseline 20% or less?	N/A	N/A	N/A	N/A
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes	N/R	Yes	Yes

QATOCCS criteria	Ponsford et al., 2003	Ponsford et al., 2010	Schönberger & Ponsford, 2010	Testa et al., 2006
1. Was the research question or objective in this paper clearly stated?	Yes	Yes	Yes	Yes
2. Was the study population clearly specified and defined?	Yes	No	Yes	Yes
3. Was the participation rate of eligible persons at least 50%?	Yes	N/R	N/R	N/R
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	No	No	No	Yes
5. Was a sample size justification, power description, or variance and effect estimates provided?	No	No	Yes	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No	No	Yes	C/D
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	Yes	Yes	Yes	Yes
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Yes	Yes	Yes	Yes
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	C/D	Yes	Yes
10. Was the exposure(s) assessed more than once over time?	No	No	Yes	Yes
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A
13. Was loss to follow-up after baseline 20% or less?	N/A	N/A	No	N/R
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes	Yes	Yes	Yes

Appendix D. Screenshots from Covidence software demonstrating search results

Covidence software was adopted for the management of systematic review results, up to the point of data extraction due to it being designed for Randomised Controlled Trials. This was due to the quantity of initial search results.

An initial search took place in April 2018 (8327 records at title and abstract screening), which was updated in September 2019 (adding 698 records, alongside 3 found through hand searching).


https://www.covidence.org/reviews/37818

In families affected by ABI, what is the influence of ne...

Chloe Ghosh-Cannel...

Review Summary

Import references 4599 total duplicates removed

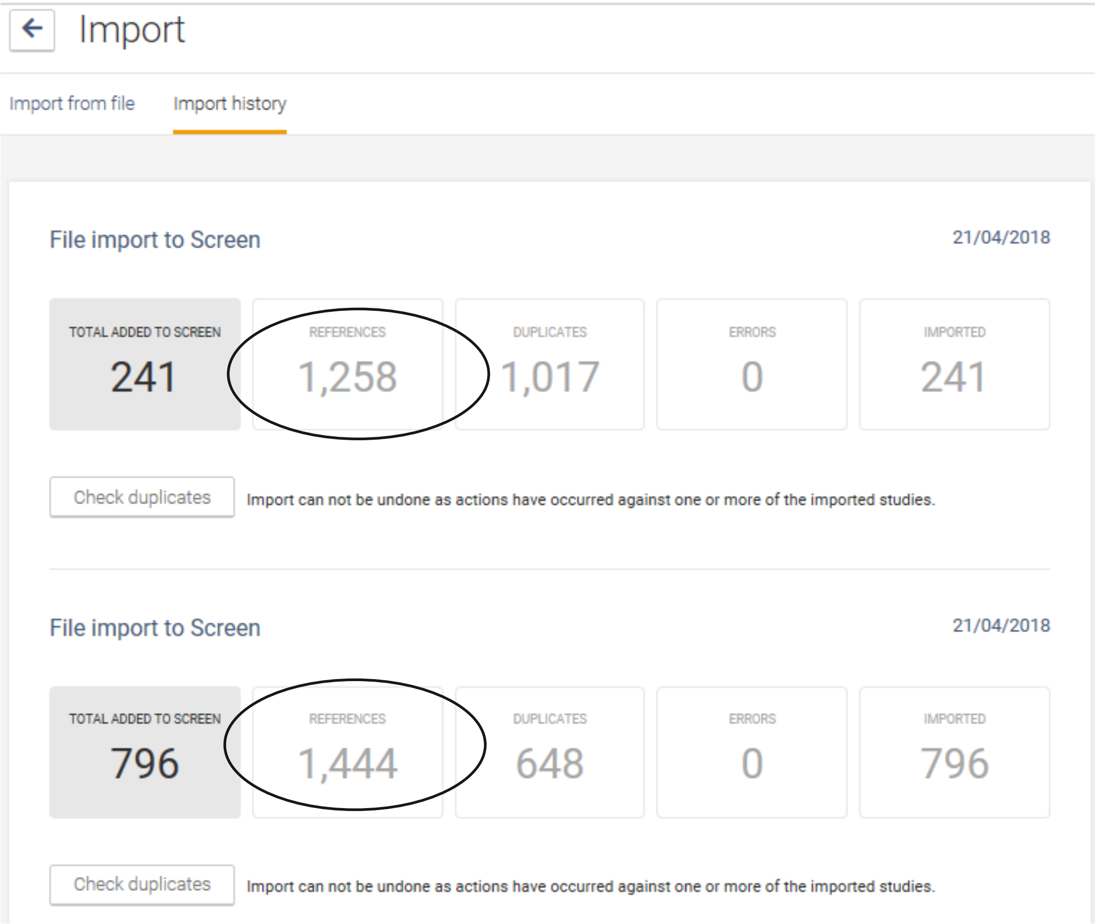
Title and abstract screening 0 irrelevant 8254 studies to screen

Full text screening 58 excluded 0 studies to screen

Extraction 0 extracted 15 studies to extract

Figure 1. Screenshots for Covidence account for initial search in April 2018.

In Figure 1, title and abstract screening results had been moved back to the “to be screened” to keep track of them during a check, however numbers shown in this row were considered irrelevant to the research question.



File import to Screen

21/04/2018

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
241	1,258	1,017	0	241

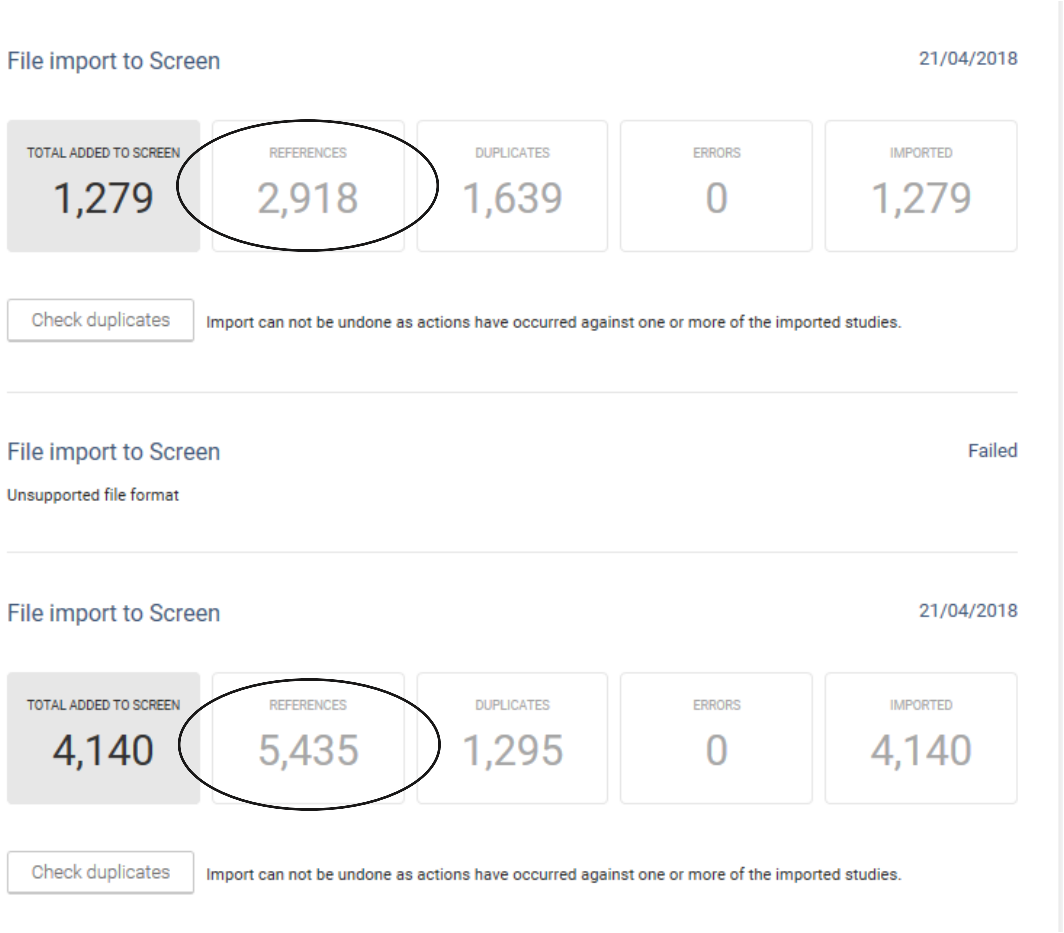
Import can not be undone as actions have occurred against one or more of the imported studies.

File import to Screen

21/04/2018

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
796	1,444	648	0	796

Import can not be undone as actions have occurred against one or more of the imported studies.



File import to Screen

21/04/2018

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
1,279	2,918	1,639	0	1,279

Import can not be undone as actions have occurred against one or more of the imported studies.

File import to Screen

Failed

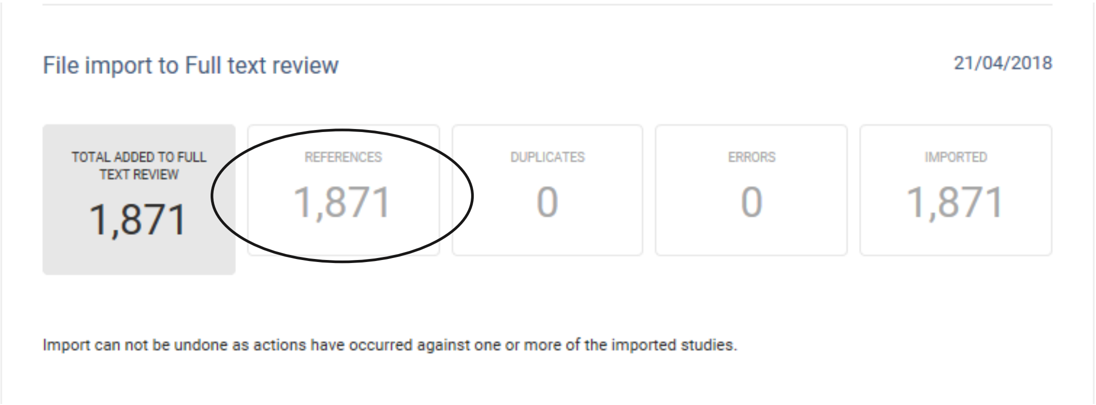
Unsupported file format

File import to Screen

21/04/2018

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
4,140	5,435	1,295	0	4,140

Import can not be undone as actions have occurred against one or more of the imported studies.



File import to Full text review

21/04/2018

TOTAL ADDED TO FULL TEXT REVIEW	REFERENCES	DUPLICATES	ERRORS	IMPORTED
1,871	1,871	0	0	1,871

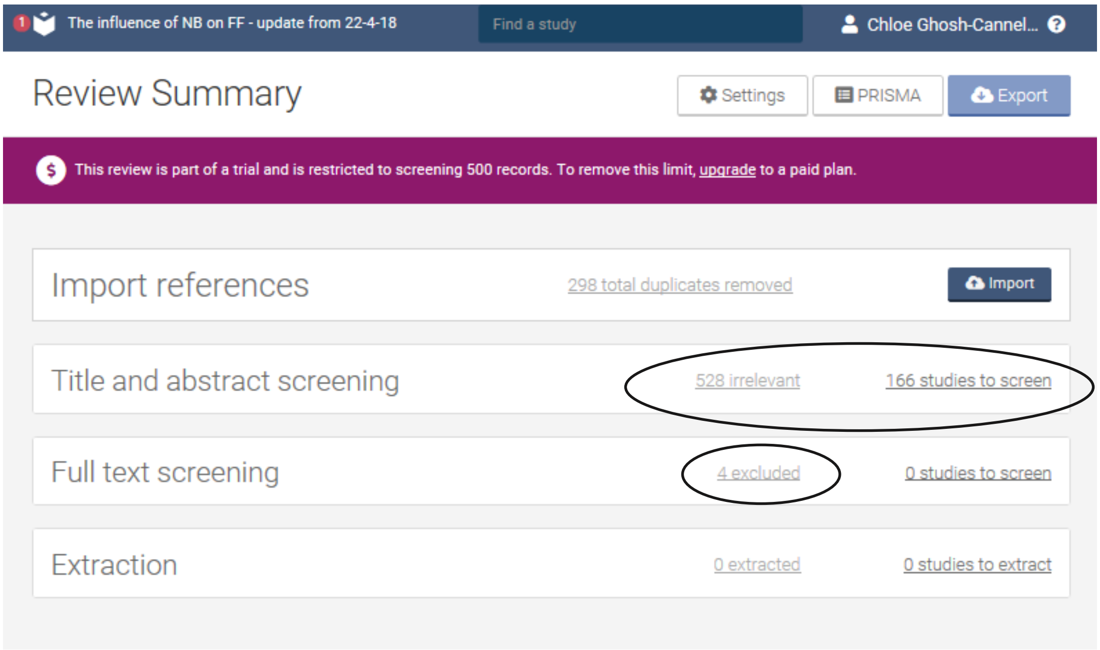
Import can not be undone as actions have occurred against one or more of the imported studies.

(Thereafter moved to screen).

Figure 2. Screenshots of individual searches per database, for initial systematic review search in April 2018.

From top down: MeSH term "brain injury", MeSH term "stroke", PsycInfo, Medline, CINAHL.

To calculate records of initial search for the systematic review flowchart (Figure 1, Chapter 1), “References” values from each search were added together and the total number of duplicates (Figure 1, Appendix B) subtracted from it.



This review is part of a trial and is restricted to screening 500 records. To remove this limit, upgrade to a paid plan.

