SPOUSAL RELATIONSHIPS FOLLOWING A BRAIN INJURY

by

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Abstract

The thesis studied how the general quality of spousal relationships is affected following a brain injury, with a specific focus on the concept of relationship continuity. Chapter One provides the purpose and thesis structure. Chapter Two is an introduction to brain injury and its impact on partners and their relationship and the kind of research that has been conducted so far. Chapter Three summarises the development of a quantitative scale to measure relationship continuity in couples, where one partner has a brain injury. Chapter Four explores the factors that predict relationship continuity/discontinuity following a brain injury. Chapter Five is a systematic review of research evaluating interventions that have been undertaken so far to help family members of individuals with a brain injury. A pilot study was carried out using Integrated Behavioural Couple's Therapy techniques to help a couple improve general relationship quality and the spouse's perceptions of continuity, which has been described in Chapter Six. The summary of all the empirical studies is discussed in Chapter Seven.

~ To my parents and my partner ~

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List of abbreviations

ABI	Acquired Brain Injury
AD	Alzheimer’s Disease
ADLQ	Activities of Daily Living Questionnaire
BI	Brain Injury
BRCM	Birmingham Relationship Continuity Questionnaire
CCS	Closeness and Conflict Scale
CSI	Caregiver Strain index
DAS	Dyadic Adjustment Scale
DASS-21	Depression Anxiety Stress Scale
DV	Dependent Variable
EFA	Exploratory Factor Analysis
HSL	Heartfelt Sadness and Longing subsccale
IBCT	Integrated Behavioural Couples Therapy
IBM	Intimate Bond Measure
ICC	Intra Class Correlation
IV	Independent Variable
KMO	Kaiser-Meyer-Olkin
LCQ	LaTrobe Communication Questionnaire
MM-CGI	Marwit-Meuser Caregiver Grief Inventory
NFI	Neurobehavioral Functioning Inventory
NICE	National Institute for Health and Care Excellence
RAS	Relationship Assessment Scale
RC	Relationship Continuity
RCI	Relationship Change Index
RCT	Randomised Control Trial
RD	Relationship Discontinuity
SCCS	Schofield Closeness and Conflict Scale
SEQ	Session Evaluation Questionnaire
TBI	Traumatic Brain Injury

List of publications and conference presentations

During my doctoral research within the School of Psychology at the University of Birmingham, a book chapter had been submitted for publication, and other papers were presented at conferences. Moreover, during the research course, Hayley Keeble worked on Stage I of my first study, and Edward Ong has helped in conducting inter-rater reliability for the systematic review.

Book Chapter

Submitted

Yasmin, N. & Riley, G. (2018). The parallels of culture and the effects of traumatic brain injury on the marital relationship. In *Mental Health in an Inclusive World,* Submitted June 2018.

Conference presentations

15th NR-SIG-WFNR Conference. Prague, 2018. (Datablitz)

Yasmin, N., & Riley, G. Predictors of marital relationship discontinuity post brain injury.

The BIRT Conference. Glasgow, 2017. (Poster)

Yasmin, N., & Riley, G. Psychometric evaluation of the Birmingham Relationship Continuity Measure: To evaluate perceived continuity of spousal relationships after brain injury.

14th NR-SIG-WFNR Conference. Cape Town, 2017. (Datablitz)

Yasmin, N., & Riley, G. Family interventions after Brain Injury: A Systematic Review.

CHAPTER 1

PURPOSE OF THE THESIS

1. Introduction

It has been well established that brain injury (BI) has a detrimental effect not only on survivors but also on their family members, especially partners/spouses (e.g., Godwin, Chappell, & Kreutzer, 2014). The primary responsibility of caregiving post-injury falls on partners, and often they start perceiving themselves more as a caregiver (Godwin et al., 2014).

There have been many studies which have explored aspects like stress, caregiver burden, and emotional changes like depression and anxiety in partners (Evans-Roberts, Weatherhead, & Vaughan, 2014). In addition to how BI changes a partner’s physical, emotional, behavioural, and social abilities, it is also necessary to understand how BI affects the relationship between the person with the BI and the non-injured partner. However, research on this topic is limited. Therefore, the purpose of the thesis was to understand more about the impact of BI on the spousal relationship, how this impact can be assessed, and what kind of therapeutic interventions can be developed to help couples experiencing relationship difficulties post-injury, with a specific focus on the concept of relationship continuity (RC).