Import references 298 total duplicates removed

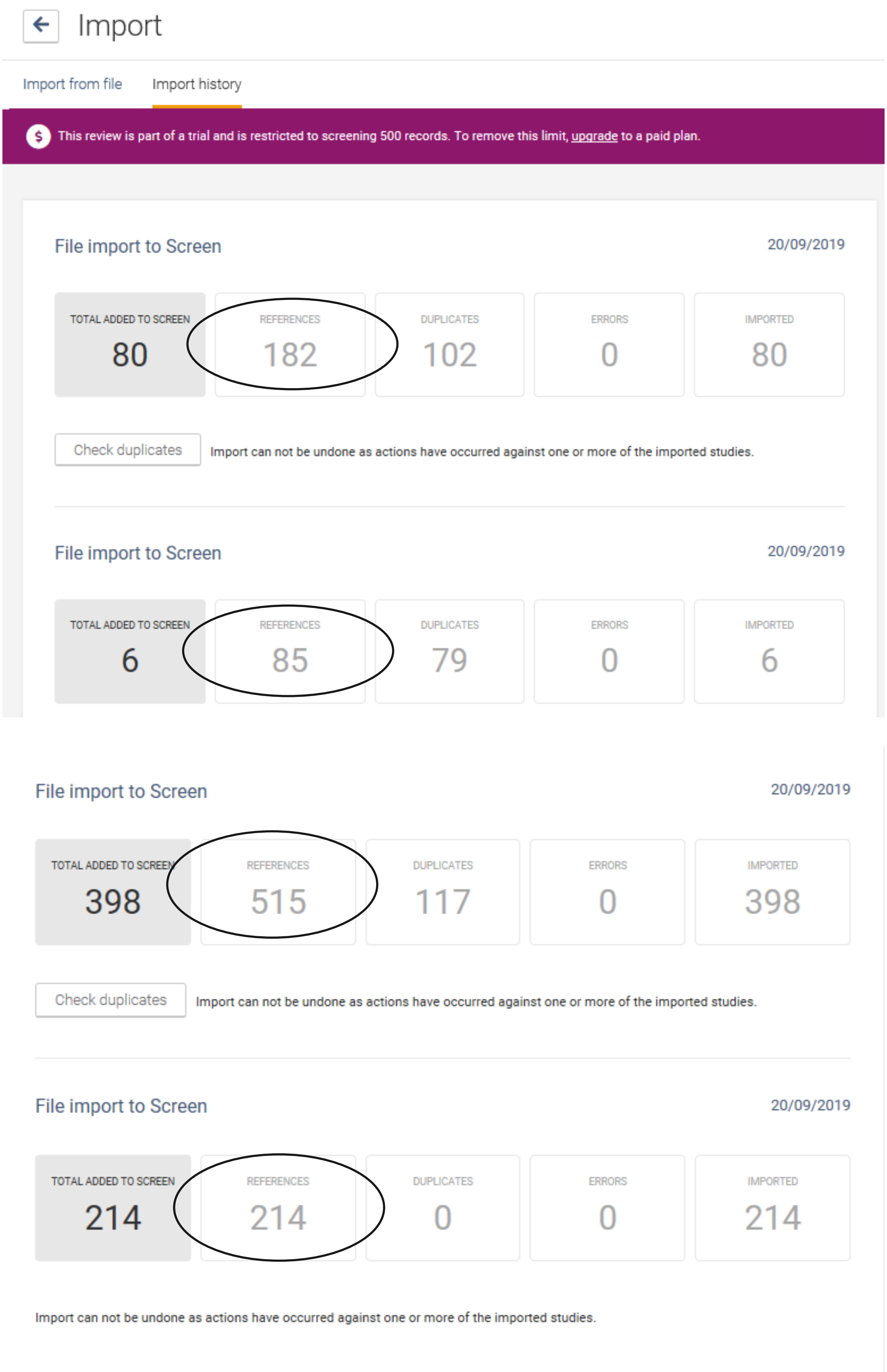
Title and abstract screening 528 irrelevant 166 studies to screen

Full text screening 4 excluded 0 studies to screen

Extraction 0 extracted 0 studies to extract

Figure 3. Screenshot of Covidence account for search update in September 2018.

Some titles and abstracts screened visually, rather than moved between folders, due to account limitations. Numbers shown in title and abstract screening row were all considered irrelevant to research question.



This review is part of a trial and is restricted to screening 500 records. To remove this limit, upgrade to a paid plan.

File import to Screen 20/09/2019

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
80	182	102	0	80

Import can not be undone as actions have occurred against one or more of the imported studies.

File import to Screen 20/09/2019

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
6	85	79	0	6

File import to Screen 20/09/2019

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
398	515	117	0	398

Import can not be undone as actions have occurred against one or more of the imported studies.

File import to Screen 20/09/2019

TOTAL ADDED TO SCREEN	REFERENCES	DUPLICATES	ERRORS	IMPORTED
214	214	0	0	214

Import can not be undone as actions have occurred against one or more of the imported studies.

Figure 4. Screenshots of individual searches per database, for initial systematic review search in September 2019.

From top down: PsycInfo, MeSH terms for "brain injury" and "stroke" (additional records only added for "stroke"), Medline Complete, CINAHL.

"References" values from each search were added together and the total number of duplicates (Appendix B: Figure 3) subtracted from it. This value (698) was then added to the total number of records (after duplicates) from the April 2018 search.

Appendix E. Topic guide

Topic Guide

Introduction: Thank you for taking part in this interview, I am going to ask you a few questions relating to your experiences since your partner/spouse acquired a brain injury. Please let me know if you feel uncomfortable about any of the questions or if you wish to stop the interview. Are you okay to continue?

1. (Set scene) I was wondering if you could tell me a bit about your life since your spouse/partner's brain injury?
   Prompt: What is life like for you now?

2. What has changed since your spouse/partner acquired a brain injury?
   Prompts: What sense did you make of he/she appearing/behaving that way? How did you interpret this? Can you tell me more about [participant's reported experience]?

3. What did these changes mean for you?
   Prompts: How did you experience these changes? Can you tell me more about [participant's reported experience]? What sense did you make of this? What did you think/feel when [participant's reported experience] happened? What has it been like to manage the changes you saw in your spouse/partner?

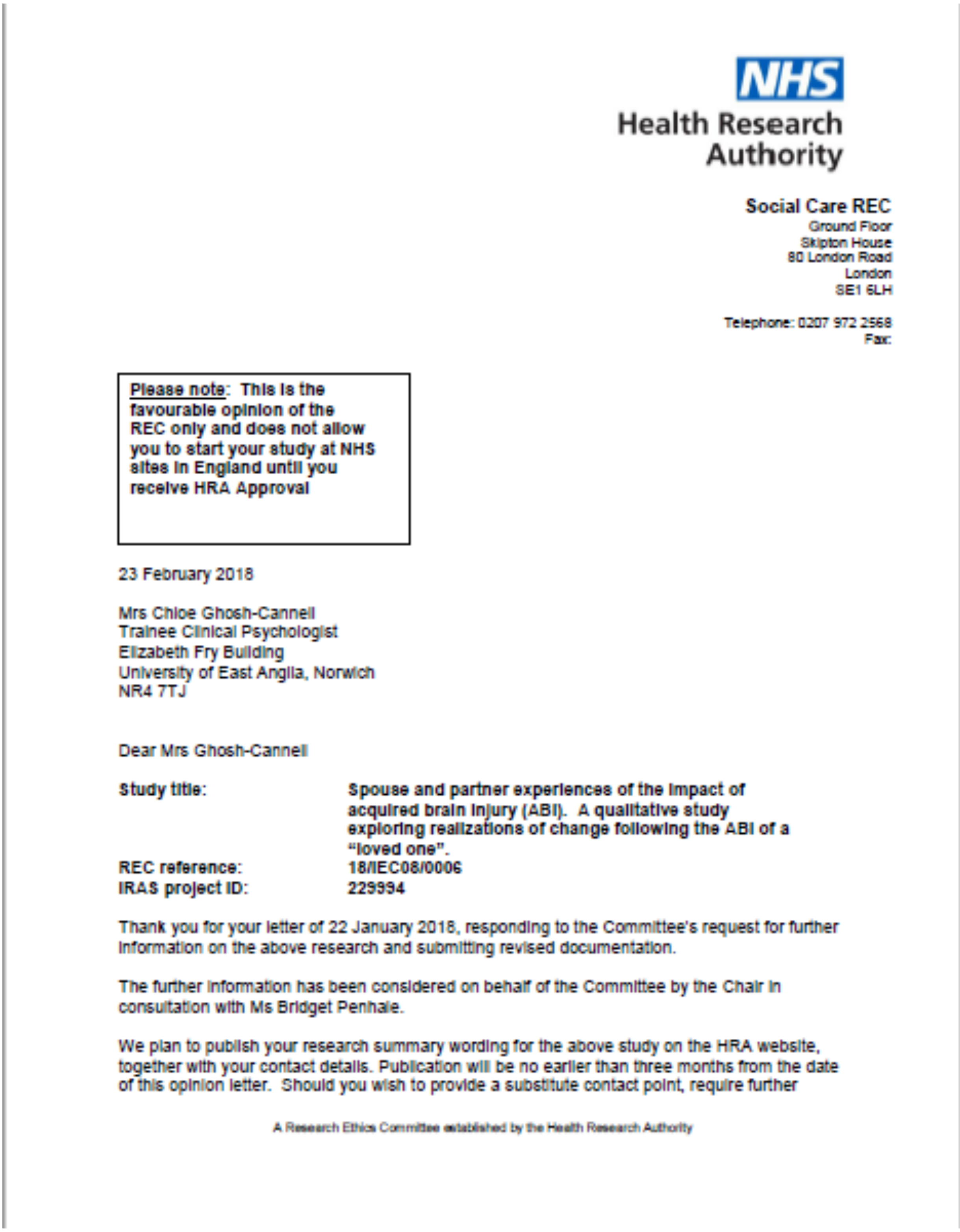
4. Could you tell me what it was like to realize that both your lives were changing?
   Prompts: What was life like at that point? What thoughts and emotions did you experience? What did you do when you noticed this change? How did you see the future at that time? Have there been any other realizations of change for you since [participant's reported experience]? Are you still noticing/realizing changes?

5. Have there been moments since the injury when you perceived yourself differently?
   Prompts: What sense did you make of this? What did this mean for you? What are your thoughts about how you perceive yourself now? What emotions do you experience when perceiving yourself in this way?

6. How did you manage changes in your life following the injury?
   Prompts: What has helped you to manage the changes themselves? Can you tell me more about what [participant's reported experience] was like for you? What personal resources did you draw on (for example, someone adapting strategies they used to manage challenges in the past)? What was it about [participant's reported experience] that eased your feeling of [reported emotion] at that time? Was there anything that you found unhelpful, how did this make you feel? What advice would you give to your past self in those moments? Is there anything else that might have helped?

7. What did it mean for your relationship when you first realized the changes to your everyday life?
   Prompts: How have you made sense of the different roles you take in your relationship? How have realizations of change influenced your relationship? What has this been like for your relationship with your spouse/partner? Do you perceive your relationship differently?

Appendix F. Research Ethics Committee letter of approval



NHS
Health Research
Authority

Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568
Fax:

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

23 February 2018

Mrs Chloe Ghosh-Cannell
Trainee Clinical Psychologist
Elizabeth Fry Building
University of East Anglia, Norwich
NR4 7TJ

Dear Mrs Ghosh-Cannell

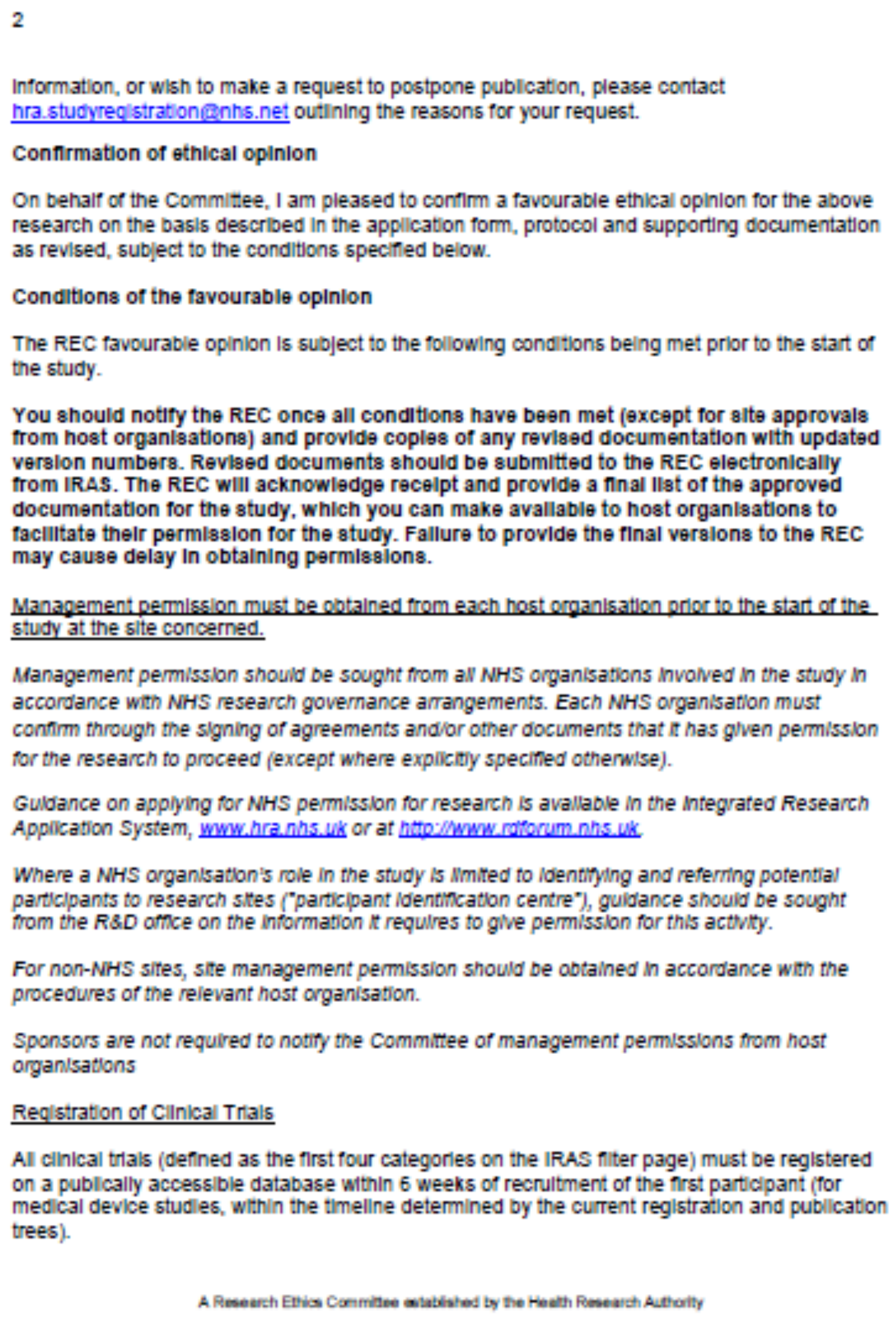
Study title: **Spouse and partner experiences of the impact of acquired brain injury (ABI). A qualitative study exploring realizations of change following the ABI of a "loved one".**
REC reference: **18/IEC08/0006**
IRAS project ID: **229994**

Thank you for your letter of 22 January 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with Ms Bridget Penhale.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further

A Research Ethics Committee established by the Health Research Authority



2

information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

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

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

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

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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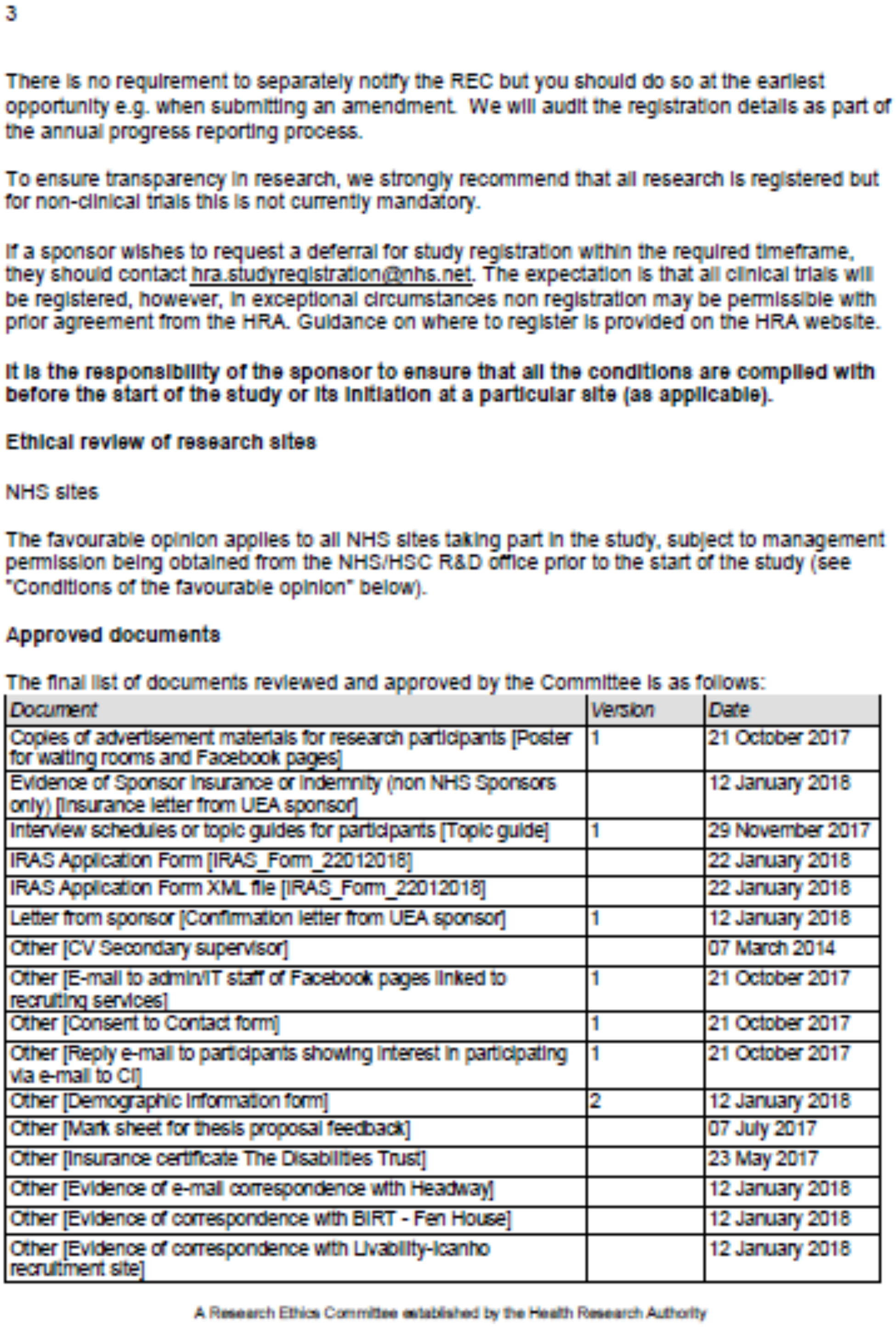


3

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

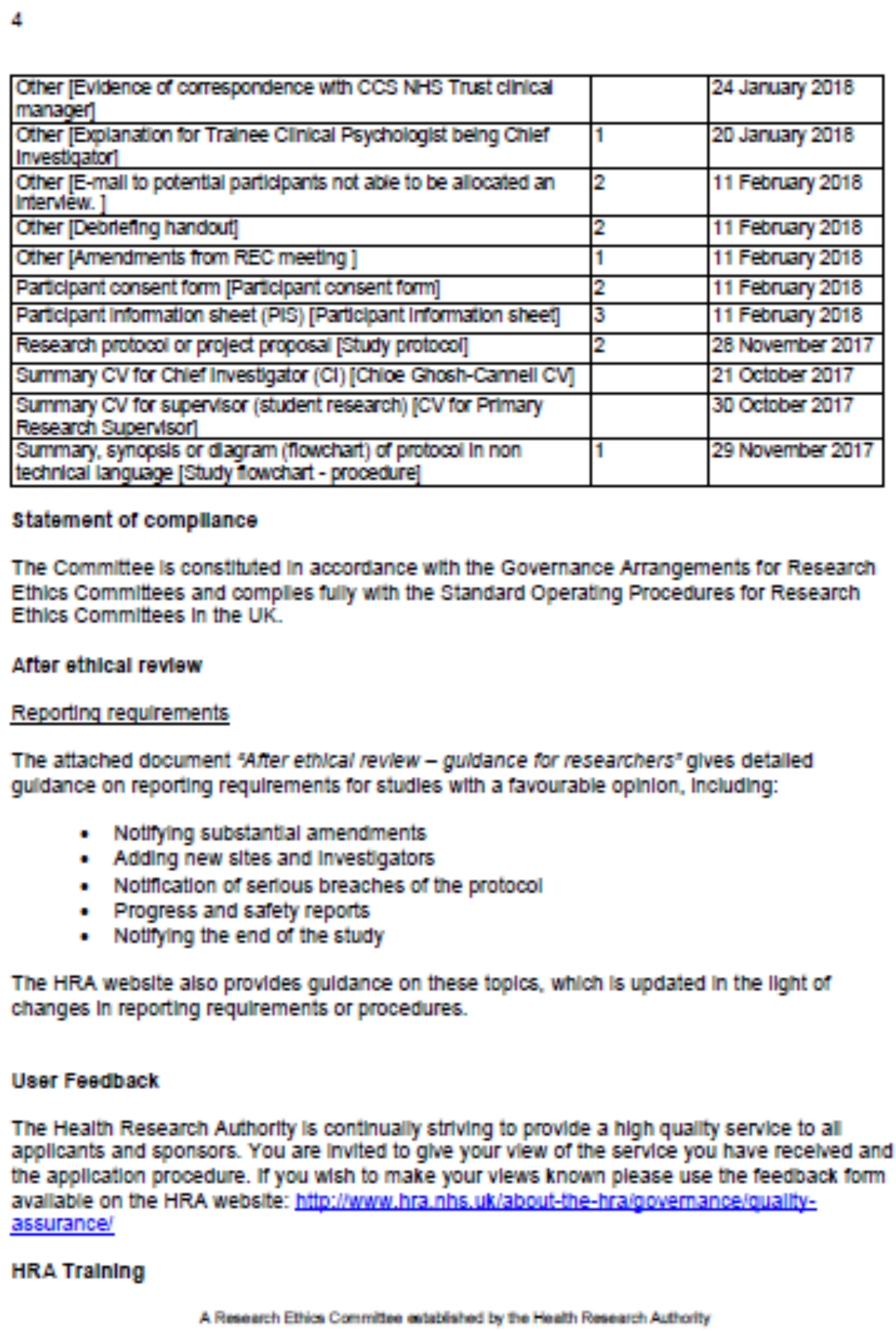
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster for waiting rooms and Facebook pages]	1	21 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter from UEA sponsor]		12 January 2018
Interview schedules or topic guides for participants [Topic guide]	1	29 November 2017
IRAS Application Form [IRAS_Form_22012018]		22 January 2018
IRAS Application Form XML file [IRAS_Form_22012018]		22 January 2018
Letter from sponsor [Confirmation letter from UEA sponsor]	1	12 January 2018
Other [CV Secondary supervisor]		07 March 2014
Other [E-mail to admin/IT staff of Facebook pages linked to recruiting services]	1	21 October 2017
Other [Consent to Contact form]	1	21 October 2017
Other [Reply e-mail to participants showing interest in participating via e-mail to CI]	1	21 October 2017
Other [Demographic information form]	2	12 January 2018
Other [Mark sheet for thesis proposal feedback]		07 July 2017
Other [Insurance certificate The Disabilities Trust]		23 May 2017
Other [Evidence of e-mail correspondence with Headway]		12 January 2018
Other [Evidence of correspondence with BIRT - Fen House]		12 January 2018
Other [Evidence of correspondence with Livability-Icanho recruitment site]		12 January 2018

A Research Ethics Committee established by the Health Research Authority



Other [Evidence of correspondence with CCS NHS Trust clinical manager]		24 January 2018
Other [Explanation for Trainee Clinical Psychologist being Chief Investigator]	1	20 January 2018
Other [E-mail to potential participants not able to be allocated an interview.]	2	11 February 2018
Other [Debriefing handout]	2	11 February 2018
Other [Amendments from REC meeting]	1	11 February 2018
Participant consent form [Participant consent form]	2	11 February 2018
Participant information sheet (PIS) [Participant information sheet]	3	11 February 2018
Research protocol or project proposal [Study protocol]	2	28 November 2017
Summary CV for Chief Investigator (CI) [Chloe Ghosh-Cannell CV]		21 October 2017
Summary CV for supervisor (student research) [CV for Primary Research Supervisor]		30 October 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study flowchart - procedure]	1	29 November 2017

Statement of compliance

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

After ethical review

Reporting requirements

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

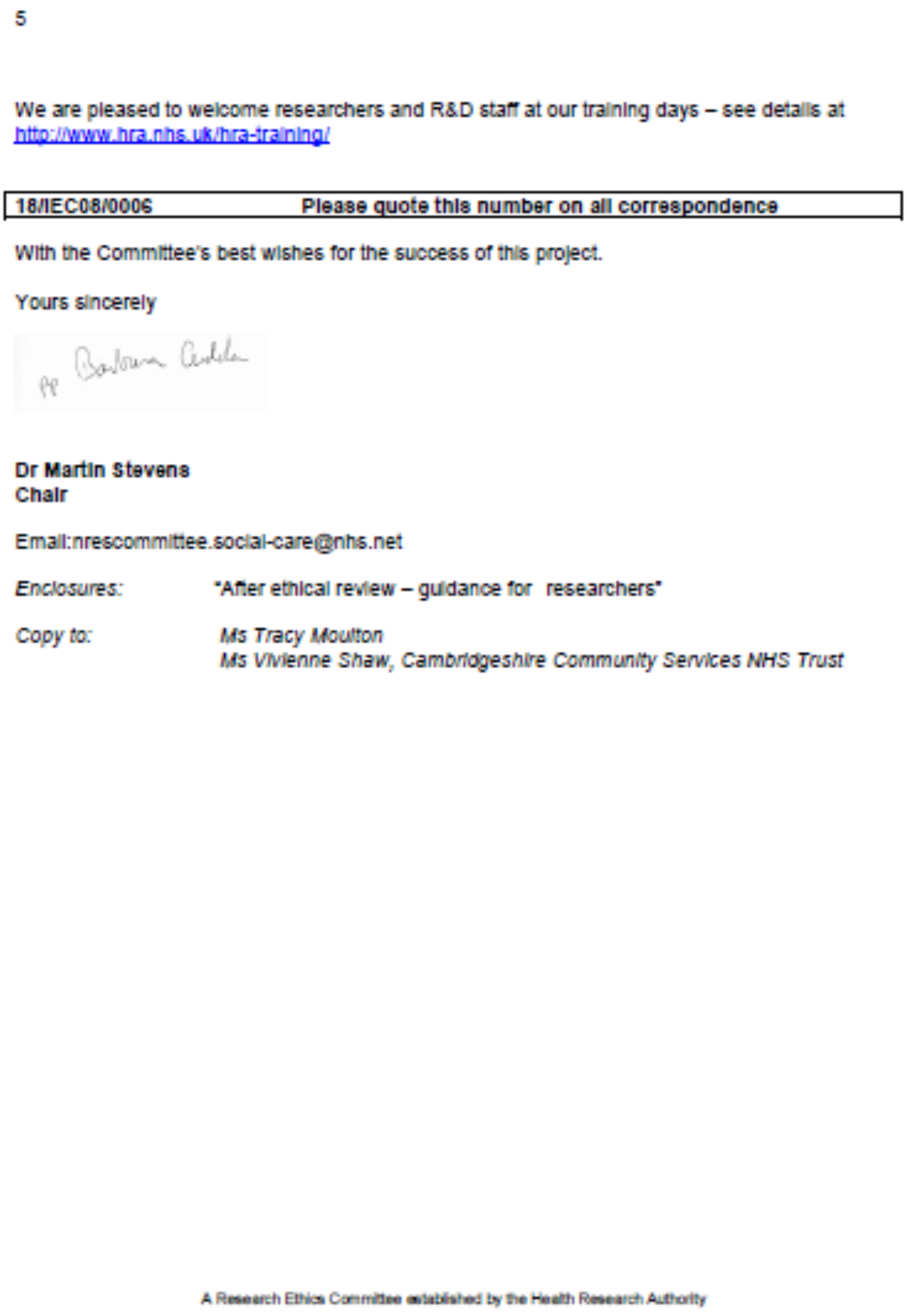
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training



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

18/IEC08/0006 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp Barbara

Dr Martin Stevens
Chair

Email:nrescommittee.social-care@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Tracy Moulton*
Ms Vivienne Shaw, Cambridgeshire Community Services NHS Trust

Appendix G. Health Research Authority letter of approval

NHS
Health Research Authority

Mrs Chloe Ghosh-Cannell
Trainee Clinical Psychologist
Elizabeth Fry Building
University of East Anglia, Norwich
NR4 7TJ

Email: hra.approval@nhs.net

23 February 2018

Dear Mrs Ghosh-Cannell

Letter of HRA Approval

Study title:	**Spouse and partner experiences of the impact of acquired brain injury (ABI).Â A qualitative study exploring realizations of change following the ABI of a "loved one".**
IRAS project ID:	**229994**
REC reference:	**18/EC08/0006**
Sponsor	**University of East Anglia**

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

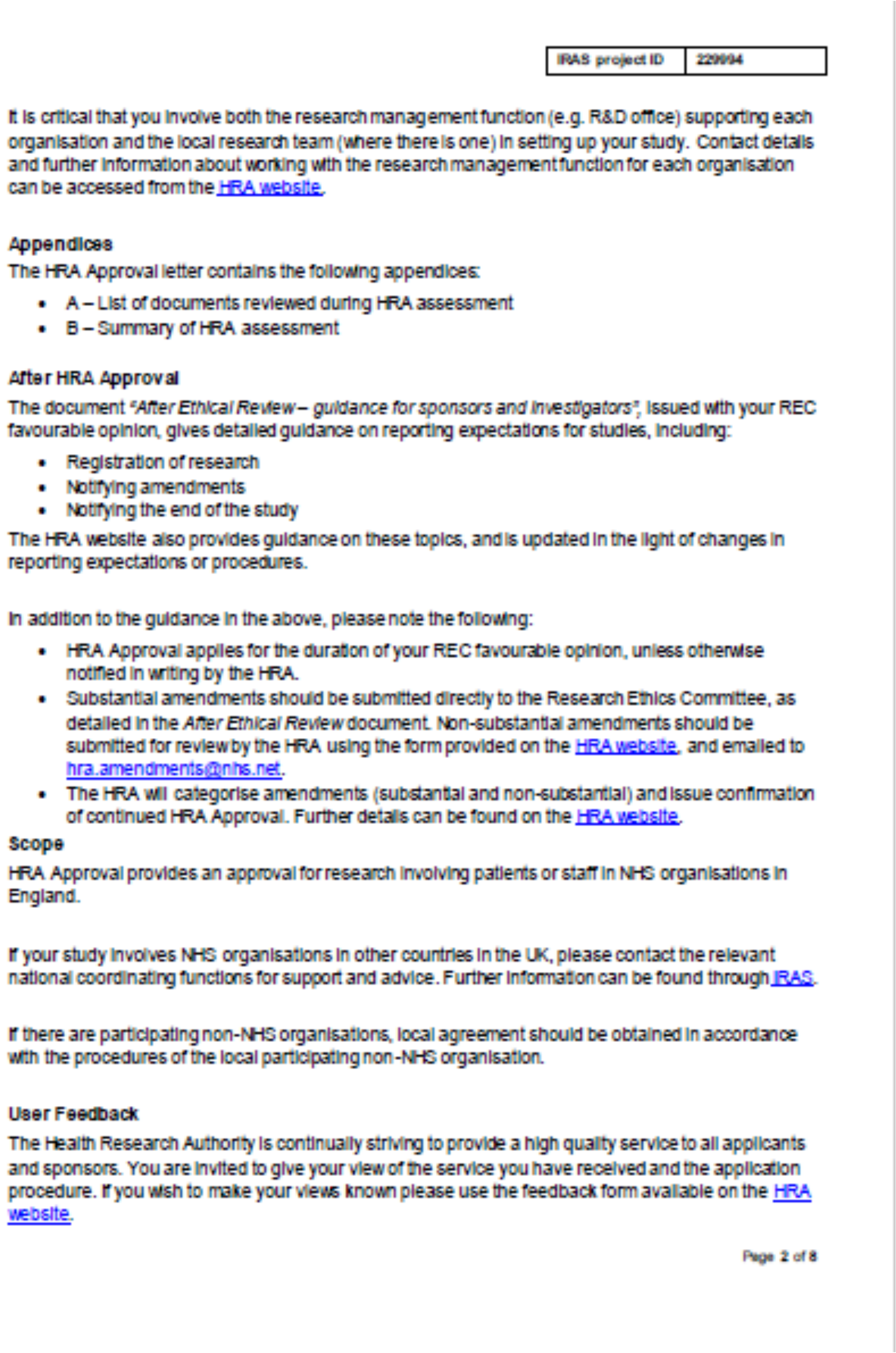
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 8