2. Thesis structure

Chapter Two of the thesis explores the impact of BI on survivors and family members. A particular emphasis was on the effect it has on spousal relationships and how the relationship quality affects rehabilitation outcomes for the survivor. The concept of RC has been elaborated, and the kind of research that has been conducted so far and what needs to be done next was discussed.

Chapter Two suggests a need to explore RC post-injury, and to do so, quantitative measures needed to be developed. Chapter Three, therefore, reports on an empirical study involving the development of a quantitative scale to measure RC in couples where one partner has a BI. It is a 23-item questionnaire (The Birmingham Relationship Continuity Measure) that was given to a group of partners turned caregivers recruited from different brain injury rehabilitation centres and carer groups across the UK. The test re-test reliability of the questionnaire was established along with other psychometric properties like validity and discriminative power. The psychometric evaluation of the scale showed promising results.

It was essential to understand why some partner's perceived continuity in their relationship after BI, and others perceived discontinuity. Chapter Four was an empirical study that explored the factors that predicted relationship continuity/discontinuity following BI. A battery of six carer-report questionnaires, measuring various impairments caused by BI, along with The Birmingham Relationship Continuity Measure were administered to a group of 53 carers, who were husbands/wives of individuals with BI and were recruited from various BI rehabilitation centres and carer groups across the UK. Correlation and regression analysis were conducted to determine which impairments were the strongest predictors of relationship continuity/discontinuity.

Future research on this issue aimed to develop therapeutic intervention strategies to help partners who perceived relationship discontinuity, experience more continuity in their relationship. However, before exploring this issue, existing interventions that have been undertaken so far to help family members, especially partners, were reviewed to provide a knowledge base for the development of an intervention focusing on RC. Chapter Five, therefore, was a systematic review of family-focused interventions in BI. Using six databases, articles written in English were used between the year 1984 and February 2018. A total number of 29 studies were selected and reviewed.

The literature review suggested a general lack of evidence about effective interventions for couples following BI and a specific lack of studies that used a theoretical account of the impact of BI on the relationship as the basis for developing the intervention. Chapter Six, therefore, reports on the pilot development of an intervention aimed at increasing the partner's experience of RC, with Integrated Behavioural Couples Therapy being used as a general framework for providing the intervention. The chapter describes an intervention to help a couple, where one partner survived a stroke. The overall aim was to improve the general quality of their relationship and the stress experienced by the carer by re-establishing the lost connection with their pre-stroke life and thereby enhancing the experience of continuity within the relationship. Quantitative assessments were used to evaluate the outcome.

Chapter Seven provides a summary of all the three empirical studies and the systematic review, including implications of the study findings and specific points for future research.

References

Evans-Roberts, C., Weatherhead, S., & Vaughan, F. (2014). Working with families following brain injury. *Revista Chilena de Neuropsicología*, *9*(1).

Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain Injury*, *28*(4), 398-413.