IRAS project ID	220904

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the HRA website.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

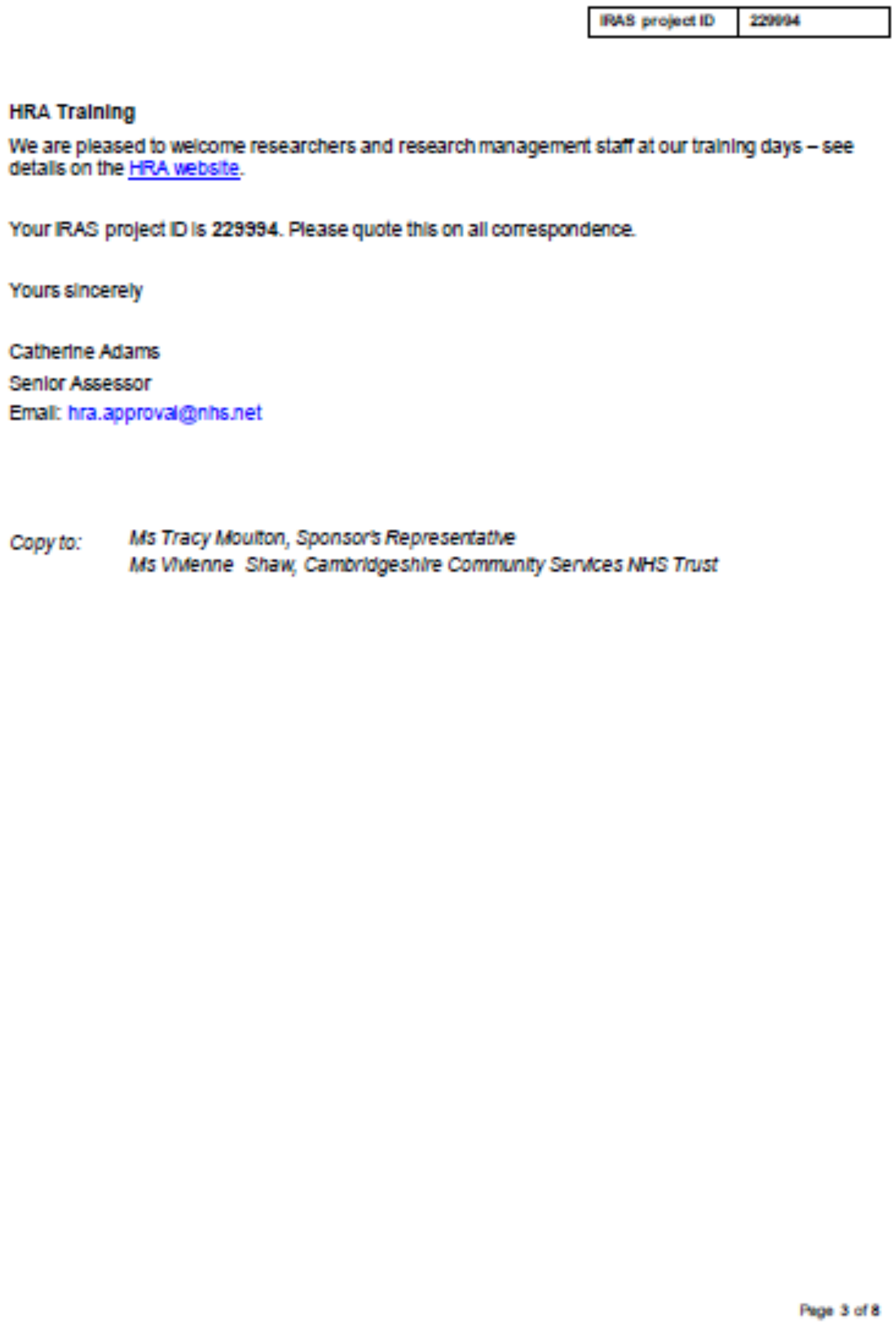
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website.



IRAS project ID	229994

HRA Training

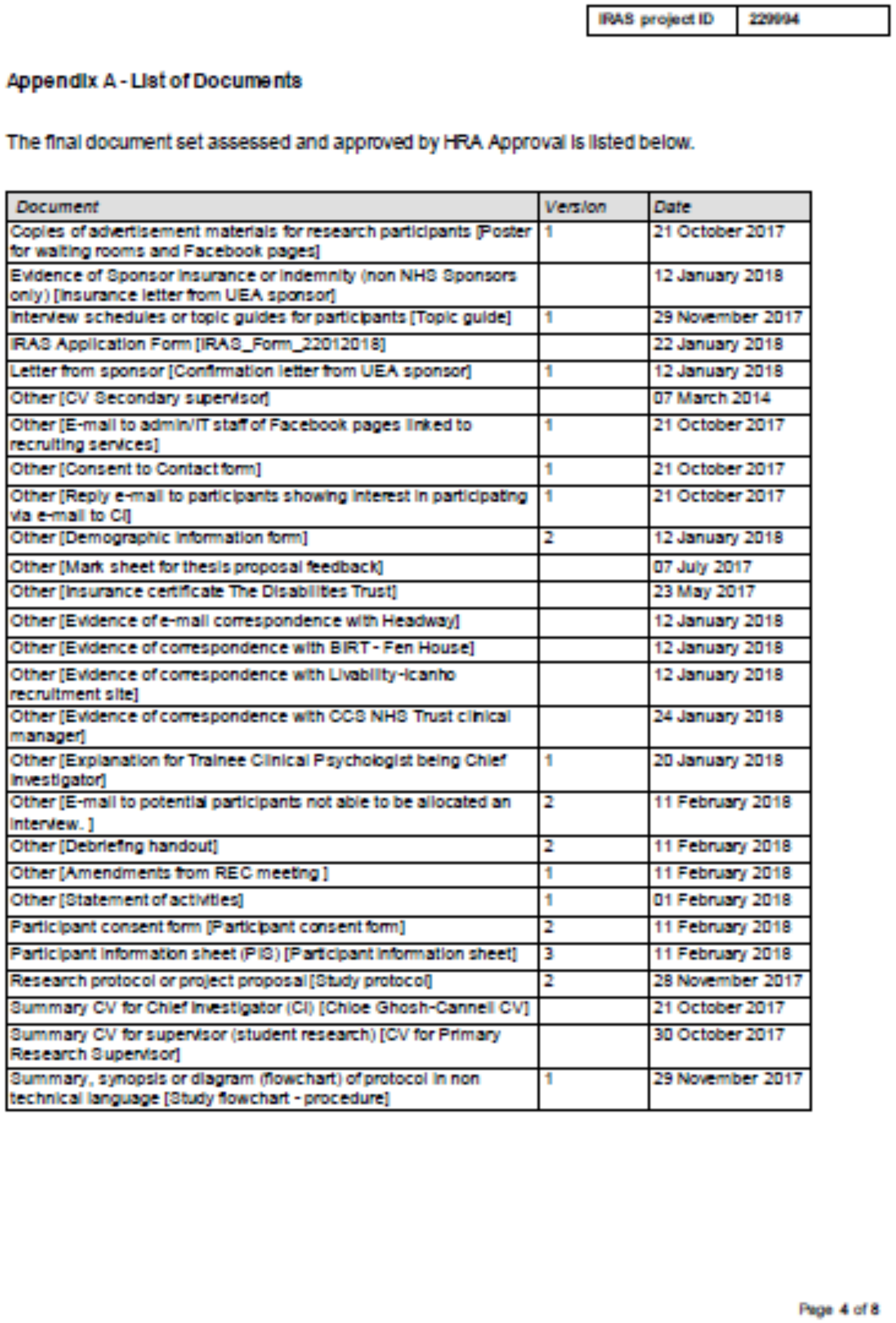
We are pleased to welcome researchers and research management staff at our training days – see details on the HRA website.

Your IRAS project ID is **229994**. Please quote this on all correspondence.

Yours sincerely

Catherine Adams
Senior Assessor
Email: hra.approval@nhs.net

Copy to: *Ms Tracy Moulton, Sponsor's Representative*
Ms Vivienne Shaw, Cambridgeshire Community Services NHS Trust



IRAS project ID	229094

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster for waiting rooms and Facebook pages]	1	21 October 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter from UEA sponsor]		12 January 2018
Interview schedules or topic guides for participants [Topic guide]	1	29 November 2017
IRAS Application Form [IRAS_Form_22012018]		22 January 2018
Letter from sponsor [Confirmation letter from UEA sponsor]	1	12 January 2018
Other [CV Secondary supervisor]		07 March 2014
Other [E-mail to admin/IT staff of Facebook pages linked to recruiting services]	1	21 October 2017
Other [Consent to Contact form]	1	21 October 2017
Other [Reply e-mail to participants showing interest in participating via e-mail to CI]	1	21 October 2017
Other [Demographic information form]	2	12 January 2018
Other [Mark sheet for thesis proposal feedback]		07 July 2017
Other [Insurance certificate The Disabilities Trust]		23 May 2017
Other [Evidence of e-mail correspondence with Headway]		12 January 2018
Other [Evidence of correspondence with BIRT - Fen House]		12 January 2018
Other [Evidence of correspondence with Livability-Icanho recruitment site]		12 January 2018
Other [Evidence of correspondence with CCS NHS Trust clinical manager]		24 January 2018
Other [Explanation for Trainee Clinical Psychologist being Chief Investigator]	1	20 January 2018
Other [E-mail to potential participants not able to be allocated an interview.]	2	11 February 2018
Other [Debriefing handout]	2	11 February 2018
Other [Amendments from REC meeting]	1	11 February 2018
Other [Statement of activities]	1	01 February 2018
Participant consent form [Participant consent form]	2	11 February 2018
Participant information sheet (PIS) [Participant information sheet]	3	11 February 2018
Research protocol or project proposal [Study protocol]	2	28 November 2017
Summary CV for Chief Investigator (CI) [Chloe Ghosh-Cannell CV]		21 October 2017
Summary CV for supervisor (student research) [CV for Primary Research Supervisor]		30 October 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study flowchart - procedure]	1	29 November 2017

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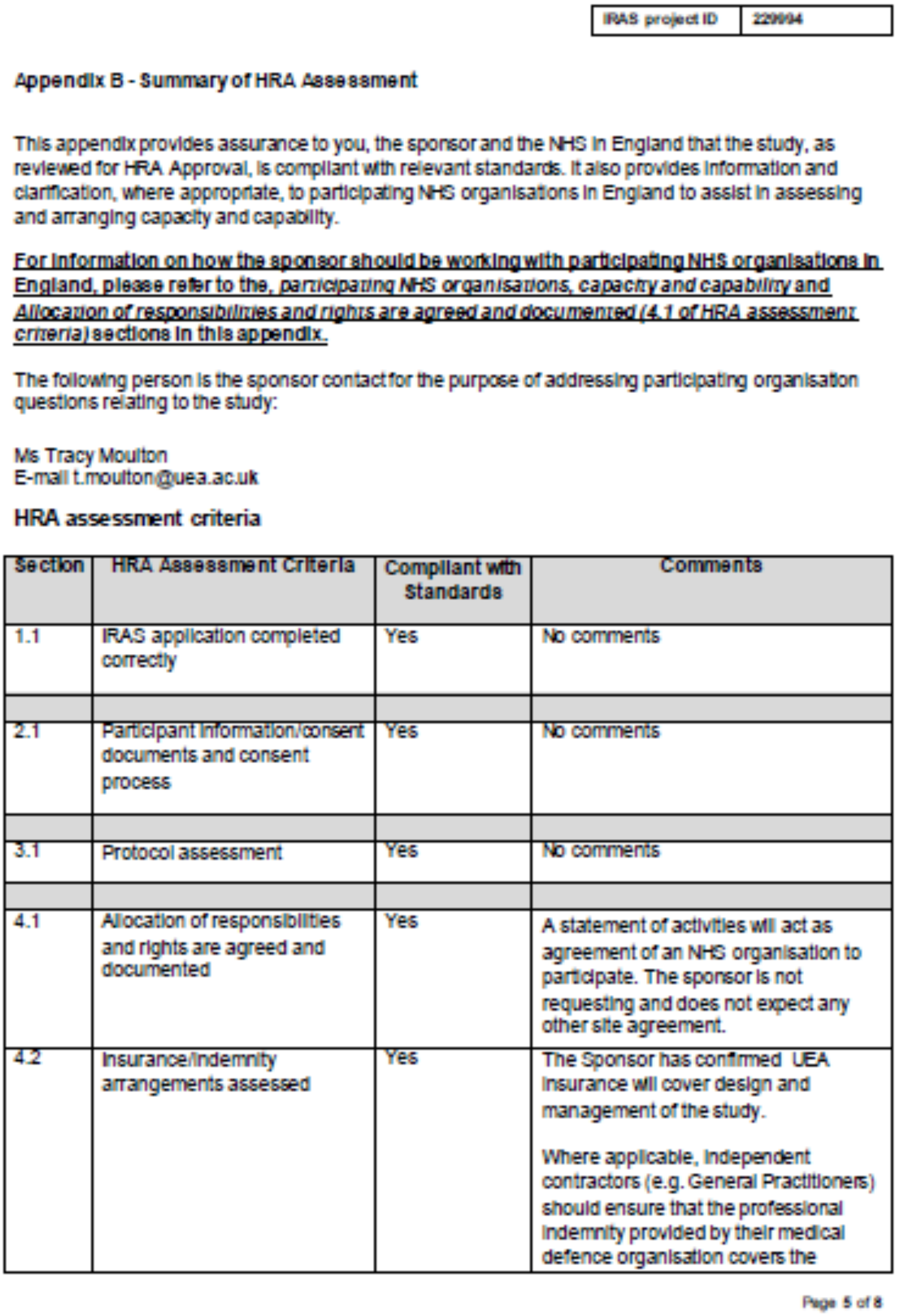

IRAS project ID	229994

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Ms Tracy Moulton
E-mail t.moulton@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities will act as agreement of an NHS organisation to participate. The sponsor is not requesting and does not expect any other site agreement.
4.2	Insurance/indemnity arrangements assessed	Yes	The Sponsor has confirmed UEA insurance will cover design and management of the study. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the

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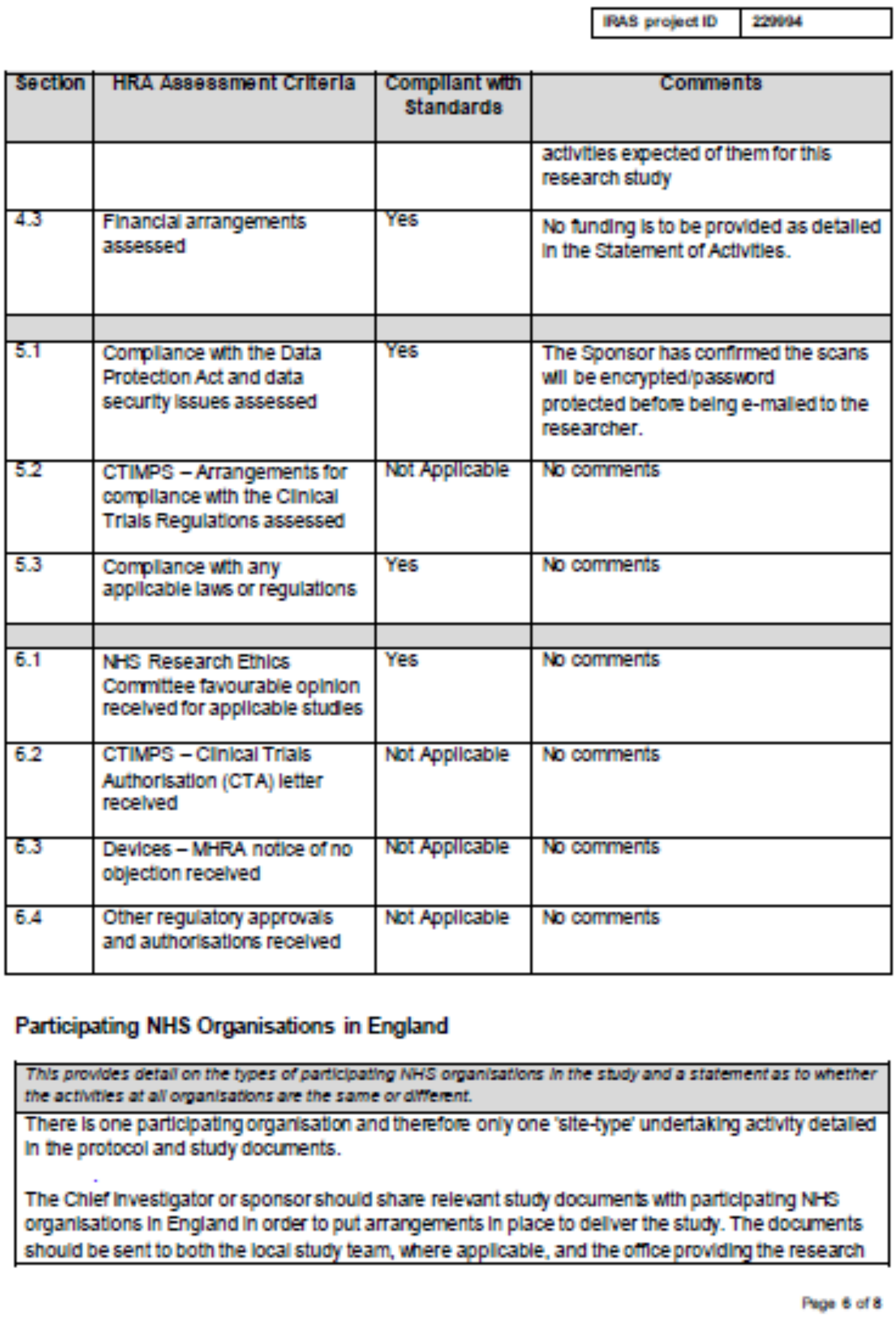


IRAS project ID	229994

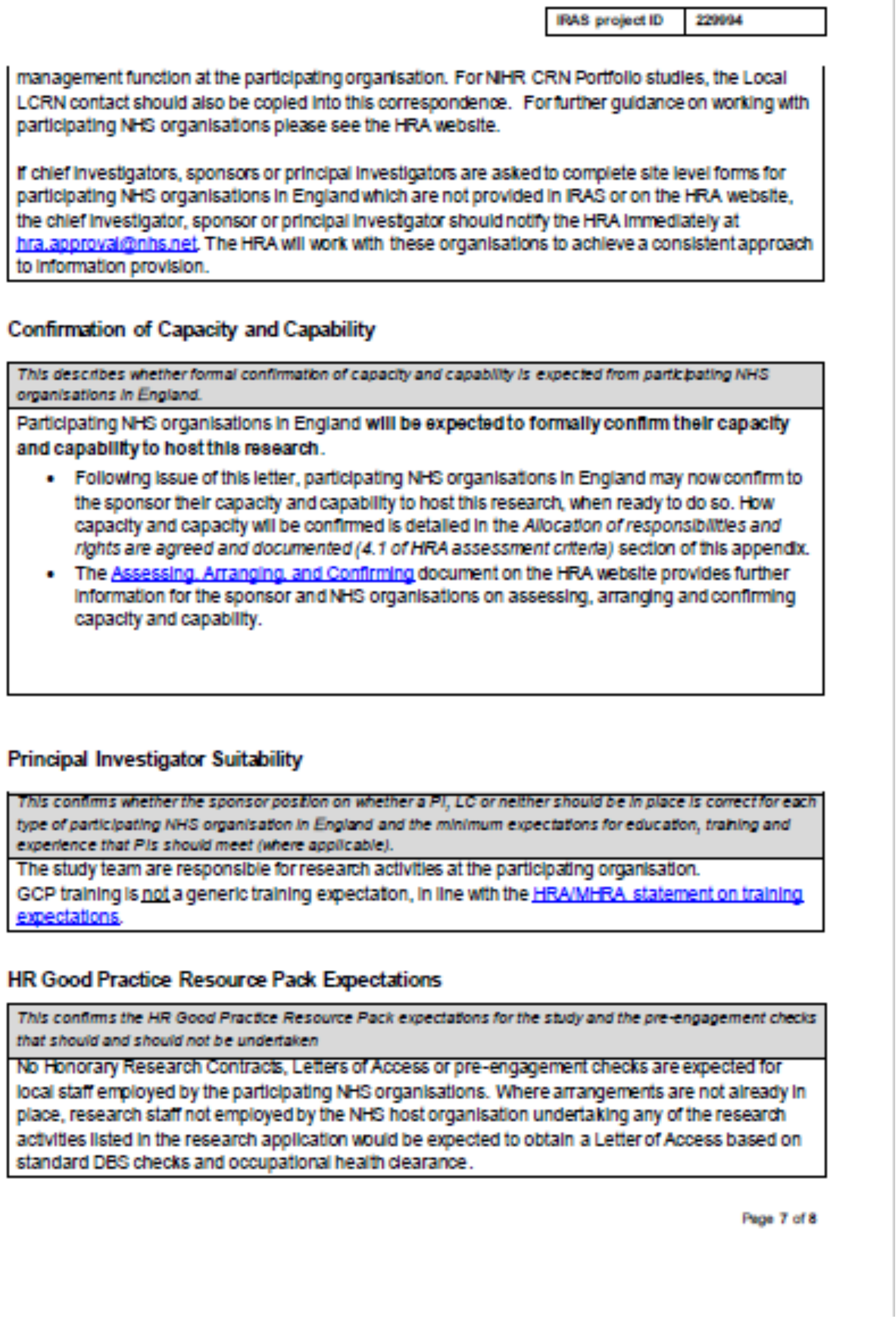
Section	HRA Assessment Criteria	Compliant with Standards	Comments
			activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding is to be provided as detailed in the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The Sponsor has confirmed the scans will be encrypted/password protected before being e-mailed to the researcher.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one participating organisation and therefore only one 'site-type' undertaking activity detailed in the protocol and study documents.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research



IRAS project ID	220904

management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The study team are responsible for research activities at the participating organisation.
GCP training is not a generic training expectation, in line with the HRA/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Page 7 of 8

IRAS project ID	229994

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

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Appendix H. Participant Information Sheet

Service logo

University of East Anglia

Participant Information Sheet

Study title:

Spouse and partner experiences of the impact of acquired brain injury (ABI). A qualitative analysis exploring realizations of change following the ABI of a "loved one".

My name is Chloe Ghosh-Cannell and I am a Trainee Clinical Psychologist at the University of East Anglia. I am conducting research to explore the experience of realizations of change in day-to-day life when somebody's partner acquires a brain injury and am inviting you to take part in the project. The information below is designed to help you decide whether this would be of interest to you.

Background and aims:

Research has found that the close family members of people with acquired brain injuries (ABI's) often experience stress, anxiety and depression. Couples may face specific relationship challenges due to needing to manage changes in relationships, reduced social support and loss within their own and their partners' lives.

The aim of this study is to find out more about how spouses and partners of people with ABI experience, make sense of and manage "moments of realization" of the changes to their own daily lives following the brain injury of their significant other.

In doing this study we hope to gain new insights into people's experiences, add to the existing literature and inform improvements to services. I am looking to recruit around twelve spouses/partners to take part in face-to-face interviews.

What will participation involve?

If you would like to take part and have been approached through a service, you can fill out a 'Consent to Contact' form and return it to a member of staff for me to contact you.

Alternatively, you can contact me using the e-mail address at the bottom of this sheet.

If you decide to take part in the study:

- Our first contact will be via phone or e-mail as preferred by you. We can discuss what the participation involves, and you can ask any questions. I may ask a couple of questions about your circumstances to ensure that this study is appropriate for you to take part.

- We then arrange a time to meet for an interview. Interviews can place at your home or at a service site if available. Due to the nature of the interview topic, it is important to ensure that your partner is not present during the interview or able to overhear the interview taking place.

- At our meeting, we will talk through a consent form and you will be asked to initial the required boxes and sign the form, if you are happy to do so.

- The interview appointment will last up to 90 minutes with the interview itself lasting one hour. The interview aims to feel like a conversation; unique to each participant.

- At the end of the interview, you will have the opportunity to ask any questions. You will be provided a handout that includes some information about further support, should you require this in the future. It also includes my contact details in-case you think of any further questions once we have finished.

- Within 18 months of your interview, you can receive details of the results via e-mail or an invite to a dissemination group, if you want to.

Confidentiality

Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

All information will be stored in a confidential manner. The interviews will be recorded on a Dictaphone and transferred immediately to a password-protected device. They will then be removed from the Dictaphone.

Any identifiable information in paper form will be kept in a lockable case and transferred to electronic storage in an encrypted UEA folder. Paper copies will then be shredded. All identifiable information will be destroyed as soon as it is no longer required for the study. It is expected that this will be after the feedback of the results.
You will also be provided a participant identification number. This helps to anonymise the data and protect confidentiality. The identification number will be printed on your copy of the consent form.

In the write up of the research, any potentially identifiable information will be anonymized with pseudonyms (made up names that replace your own). The nature of the report involves using key quotes from the interviews to illustrate the results, which will also be anonymized. The research data is stored securely at the UEA for 10 years.

Right to withdraw

You have the right to end the interview and withdraw at any point. If you decide to withdraw your contribution after the interview you need to do so **within two weeks of the date of our appointment.** This is to enable your data is fully removed from the analysis.

You do not have to give a reason for choosing to withdraw and the care/support you receive will not be affected. If you choose to withdraw after the appointment it is helpful to quote the participant identification number from your debriefing handout, so your interview can be quickly and easily removed. You can still withdraw if you do not have this information to hand.

Possible benefits of taking part

By taking part in an interview, you will be contributing to the wider knowledge about the needs of spouses and partners following brain injury, which we hope may also inform services involved in family support.

It is also hoped that the interview can provide a safe and meaningful place to talk about and reflect upon your experiences.

Possible risks of taking part

You will be asked about your experiences of a loved one's ABI, which is an understandably difficult topic to talk about, and will be approached sensitively. Should either of us feel that you are becoming distressed, the interview can be stopped at any point. If you still wish to continue the interview, the remainder may be rearranged for another day if preferred.

What would happen if there are any problems?

In the event of significant concerns around your wellbeing I would advise you to contact your GP.

For further information or to take part:

Please e-mail me at c.ghosh-cannell@uea.ac.uk.
Alternatively, please complete a Consent to Contact form and I will get in touch.
Should you have any concerns about this project and wish to speak to another member of the research team, please contact my supervisors:

Dr Fergus Gracey: Tel. 01603 593084
f.gracey@uea.ac.uk
Dr Paul Fisher: Tel. 01603 593084
p.fisher@uea.ac.uk

If you wish to speak to someone outside of the research team, please contact Prof. Ken Laidlaw, Head of Department, Department of Clinical Psychology:

Tel. 01693 593600
k.laidlaw@uea.ac.uk

Appendix I. Consent form

Participant ID:

Service logo

University of East Anglia

Study title: Spouse and partner experiences of the impact of acquired brain injury (ABI). A qualitative analysis exploring realizations of change following the ABI of a “loved one”.

Name of Researcher: Chloe Ghosh-Cannell
Name of Primary Research Supervisor: Dr Fergus Gracey

Please initial:

1. I confirm that I have read and understand the Participant Information Sheet for the above study. I have had the opportunity to consider the information and ask questions, which have been answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. The care of my partner/spouse with ABI will not be affected. ☐

3. I understand that the study may be published in a journal, but that the information I provide will be presented anonymously. The conclusions drawn from this research may inform the development of future projects. ☐

4. Relevant sections may be looked at by individuals from the University of East Anglia and/or regulatory authorities from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

5. If any concerns about my mental health arise during the interview, I may be advised to contact my General Practitioner to access long-term support. ☐

6. Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. ☐

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

______________	______________	______________
Participant name	Date	Signature
______________	______________	______________
Researcher name	Date	Signature

Thank you for your help!

Chloe Ghosh-Cannell, Trainee Clinical Psychologist: c.ghosh-cannell@uea.ac.uk

Sharing the results

Thank you for agreeing to take part in this study! The research team would like to be able to share the results with you, once all the interviews have been collected and analysed. It would also be really helpful to hear about how the interviews were for you and your thoughts on the results. This is entirely optional and will not influence any other part of the interview or analysis.

Please choose an option below for how would prefer the results to be shared:

☐ I would like to be invited to a feedback group at *[service of recruitment]* to discuss the results.
The preferred number to contact me on is
___________________________.

☐ I would like to receive an e-mail summarising the results.
My e-mail address is
_____________________________________.

☐ I do not want feedback on the results of the study.

Appendix J. Demographic information form

Participant ID:

Service logo

University of East Anglia

Demographic Information Form

Thank you for agreeing to take part in this study. To place our interview in context, please could you answer the following questions. All information will be anonymized during the analysis and reporting of this study.