CHAPTER 2

BRAIN INJURY AND ITS IMPACT ON THE MARITAL RELATIONSHIP

1. Classifying brain injury

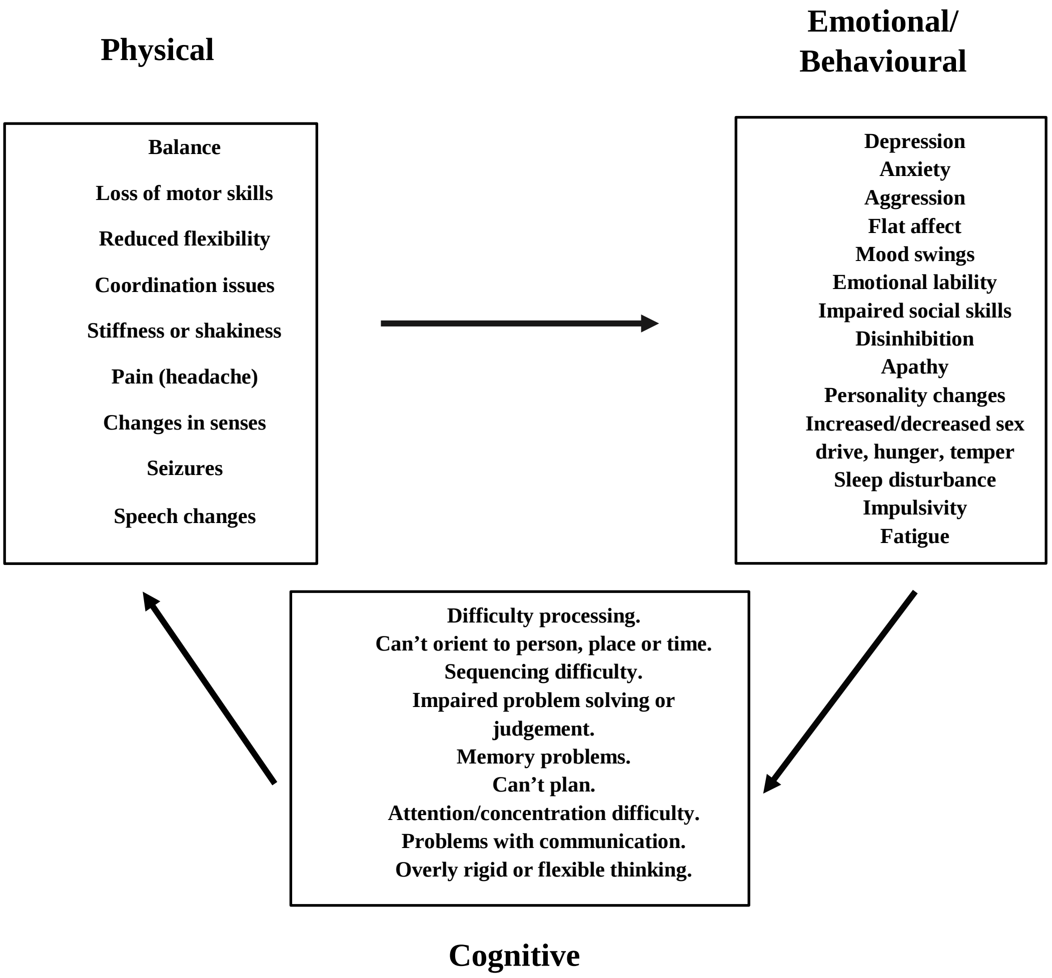
Brain injury (BI) is one of the major causes of long-term disability worldwide, and studies state that approximately ten million people are affected by it annually (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007; Langlois, Rutland-Brown, & Wald, 2006).

Acquired brain injury (ABI) is brain damage caused by events after birth and has a sudden onset (Yochelson & Wolfe, 2010). Typically, the symptoms are non-progressive and often show improvement over time. There can be various causes of ABI, for example, a road accident or a fall (usually known as traumatic brain injury (TBI)), stroke, brain haemorrhage and aneurysm, to name a few. Some authorities include brain tumours as a type of ABI, even though they are not sudden onset or progressive (e.g., Yochelson & Wolfe, 2010).

2. Effects of brain injury on survivors

BI inflicts a range of impairments that comprises physical, cognitive, behavioural and emotional difficulties (Langlois et al., 2006). Figure 1.1 shows the various effects of BI that restricts a survivor’s life to the extent that, in more severe cases, they do not return to work and become dependent on caregivers (Langlois et al., 2006; Shames, Treger, Ring, & Giaquinto, 2007; Wood, Liossi, & Wood, 2005).

Figure 2.1. Diagram representing the varying effects of brain injury on a survivor (Winkelman, 2016)



3. Effects of brain injury on relationships

Studies frequently state that BI often has a detrimental impact on family members (e.g., Godwin, Chappell & Kreutzer, 2014). During and post-hospitalization, the primary responsibilities for caring and recovery of a person with a BI often falls on the family members, starting from personal care, food, medication, other activities of daily living such as bathing and dressing, emotional care, cognitive stimulation and behavioural management (Oddy & Herbert, 2003; Ramkumar & Elliott, 2010). There is a sudden change in their lifestyle and the relationship they share with the injured, with an insignificant amount of time to prepare themselves both physically and emotionally for the caregiving role (White, Cantu & Trevino, 2015). It is usually a permanent role which is challenging, stressful, and demands a lot of sacrifices (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007). Therefore, it affects their physical health, psychological well-being, and social relationships with friends and other family members in the long run (Gaugler, 2010; Simon, Kumar, & Kendrick, 2009). Such effects are long-term and have often been referred to as caregiver burden (Nabors, Seacat, & Rosenthal, 2002).