Age:		**Gender:**	
Marital status:		**Ethnicity:**	
Length of relationship with partner:		**Occupation/previous occupation:**	
If you are no longer working, how long ago did you leave your job?		**How long has it been since your spouse/partner acquired a brain injury?**	
What happened to cause the brain injury?		**What are the key impairments resulting from the injury?**	
What service involvement is your spouse/partner currently receiving?		**Do you live in the same home as your spouse/partner?**	
Does anyone else live in your household?		**Any dependents or children (quantity and ages)?**	

University of East Anglia

Appendix K. Debriefing handout

Thank you!

Thank you for taking part in this study. This study aims to explore the experiences of spouses and partners of people with acquired brain injuries, with particular focus upon the realizations of change. We hope that this will lead us to define a meaningful interpretation of unique accounts. By taking part in this interview, you have made an important contribution to the knowledge base around how family members cope in the event of a brain injury, which will help inform those in roles of supporting families.

If you have any further questions or concerns following the interview, please contact me on the details below:

Researcher contact details:
Chloe Ghosh-Cannell, Trainee Clinical Psychologist
c.ghosh-cannell@uea.ac.uk Tel. 07902527685

I wish to take this opportunity to remind you that you have the right to withdraw your interview from the study. You do not need to give a reason for this and it will not affect any care or support that you may be receiving. If you do decide to withdraw, please let me know by two weeks from the date of your interview. Due to the nature of the analysis, it may be more difficult to fully remove your contribution after that time.

Should you feel that you need more formal support, the services below may be able to provide further advice and assistance:

SAMARITANS
Tel. (UK): 116 123
(free)
E-mail:
jo@samaritans.org
Helpful website:

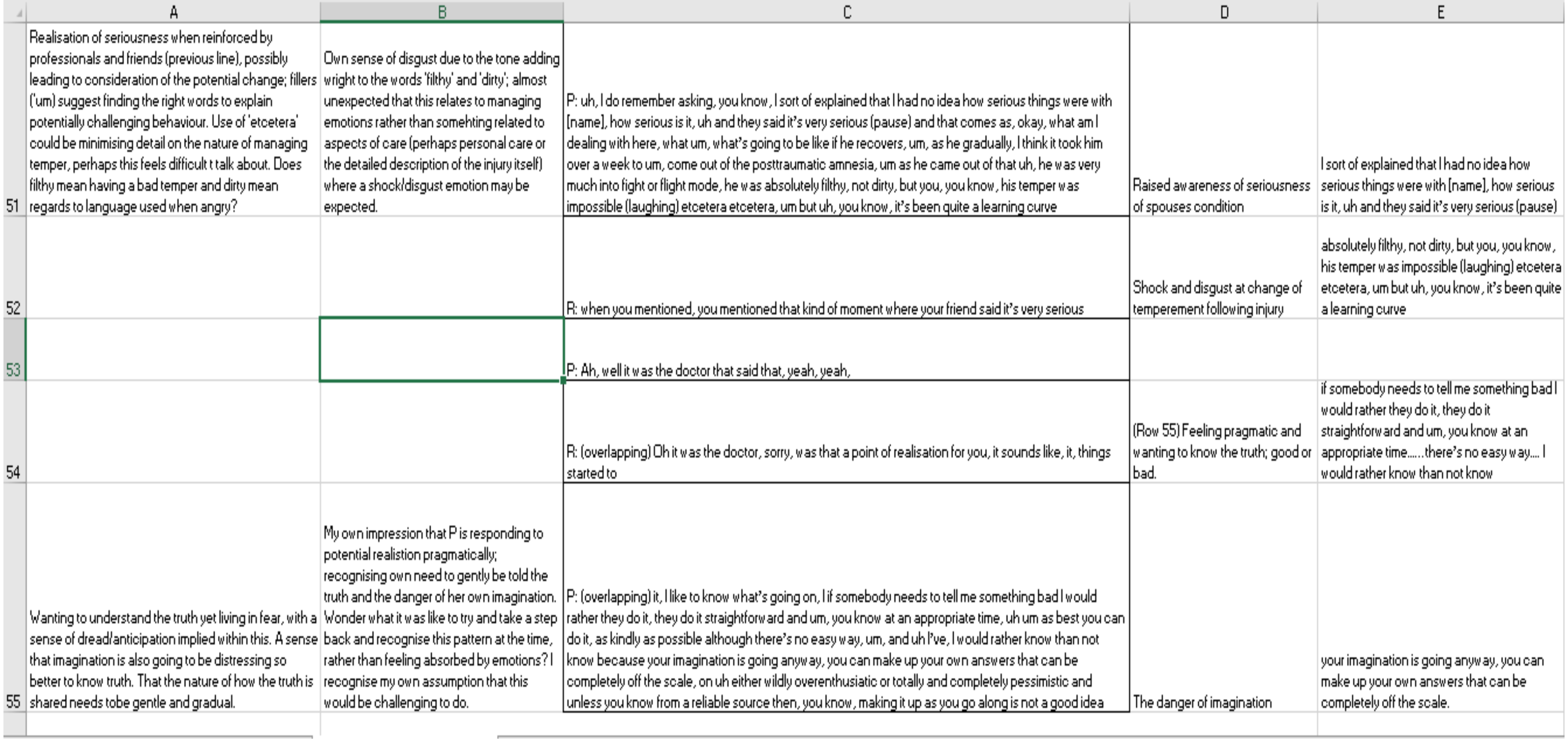
mind
Mind Infoline:
0300 123 3393
Text: 86463
Helpful website:
www.mind.org.uk

Headway
(Details of local headway service to participant)

Stroke association
Stroke Association helpline: 0303 303 3100
E-Mail:
info@stroke.org.uk

Appendix L. Demonstration of analytic process for emergent themes

Key: Rows A = initial noting B = researcher reflections C = transcript D = emergent themes E = identified quote. P = participant R = researcher.



	A	B	C	D	E
51	Realisation of seriousness when reinforced by professionals and friends (previous line), possibly leading to consideration of the potential change; fillers ('um) suggest finding the right words to explain potentially challenging behaviour. Use of 'etcetera' could be minimising detail on the nature of managing temper, perhaps this feels difficult t talk about. Does filthy mean having a bad temper and dirty mean regards to language used when angry?	Own sense of disgust due to the tone adding wright to the words 'filthy' and 'dirty'; almost unexpected that this relates to managing emotions rather than somehting related to aspects of care (perhaps personal care or the detailed description of the injury itself) where a shock/disgust emotion may be expected.	P: uh, I do remember asking, you know, I sort of explained that I had no idea how serious things were with [name], how serious is it, uh and they said it's very serious (pause) and that comes as, okay, what am I dealing with here, what um, what's going to be like if he recovers, um, as he gradually, I think it took him over a week to um, come out of the posttraumatic amnesia, um as he came out of that uh, he was very much into fight or flight mode, he was absolutely filthy, not dirty, but you, you know, his temper was impossible (laughing) etcetera etcetera, um but uh, you know, it's been quite a learning curve	Raised awareness of seriousness of spouses condition	I sort of explained that I had no idea how serious things were with [name], how serious is it, uh and they said it's very serious (pause)
52			R: when you mentioned, you mentioned that kind of moment where your friend said it's very serious	Shock and disgust at change of temperement following injury	absolutely filthy, not dirty, but you, you know, his temper was impossible (laughing) etcetera etcetera, um but uh, you know, it's been quite a learning curve
53			P: Ah, well it was the doctor that said that, yeah, yeah,		
54			R: (overlapping) Oh it was the doctor, sorry, was that a point of realisation for you, it sounds like, it, things started to	(Row 55) Feeling pragmatic and wanting to know the truth; good or bad.	if somebody needs to tell me something bad I would rather they do it, they do it straightforward and um, you know at an appropriate time……there's no easy way…. I would rather know than not know
55	Wanting to understand the truth yet living in fear, with a sense of dread/anticipation implied within this. A sense that imagination is also going to be distressing so better to know truth. That the nature of how the truth is shared needs tobe gentle and gradual.	My own impression that P is responding to potential realistion pragmatically; recognising own need to gently be told the truth and the danger of her own imagination. Wonder what it was like to try and take a step back and recognise this pattern at the time, rather than feeling absorbed by emotions? I recognise my own assumption that this would be challenging to do.	P: (overlapping) it, I like to know what's going on, I if somebody needs to tell me something bad I would rather they do it, they do it straightforward and um, you know at an appropriate time, uh um as best you can do it, as kindly as possible although there's no easy way, um, and uh I've, I would rather know than not know because your imagination is going anyway, you can make up your own answers that can be completely off the scale, on uh either wildly overenthusiatic or totally and completely pessimistic and unless you know from a reliable source then, you know, making it up as you go along is not a good idea	The danger of imagination	your imagination is going anyway, you can make up your own answers that can be completely off the scale.

Appendix M. Table of superordinate themes for single interviews, grouped via assessment of commonalities across interviews

Superordinate themes for each case	1 - Debbie	2 - Maureen	3 - Sheila	4 - Tina	5 - Iris	6 - Alice	07 - Hazel	8 - Florence	9 - Grace
Accepting being 'me'	Yes	Yes	No	No	Yes	Yes	No	No	Yes
Fear and questioning around spouse loss of functioning	Yes	No	No	No	Yes	No	Yes	Yes	Yes
Feelings of empathy versus frustration	Yes	No	No	Yes	Yes	Yes	No	No	No
Pushing the bad emotions away; persistent positivity	Yes	No	No	No	No	No	Yes	No	Yes
Spouses vulnerability 'hitting home'; a lot to learn	Yes	No	Yes	No	Yes	No	No	No	Yes
A sadness of intensity; a struggle to express through language	Yes	No	No	Yes	Yes	No	No	No	No
A shaken partnership taking diverging trajectories	No	Yes	Yes	Yes	No	No	Yes	No	No

Being a home maker or woman intensifies the experience of feeling trapped	No	Yes	Yes	Yes	No	No	No	No	No
Unfolding events leading to new perceptions	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes
Bravery to face lingering awareness and emotions of post-BI change	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Letting go' of the pressure and finding empowerment	Yes	Yes	No	No	No	No	No	Yes	Yes
Urgently striving for recovery and a return to pre-BI life	No	No	Yes	No	Yes	No	Yes	Yes	No
'Reality hitting home': Spiralling out of control in the face of unresolvable change	No	Yes	Yes	No	Yes	No	Yes	No	No
Encumbered by forced roles that were not supposed to be	No	Yes	Yes	No	No	No	Yes	No	No
Ever-widening space between the self and others: isolation and loneliness	No	No	Yes	Yes	No	Yes	Yes	No	No
Gathering back pieces, the self and keeping going	No	Yes	Yes	Yes	Yes	No	No	No	Yes

The weight of persistence being lifted through witnessing spouse's realisation of their own limitations	No	No	No	Yes	Yes	No	No	No	No
Re-living and repeating the realisation of loss and abandonment through difficult post-BI incidents	No	Yes	Yes	Yes	No	No	Yes	No	No
Battling absorption of distress versus determination for hope and persistence	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No
Lost and trapped in an unsolvable maze	No	Yes	Yes	Yes	Yes	No	Yes	No	Yes
The danger of imagination versus living with the unknown	No	Yes	No	No	Yes	No	No	No	No
Riding the wave of change to navigate the unknown	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Our change is the 'new normal'	No	No	No	No	Yes	Yes	No	No	Yes
The feeling of 'unbelief'; gradually facing the emotional self	No	No	Yes	Yes	Yes	Yes	No	No	No

Recognising a familiar, parent-like approach within newfound dependency	No	No	No	No	Yes	Yes	Yes	No	Yes
Turning to focus on what really matters amongst the chaos or emergency	Yes	No	No	No	No	Yes	No	No	No
Finding personal acceptance towards adapting to post-BI life together	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes
Capturing and holding onto personal connection	No	No	No	Yes	Yes	Yes	No	No	Yes
feeling unprepared for the winding emotional path towards recovery	No	No	Yes	No	Yes	No	Yes	Yes	Yes
A carer being 'me'; trapped between familiarity and commitment versus facing the demands of a changed future	No	Yes	Yes	No	No	No	Yes	Yes	Yes
Pushed apart by brain injury; emotional connection drifting away from spouse	No	Yes	Yes	Yes	No	Yes	Yes	Yes	No
Humour as a strength of connection with the present moment	Yes	No	No	No	No	No	Yes	No	Yes

Grappling with the untrodden journey of loss and multiple change	No	No	Yes	No	Yes	No	Yes	Yes	Yes
Determined to cope; a spectrum of hidden and accepted emotions	No	No	Yes	Yes	No	No	Yes	Yes	Yes
Swinging between holding onto hope versus anticipation of further deterioration and change	No	No	Yes	Yes	No	No	No	Yes	Yes
Finding the strength to accept a new life together	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes
Like a goldfish in a bowl'; sadness within a permanent regime	No	Yes	Yes	No	No	No	Yes	No	Yes
Jumping into overwhelming responsibility	No	Yes	Yes	No	No	No	No	No	Yes
Lost hope with impending permanency	No	No	Yes	No	No	No	Yes	No	Yes
Recognising the changed 'me' that I never thought I'd be	No	Yes	Yes	Yes	No	No	No	No	Yes

Appendix N. Tables depicting additional subthemes and superordinate themes (within cases), which formed the subthemes and main themes across accounts

Table 1. Themes forming "Pushed apart by brain injury".

Superordinate theme across cases	Pushed apart by brain injury		
Subthemes across cases	Navigating a changed marriage	Being alone in a partnership	
Superordinate themes within cases	(Hazel) Pushed apart by brain injury; emotional connection drifting away from spouse	(Maureen) A shaken partnership taking diverging trajectories	(Alice) Capturing and holding onto personal connection [polarized]
Subordinate themes within cases	Experience of marriage ending to make room for dependency	perceiving a personal boundary between self and post-BI life.	Recognising spouses personality amongst the chaos
	Perceiving spouse as a different person	An intrusive third person	Holding onto conviction that spouse could hear and personality was still intact
	Witnessing a child-like spouse	Feeling of no longer having a partner on journey through life	Feeling empowered towards unknown future alongside spouse

Table 2. Themes forming "Bravery to face lingering awareness and emotions".

Superordinate theme across cases	Bravery to face lingering awareness and emotions			
Subthemes across cases	Facing the boundaries of being a wife		Holding the emotion of unexpected change	
Superordinate themes within cases	(Florence) Swinging between holding onto hope versus anticipation of further deterioration and change	(Maureen) Bravery to face lingering awareness and emotions of post-ABI change	(Iris) The feeling of 'unbelief'; gradually facing the emotional self	(Tina) Battling absorption of distress versus determination for hope and persistence
Subordinate themes within cases	striving for things to be better versus preventing rumination on negative thoughts	Acknowledging and experiencing guilt for the presence of 'taboo' thoughts	Distancing self from situation - sense of surrealness that is a struggle to express without metaphor	Hidden struggles; working to appear calm but constantly striving to manage underneath
	swinging between hope for things getting better and worry around irreparable nature of change	Pressure and worry of society-imposed responsibility	Unbelief' - not being able to acknowledge and attend to reality in the moment	Absorbing all emotions with no outlet for expression
	recognising own limitations and sense of powerlessness	Emotional heaviness of holding and managing spouses' emotions	Fearing yet gradually approaching the presence of emotional pain	Personal distress and heartache leads back to "absorbsion" of own emotions

Table 3. Themes forming "Lost and trapped in an unsolvable maze".

Superordinate theme across cases	Lost and trapped in an unsolvable maze		
Subthemes across cases	Trapped and isolated from the life that once was		Balancing dilemmas within muddled changes
Superordinate themes within cases	(Tina) Lost and trapped in an unsolvable maze	(Grace) 'Like a goldfish in a bowl'; sadness within a permanent regime	(Iris) The danger of imagination versus living with the unknown
Subordinate themes within cases	Incredibly hard to try and attribute emotional responses to injury preventing feeling that sense has been made of change	A continuous and never-ending regime	Feeling that sometimes not knowing is the better option
	Difficult to describe analogy as feeling of "stuckness" leads to sense of any pattern stopping.	Living with the permanency of responsibility	Feeling pragmatic and wanting to know the truth; good or bad
	Losing perception of self and seeing self as weakened	Continuously holding never-ending appointments in mind; a constantly busy regime	Facing multiple unknowns; emotionally sitting with uncertainty

Table 4. Themes forming "Unfolding events leading to new perceptions".

Superordinate theme across cases	Unfolding events leading to new perceptions		
Subthemes across cases	A realisation of personal acceptance	A gradual shift in perception of self and other	
Superordinate themes within cases	(Grace) Finding the strength to accept a new life together	(Iris) Riding the wave of change to navigate the unknown	(Alice) Turning to focus on what really matters amongst the chaos or emergency
Subordinate themes within cases	Holding onto a shared connection despite changes	Adjusting expectations and managing shock of 'in the moment' change	Potential end of life leading to consideration of possible regrets
	Personal commitment to making lifestyle change together	Early noticing of anger in spouse and feeling of not knowing what to do for the best	Being brought further together by occurrence of stroke
	Deciding to accept unchangeable circumstances		Reflection and re-evaluating values following stroke

Appendix O. Tables to demonstrate superordinate themes with within-case subthemes and quotes for a single transcript

Table 1. First superordinate theme and subthemes.

Superordinate theme Unexpected change in the spouse I knew; a multitude of emotions	Quotes
Overnight dependency; noticing a sudden contrast pre and post stroke	I went from having a man who used to love walking and being outside cos' we'd always been in, suddenly to somebody who was on, on fourteen medications a day, insulin injections and just totally dependent
Mood changes holding less of an overt than change to subdued spouse	personality wise in some ways he's much kinder because he was always a foray Italian and now, he's, he's very much subdued....we get some little outbursts.......I've got a nice dented freezer where he had, with his walking stick one morning.....but thankfully, I mean this don't happen often....
Finding positives in some aspects of personality change; making post-BI life manageable	If he'd had been the hot headed person he was before I don't know if I could have coped or if I'd have wanted to cope to be honest, cos I think you don't, nobody want to be a whipping horse….
Child-like reliance, change in role from confident to anxious; role change	He can't go out there without two sticks and my arm, you know, to take, to go out in the garden that's hold me, hold me, because he's got that fear of falling…..
Loss of an expected future to dependency at home	...said right [name] when we retire we'll sell off bit by bit and we'll have nice holidays, suddenly you know, I took him away in June……. he cried because he didn't know where he was and he wet himself

Sadness and shock at seeing spouse loss of role	I did find that hard and I think he found that hard to accept and I must admit when I sent his licence back I, I did find that hard, and when I took the first car insurance to my name I said do you have to take his name off....I just feel I can't strip him of everything
Sadness and empathy with loss of previously-engaged aspects of daily life for spouse	He used to play golf and he used to play [inaudible] and, you know, we could do things together go out for the day and that sort of thing, but now, no none of that
A symbolic and lost spouse	Lost my husband with him, he's just, he is, he still has his wedding ring on but he int, he int wha-
Heartache from witness spouse be present yet also gone	Although he's there, he's still your husband, but that's regarding, with life there is nothing, there's nothing, and I think what hurt me the most is that he can't do anything
A flood of emotions when witnessing helpless spouse	That ain't a nice feeling, very, you feel very empty inside, you know, you feel sad, you feel empty, you feel overcome, a whole hoard of emotions really

Table 2. Second superordinate theme and subthemes.

Superordinate theme: Finding the strength to accept a new life together	Quotes
Holding onto a shared connection despite changes	We still manage to have a smile together….
Personal commitment to taking lifestyle change together	We've been married now for forty-six and a half years, you just, ah, you know he's my husband and I'll do my very best to the end
Sudden jump to acceptance of post-BI life	I had to accept it and just get on with it as, as you would say really, I means, that's no big jump that anybody want, you could probably do it gradually but because that all happened so quickly
Personally better to work hard supporting spouse than experience the emotional repercussions of putting spouse in a home	People have said to me why do you do it, why do you not [name] in a home and have your life, but I couldn't do that you see, I'd beat myself up far more than, working myself very hard to look after him
Personal commitment to taking lifestyle change together	I never thought oh what's he doing to my life, I just accepted that we're together as a couple and whatever come, have gotta be faced
Making a decision to accept unchangeable circumstances	…..I told myself if you fight it, that's not going to change, just going to make life worse for both of us and that's not going to alter anything, we're still going to be in this situation

Personal commitment to taking lifestyle change together	Whatever come you sort of have to, cope with, you know, I don't know if I'm lucky or stupid but that's the way it's been really (laugh)
Recognition personal strength in own values caregiving role	I'm a lot stronger than I thought I could be, cos' I had to be, you know, a lot of us oh, you know, a lot of us 'oh you are strong you carry on day by day'
Putting own life on hold to commit to supporting spouse	...but my whole life to be honest [my name] is my husband, I mean as I said other people say oh I, I've emails saying oh can you come to the pictures you know, we're all going to the pictures…..
Feeling of personal agency in being able to manage post-ABI life	I just thank god that I can accept [my name] cos' we'd be in a real old muddle if not, I don't think he would have been here to be honest.....I never could see that for a long while when [name] used to say 'oh mum you've kept him alive, you know, dad wouldn't be here now' I used to say to myself, oh it's a silly sort of thing but you know, but I realise now it, it's right (pause) because when I aren't, aren't there you know, is fort of 'ohh ohh you're back' you know he's anxious that I'm there

Table 3. Third superordinate theme and subtheme.

Superordinate theme "Like a goldfish in a bowl"; sadness within a permanent regime	Quotes
Sadness and empathy with loss of previously-engaged aspects of daily life for spouse	He have bouts when he can't quite understand anything and we get asked just sort of questions well, so 'do this house belong to us [name]' yes, 'but is it our house I don't think that is our house', yes, yes it is, 'well that cabinet don't belong to us, that int, that shouldn't be here that doesn't belong to us' yes it is....and we'll have bouts like that where the brain, you can see the blankness in his eyes
Loss of engaged spouse; 'zombie-like' helplessness	Washing him and that sort of thing er, it, like a zombie, you know nothing was registering he'd he's always loved food, he's always had a brilliant appetite and is always enjoying, I love, love home cooking I do, around food, and erm, he'd say, he'd sit and have it and he said 'well have I had lunch today' and obviously we had, do you remember what we had 'no, no' ......
A continuous and never-ending regime	Sometimes I feel like a goldfish swimming round in a medical bowl, because erm, there's never no release you know, there's always something
Living with the permanency of responsibility	Never got any better (pause)….I realised that this was like, that weren't, that weren't go-going to be any different

Continuously holding never-ending appointments in mind; a constantly busy regime	I'd said to the nurse can you please put us down for after half past two cos' we aint going to be here until, and it for-four o'clock......I phoned the nurse and they said well we've been to yours twice well I said I did say you know, and she looked at me and she said [name] I apologise that's here as clear as anything for half past two, so she said well can I come at seven o'clock tomorrow morning and take, do his blood and fax it through and I said yeah course you can, that is what our lives were, oh, constantly.....cos there was never a day went by where there weren't something medical
Agreement with perception of repetitive regime as a 'life sentence'	[Brother said] 'here you are girl you've got yourself a life sentence' and I thought well that's a bit harsh and he was right, because that is, that's a regime of not being how you want to be or doing what you want to do

Table 4. Forth superordinate theme and subthemes.

Superordinate theme Jumping into overwhelming responsibility	Quotes
Feeling overwhelmed from juggling multiple responsibilities	I'm always having blood test and every week we more or less have to go for the warfarin because his blood thickness is, is wrong at the moment and they can't get it right and we had, we had so many medical appointments and we still do because eyes are affected, he was more or less blind when he come out of hospital, erm, with the inflammation, ear were affected, the physical is affected…….
Feeling of needing luck when taking on new carer role	I remember the sister coming to me that afternoon they were sending him home, she pat me on the shoulder and way 'well good luck' and I said I look as though I'm going to need it, you know there's great big, big, big thing
Emotional weight of undertaking full responsibility for someone else	When they're in a medical field they're looking after him aren't they, you're seeing him but that's when you get 'em home you know that you're responsible for that person, that impact really hit you then
Emotional pressure of navigating the unknown with full responsibility and spouse helplessness	The first day they sent him home and I had him the bath and was washing him and he was (sigh) just like a limp rag you know and I thought, you know, oh my god I got a zombie, they were the feelings I had then, you know I just thought that was sheer weakness I didn't realise exactly why
An overwhelming and unexpected enormity of responsibility	Overwhelming, really, you can say overwhelming, because, you know, suddenly you think here am I and you got, you got all this responsibility

Facing the accumulation of own and spouse’s former role at home	When you see somebody that could do, do manual stuff and that, and now whatever happen......you’ve gotta do it, there’s nothing that I can ask him to do you see, I mean he used to before, I used to say do all the home cooking and he’d chop the vegetables and that sort of thing, but you can’t because he can’t stand to do it, so you, you just accept that he can’t do anything that you’re the one who gotta do it

Table 5. Fifth superordinate theme with subthemes.

Superordinate theme Lost hope with impending permanency	Quotes
Hope being changed to feelings of loss	Came home in such a bad state and I think that more or less hit me straight away but you're always hopeful, you're always hopeful that with time, things are gonna get better..... but then after a while you realise no they're not, and then, you know when you have the diagnosis of dementia as well as the brain injury and you look into it a little bit more you realise no this is it, the life we had is gone
This is it'; lost hope and life being changed forever	Hopeful that with time, things are gonna get better…..after a while you realise no they're not…..you look into it a little bit more you realise no this is it, the life we had is gone
Sudden change in social life and recognition of permanency	This isn't a temporary measure this is your life, you suddenly think to yourself well, and I have friends send me e-mails and oh we've just finished this holiday we've planned another one we, I, I mean three, three weddings we were invited to we can't go....
Time reinforcing sense of permanency; a forever changed spouse	As time went by and there's no progress only, you know, you realise that even more, this is life, this is my husband this is how he is

Table 6. Sixth superordinate theme with subthemes.

Superordinate theme Recognising the changed 'me' that I never thought I'd be	Quotes
Taking on responsibility for spouses fight; new role of being the assertive one	I surprised myself most I, suddenly I could assert myself more, you know, because when you're fighting someone else's corner sometimes that's necessary, you do it for them perhaps where you wouldn't have done it for yourself
Returning to being a 'mum' rather than continuing being a wife	Sometimes I don't feel that I'm any more me, I'm not [name] anymore I'm mum the carer
Feeling different from others; living a different life from those around them	You see everybody else as couples walking about and doing things and, you can't
Loss and emotionally missing pre-BI hobbies and social life	I can't say that I didn't miss it, cos' I'm a talker as you can see, and I like people I love people and so, to suddenly not be able to do any of those things it was hard
Realising previously unnoticed change towards being more direct with others	Suddenly without you realising that you have to be far more direct, you don't, you don't, sort of half say what you want to say you say the whole lot and you have to ask questions

Shaken identification to shared family traits	....well I thought, I'm getting more like my brother......my mother, because they were always very outspoke, I was more like my dad…..held things back more, but then, so I phoned back and I just said I do understand and I apologised
Adjusting view on allowable interactions with others to accommodate new role	I'd always been a person to sort of, not to be what I would class rude which now, now I class nearly as necessary
Feeling light hearted at return to familiar 'mum' role	I suppose I probably laughed at the time (laugh) thought oh I'm a mum again, had two sons got another one wha-that, but even before in all fairness he bought me a birthday card once and that was to mum….
Returning to a familiar role in later life	You know you retire, you're nearly seventy, but you're still being a mum

Appendix P. Summary of findings

Spouse and partner experiences of the impact of acquired brain injury (ABI). A qualitative analysis exploring realisations of change following the ABI of a "loved one".

Chloe Ghosh-Cannell, Dr Fergus Gracey, Dr Paul Fisher, Julia Ajayi

Results summary

Throughout the interviews, all participants were open and expressive in describing their experiences of their spouse's injury. At times, this could be an incredibly emotional topic and everyone who took part went above and beyond to inform the study. I would like to thank everyone who took part or supported recruitment for your support in the success of this project.

Following completion of the interviews, all were transcribed and analysed to draw out themes. These were summarised to derive the four main, overarching themes presented below, along with underlying subthemes presented in Figure 1.

Main themes

Pushed apart by brain injury

Participants experienced a change in emotional connection with their spouse following the injury. In most cases, this was experienced as a distancing in personal connection when navigating post-injury life. People described feeling that they were no longer in a partnership, or that their spouse was not the person they had been prior to the injury; an emotional moment within the interviews themselves. Realisation of having been pushed apart by the injury onset changed how the relationship was thought about; such as experiencing an internal contradiction of being both alone whilst also still having a life partner.

Notably though, there was also some variation across accounts. For some a continued or strengthened connection accompanied the realisation of the life-threatening nature of the injury, triggering recognition of personal values regarding the relationship. This presented a contrasting experience to otherwise shared experiences of emotional distance.

Bravery to face lingering awareness and emotions

Participants had regularly showed great bravery in reaching the point of realisation, which may not have been noticed previously due to the demands of focussing on the practical aspects of supporting their spouse.

In contrast, sometimes participants talked about how the life-threatening nature of the brain injury drew them closer together in their relationship. This led them to realise the values and aspects that they still shared following the injury, which contrasted with other experiences of feeling "pushed apart" or being more distant emotionally.