3.1. Effects on parents

When a child is injured, it is demanding for parents to adapt themselves to the role of a caregiver. The demands of a child BI survivor can increase and change as the child matures into adulthood (Boschen et al., 2007). Even when they are adults, their behaviour and demands are often childlike (Hawley, Ward, Magnay, & Long, 2003).

3.2. Effects on children

Parental BI affects the development and well-being of their children and their relationship with the affected parent. Children are found to be less disciplined, have behavioural problems, and suffer from emotional difficulties like depression when one or both of their parents have a BI (Pessar, Coad, Linn, & Willer, 1993). Sometimes, they are ill-treated or ignored because parenting ability is affected by the injury (Pessar et al., 1993).

3.3. Effects on siblings

BI changes the whole family dynamic and, therefore, siblings can find it difficult to cope with the changes (Hawley, Ward, Magnay, & Long, 2002). Studies show that siblings experience higher stress levels, anxiety, nightmares, fear, behavioural problems, jealousy regarding the attention the injured sibling receives, and even resentment towards the injured sibling that might lead to open hostility, indifference, and family friction (E.g., Hawley et al., 2002; Middleton, 2001).

3.4. Effects on partners

In one study, mothers and wives of individuals with a TBI were compared regarding their experience of stress regarding aspects of daily living (Maus-Clum & Ryan, 1981). Results showed that the wives of the survivors had significantly higher levels of stress in comparison to the mothers. A recent study assessed 64 spouses and 58 parents of TBI survivors using the Neurobehavioral Problem Checklist, Family Assessment Device and the Brief Symptom Inventory (Anderson et al., 2009). Findings suggested that spouses were affected more than parents of the injured. Such results are attributed to the fact that, for parents, it is usually easier to accept that their child has some physical and functional difficulties and they need to play the role of a carer, mainly when they are already at a stage of life where they have a maternal instinct in place. However, spouses, on the other hand, are not prepared for caring for their partner, which causes frustration and anxiety regarding their future together (Anderson et al., 2009). The inappropriate and childlike behaviour of partners is unacceptable in marriage, and such behaviour puts a strain on the marital relationship (Anderson et al., 2009).

Loss of connection in relationships is widespread in neurological disorders (Edwards, Murray, Creamer, Mahadevan, & Yeates, 2013) and BI is no different. Partners may feel that they are living with a stranger for whom they are just carers and share no other intimate relationship with. Qualitative studies have shown that non-injured partners often report that their injured spouse is not the same person anymore (e.g., Villa & Riley, 2017). It affects how they view the injured partner and their overall relationship (Bodley-Scott & Riley, 2015; Godwin et al., 2014). Future family plans once made in anticipation go through a significant change, which often makes them feel frustrated (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). Loss of self-identity, anxiety and depression are often the consequence partners suffer, leading to marital dissatisfaction (Anderson et al., 2002; Riley, Hough, Meader, & Brennan, 2015). Sometimes they opt for separation or divorce, as it gets too much for them to deal with on their own (Bodley-Scott & Riley, 2015; Godwin et al., 2014; Kitter & Sharman, 2015).

3.4.1. New roles and responsibilities

Before the injury, families tended to function as a unit where different family members had different roles to play. However, post-injury there are significant changes in these roles. The non-injured partner has to play the role of a carer, and the whole responsibility of the family and everyday household chores is also on them (Arango-Lasprilla et al., 2008; Doser & Norup, 2016; Gagnon, Lin & Stergiou-Kita, 2016). Everyday household activities like maintaining their home, managing finances, planning and organising family activities, taking care of their children (if they have any) are now the partner's responsibility. Due to a range of impairments that a person suffers after a BI, they often become functionally dependent and need the support of a personal carer (Arango-Lasprilla et al., 2008). Sometimes to fulfil all these duties partners often let go of other responsibilities like their job.