Lost and trapped in an unsolvable maze

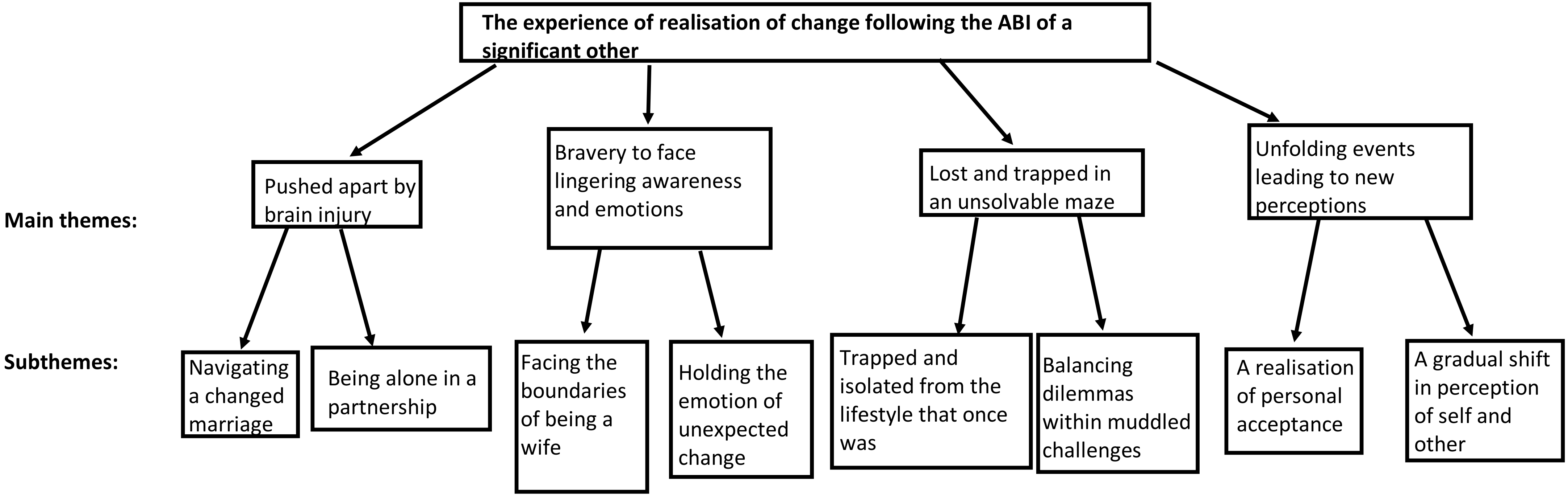
Some accounts described the experience of a repetitive and limiting routine around taking on a caregiver role for their spouse since the injury, which could be difficult to personally make sense of or accept. Metaphors were observed to express this challenging and powerless dilemma.

Participants described a desire to solve difficult changes in post-injury life whilst also being aware that this was not necessarily possible. For some there was also a sense of being in-between contradicting paths on their post-injury journey, for example swinging between fear and awareness of further change versus hope and optimism. A wariness of the potential impact of one’s own imagination following onset of the injury was also present, expressing an experience of tolerating the unknown. Such ever-changing perspectives, dilemmas and sense of an undefined way forward made it seem as if the experience was like being “lost and trapped in an unsolvable maze”.

Unfolding events leading to new perceptions

Participants expressed a gradual, or “unfolding” experience of realisation of change, which was not fixed to a specific moment but generated through multiple experiences. Consequently, realisations of change continued to be experienced years after the onset of injury, with different meanings related to them. This included an ongoing determination to continue coping alongside recognition of self-change as part of having adapted to post-injury life; questioning personal identity. Realisation of having found personal acceptance of post-injury life was also present, perhaps enabling normality (a “new normal”) to be experienced. In some cases, empowerment was experienced through the recognition of coping and noticing aspects of personality that had remained the same following the injury (such as sense of humour), enabling hope and a feeling of relationship commitment.

Figure 1. Diagram depicting main themes and subthemes for spouse experiences following the ABI of a loved one.



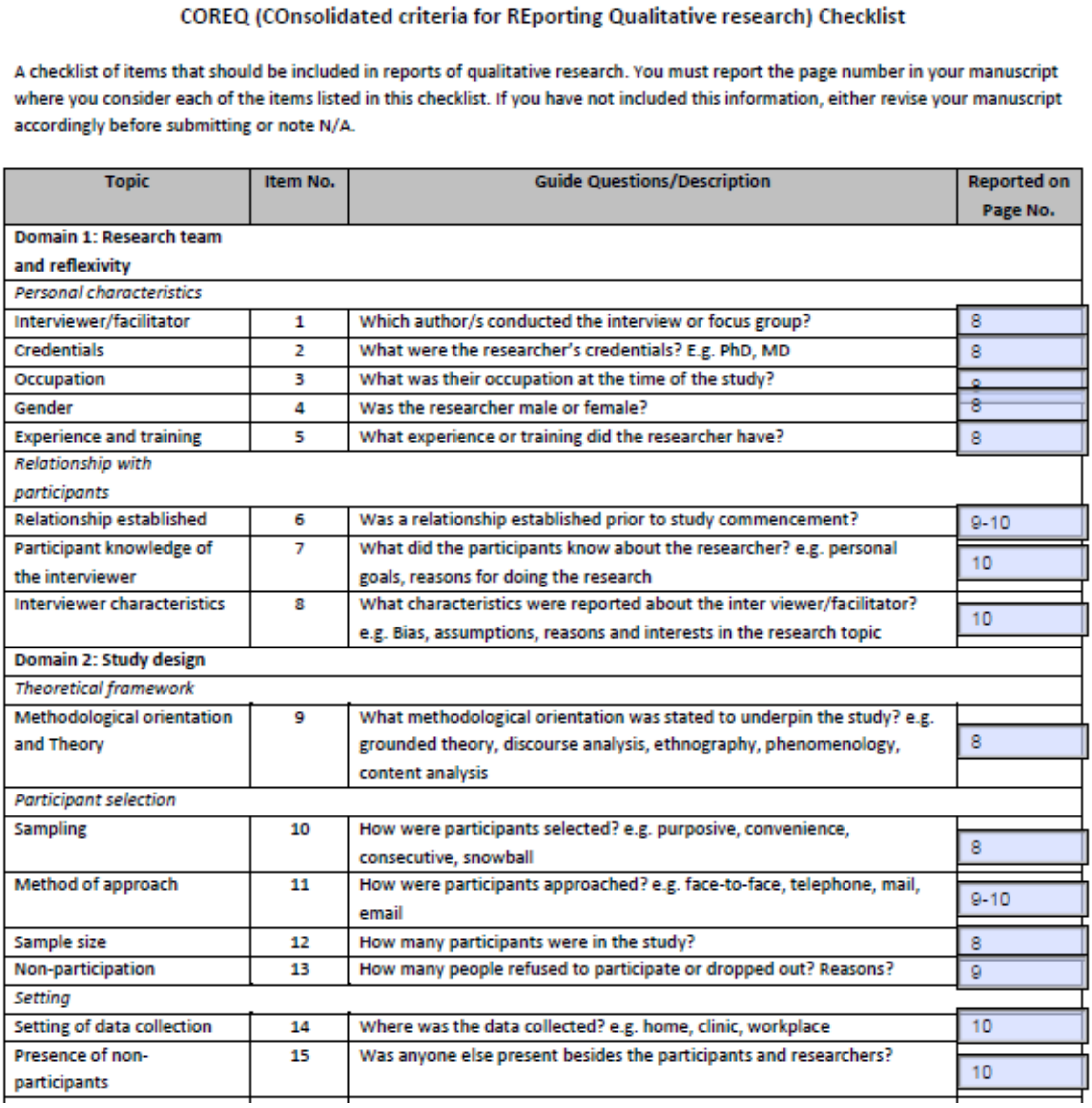
Conclusion

This brief summary highlights the bravery and dilemmas experienced by those realising change following their loved one experiencing a brain injury. The study aimed to provide a meaningful account for readers who have experienced similar circumstances and inform those supporting them.

Overall, participants tended to experience gradual realisations leading them to question the nature of their connection with their spouse. They felt both with and without a partner and/or that their partner is a different person to pre-injury life. Participants also experienced a range of emotional responses and uncertainty whilst often living within a predictable routine. Initial realisations, such as bereavement, could also be re-experienced in response to repeated witnessing of post-injury change.

Alongside these challenges however, participants recognised the importance of finding personal acceptance, allowing a sense of normality. Noticing a continuation of personal values post-injury also supported commitment and hope. Additionally, participants showed great bravery and determination in facing the unknown nature of post-injury life.

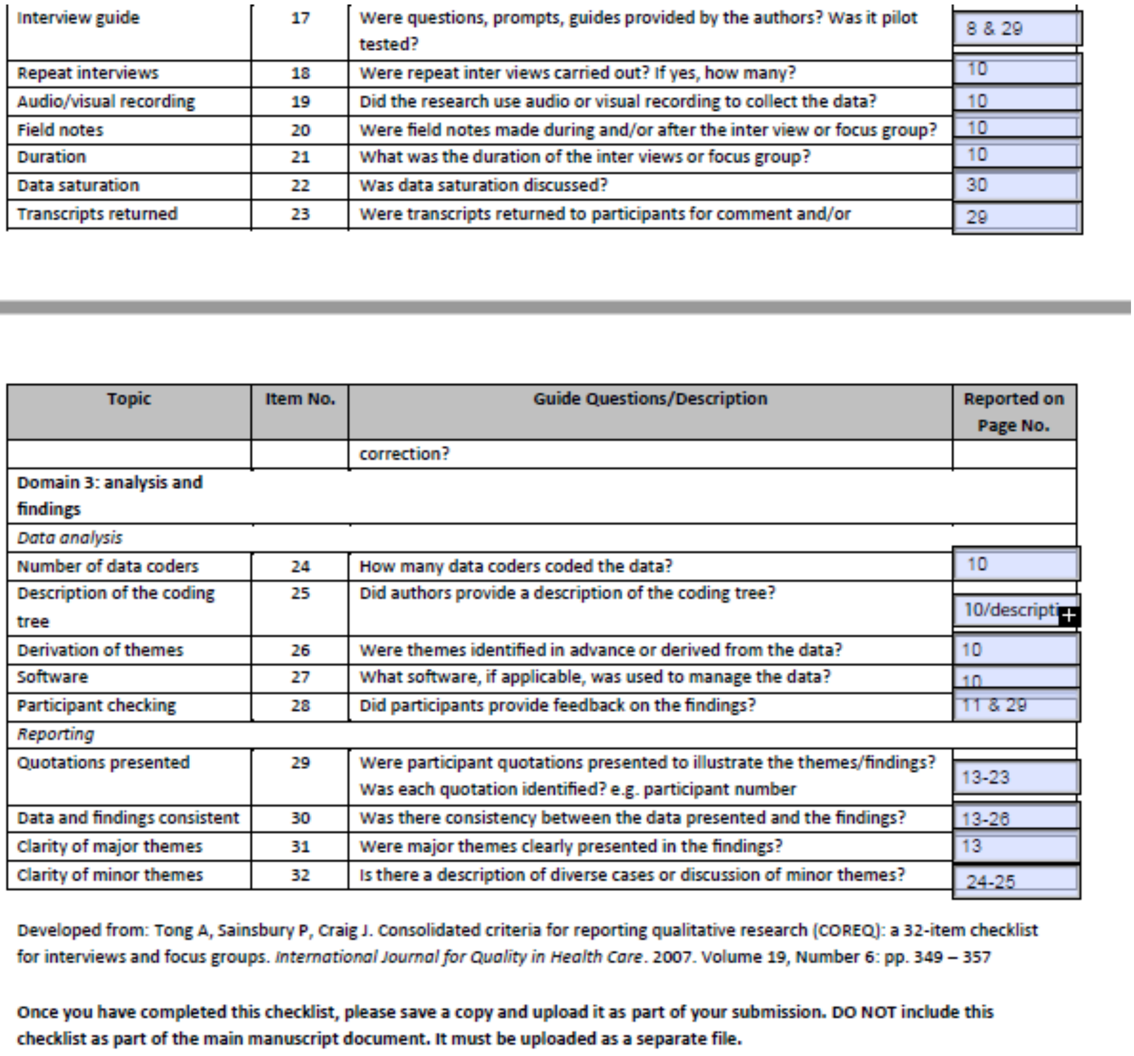
Appendix Q. COREQ publication checklist for empirical study (Chapter 3)



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	8
Occupation	3	What was their occupation at the time of the study?	8
Gender	4	Was the researcher male or female?	8
Experience and training	5	What experience or training did the researcher have?	8
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	9-10
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	10
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	10
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	8
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	9-10
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	9
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	10
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	10



Topic	Item No.	Guide Questions/Description	Reported on Page No.
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8 & 29
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	10
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	10
Field notes	20	Were field notes made during and/or after the inter view or focus group?	10
Duration	21	What was the duration of the inter views or focus group?	10
Data saturation	22	Was data saturation discussed?	30
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	29
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	10
Description of the coding tree	25	Did authors provide a description of the coding tree?	10/descripti
Derivation of themes	26	Were themes identified in advance or derived from the data?	10
Software	27	What software, if applicable, was used to manage the data?	10
Participant checking	28	Did participants provide feedback on the findings?	11 & 29
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-23
Data and findings consistent	30	Was there consistency between the data presented and the findings?	13-26
Clarity of major themes	31	Were major themes clearly presented in the findings?	13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	24-25

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix R. Study introduction to service user groups

Presentation to service user groups to introduce study

My name is Chloe Ghosh-Cannell, I'm a trainee Psychologist. Thank you for letting me take the time to introduce my study. As part of my job, I think about the importance of family relationships and how they adapt to changes that happen in our lives. Research shows that the family can be seen as a system and how we relate to each other can play a big role in how we feel emotionally. Changes to one person's health, including the events that lead to acquired brain injury, often mean that the family and the relationships within them need to adjust to new aspects of life.

My research is exploring times when spouses/partners of those who have acquired a brain injury came to realise that life was changing. It is hoped that the results of the research will help inform services around how to help both those with brain injuries and their families. I have recently been interviewing spouses/partners to find out what their experiences have been like. The interviews aim to feel like a conversation and have received positive feedback so far. If you feel that your spouse/partner may be interested in taking part, please pass a Participant Information Sheet on to them [*Participant Information Sheets provided as handouts*].

Appendix S. Recruitment poster

Service logo

University of East Anglia

Research Participants Needed:

Help us find out about the experiences of spouses and partners after their loved one has acquired a brain injury.

Hi, my name is Chloe Ghosh-Cannell and I am a Trainee Clinical Psychologist at the University of East Anglia. I am interested in finding out about the experiences of spouses and partners of people with acquired brain injuries (ABI).

I am looking to recruit spouses and partners of people with ABI to take part in a face-to-face interview. The questions will be about moments where changes to day-to-day life after the brain injury were personally realized and acknowledged. This study aims to help inform services who are in roles supporting families and build upon knowledge of family experiences following brain injury.

Who? You must be over eighteen and fluent in English. You need to have a spouse or partner with an acquired brain injury (ABI), with whom you still have a relationship. The onset of the ABI needs to be at least a year ago.
Where? You need to live within Essex, Suffolk, Norfolk or Cambridgeshire.
How long will it take? I will initially send you a more detailed (3 page) Participant Information Sheet to read and consider. Following this, we will talk over telephone (15 minutes) or via e-mail to answer any questions you may have and arrange a face-to-face interview. The whole interview appointment will last 90 minutes to give time for the consent form and debriefing, with the interview itself lasting one hour.
How will my information be used? Your data will be anonymised for the analysis and all reports. It will be stored through password-protected devices and kept in locked facilities.

Interested?

Please e-mail me for more information:

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Appendix T. Consent to contact form

Service logo

University of East Anglia

Consent to contact form

Please complete this form and return it to either myself or [gatekeeper/contact name and/or reception as arranged] at [service name], who will pass it along to me. This form is not a consent form and you are not obliged to take part after being contacted. I will only contact you if you have provided your details for me to do so.

Last name:	First Name:
E-mail:	Mobile number:
Landline Number:	Address:

What is your preferred method of being contacted?

Thank you for your interest in this study.

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