3.4.2. Behavioural difficulties

The most common factor for relationship issues appears to be behavioural problems (Gill, Sander, Robins, Mazzei, & Struchen, 2011). Many individuals with TBI are not self-aware, which affects their behaviour, their social surrounding, and the emotional state of people around them. Therefore, they often fail to have insight into their situation, making it awkward for their partners in social situations (Gill et al., 2011). For example, they can sometimes dress inappropriately or enact socially inappropriate behaviour. This not only makes social and family gatherings awkward for the partners but also creates a constant demand to take care of them which creates extra burden (Doser & Norup, 2016; Gagnon et al., 2016; Kratz et al., 2017). Sometimes, because of this, they also lose contact with many relatives and friends, which creates a sense of loneliness and loss of support in the long run (Bodley-Scott & Riley, 2015; Kitter & Sharman, 2015).

3.4.3. Lack of support

As mentioned earlier, often partners do not get the support they need, regarding managing the injured partner’s situation and dealing with their well-being. Some partners describe feeling alone in facing the challenges posed by the BI and by life in general (Gill et al., 2011; Godwin et al., 2014; Kratz et al., 2017). Often, they feel abandoned by clinical services once the injured person is discharged from the hospital (Gagnon et al., 2016). Contact with the extended family, friends and the wider community sometimes diminish, and support from family and friends becomes limited (Gill et al., 2011; Kitter & Sharman, 2015; Kratz et al., 2016). If relatives and friends also become distant, it creates the feeling of isolation and loneliness for the member with BI. The partner might no longer feel able to confide in, or seek support from, the person with the BI, partly because of their disabilities and partly because of their apparent self-centeredness and unresponsiveness to the needs of the partner (Gill et al., 2011; Godwin et al., 2014; Kratz et al., 2016). Studies have frequently reported that lack of support creates feelings of helpless and hopeless of the non-injured partners, and in turn puts a strain in their marital relationship (Bodley-Scott & Riley, 2015; Kitter & Sharman, 2015).

3.4.4. Communication issues

Communication is an essential aspect of marriage. Regarding gestures or facial and bodily expressions, affectional expression, and physical interactions, it is vital to communicate with partners to strengthen the bond (Godwin, Kreutzer & Kolakowsky-

Hayner, 2012). However, after BI, the communication skills of the injured are often compromised. They may have trouble starting a conversation, to find the right words, and sometimes they fail to understand or appreciate their partner’s feelings or emotions (Neumann & Leqerica, 2009).

3.4.5. Sexual difficulties

Sexual difficulties are considered to be one of the most critical factors that can deteriorate after a BI (Aloni & Katz, 2003). In some cases, a reduced sexual drive is an effect of BI due to hormonal changes or, change in libido, or because the person with BI starts considering themselves to be less attractive (Gill et al., 2011; Godwin et al., 2012). On the other hand, for their partner, it can become more difficult to get intimate, mainly if they feel they are living with someone they do not recognise anymore (Bodley-Scott & Riley, 2015; Gill et al., 2011; Godwin e al., 2014). However, sometimes it can be the other way around. The individual with the injury can experience an increased sex drive (Acorn & Offer, 1998) and that can also create difficulties for the partner.

3.4.6. Emotional/dependency needs

Often, in a marital relationship, there is a mutual dependency regarding emotional needs. However, qualitative studies have shown that injured partners sometimes “appear self-centred and unresponsive to the needs of the partner, showing little awareness to the needs or appreciation of how the partner is feeling” (Riley, 2016, p. 3). Non-injured partners, therefore, find it difficult to share their emotional needs with them.

On the other hand, the survivor is also emotionally dependant on the partner. Often, survivors have more free time than the partner. It can create a state where the survivor demands more attention and fails to understand the partner does not have equally free time which can often be a cause of a dispute (Godwin et al., 2012). This becomes more stressful when the partner has no support to share their emotions with, and now they also have to be the one to take care of the emotional needs of the person with the injury (Gagnon et al., 2016; Kratz et al., 2017; Turner, Fleming, Ownsworth & Cornwell, 2011).

4. Relationship continuity/discontinuity

Relationship continuity/discontinuity is an idea that developed in research on spouses providing care for people with dementia. One of the first qualitative studies to explore continuity/discontinuity among family members was conducted by Chesla, Martusan, and Muwases (1994), in Alzheimers Disease. The study was conducted to understand relationship adaption over time, where 15 spouses whose partners had Alzheimer’s Diseases (AD) and 15 adult-child family members were interviewed over a span of two years. The study reported three forms of relationships that the spouses shared with their partners post-Alzheimers; “a relationship that is maintained as continuous with the relationship between caregiver and AD patient prior to the disease”, “a relationship that is continuous but is transformed by the disease”, and, “a relationship in which there is radical discontinuity between the present and prior relationship” (Chesla et al., 1994, p. 5).

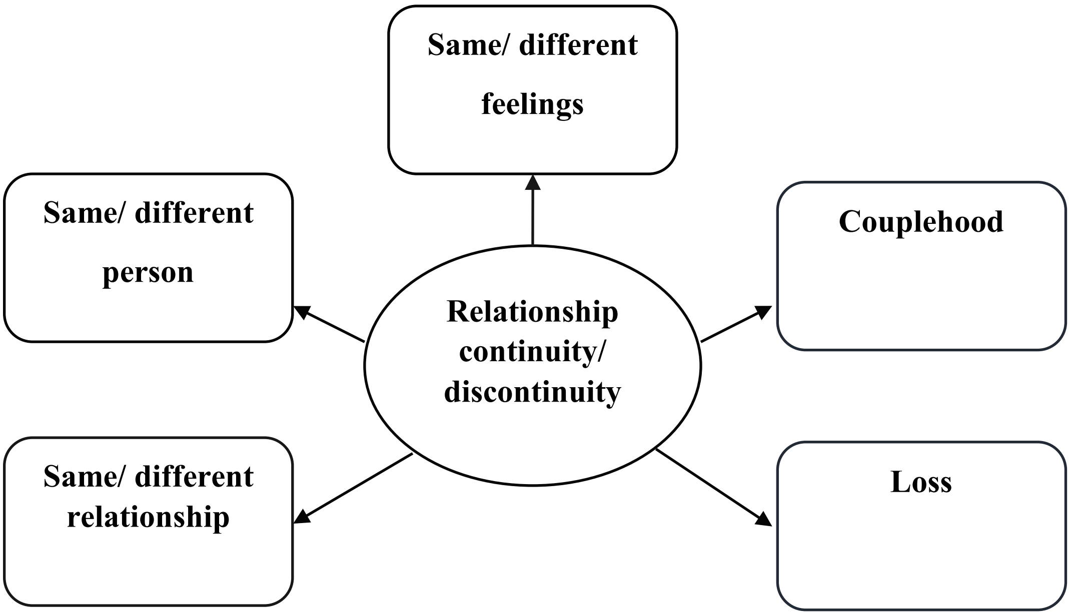
Some family members reported changes in the person with the AD, but despite those changes, they reported a sense of connection with the patient (continuous relationship). They “continued to define themselves in relation to the patient in ways that paralleled their relations prior to the AD” (Chesla et al., 1994, p. 5). Some family members also reported changes, but they perceived a transformation in the relationship they shared prior to the AD, and what remained was a strong commitment to the relationship and “the person that the patient had become in the disease” (relationship was continuous but transformed) (Chesla et al., 1994, p. 6). For example, some spouses felt that they were living in a difficult ambiguous relationship “because they could no longer relate to their partner as an intimate friend or sexual partner and at the same time they remained married and deeply committed to the spouse” (Chesla et al., 1994, p. 7). However, some family members found a discontinuity in the patient’s personality, and felt that the disease had changed the person to the point of being unrecognisable. These relationships were perceived as “less emotional, less personal, and more clinical” in comparison to the other two forms (relationship was radically discontinuous) (Chesla et al., 1994, p. 7).

A similar study was conducted by Kaplan (2001) on 68 spouses with partners with the AD, to understand their perception of their spousal relationship. The qualitative data revealed five themes that described their state of couplehood. Some spouses reported perceiving a sense of “We”, where they felt that despite their partners being unable to participate in their marital relationship, they still felt a strong sense of couplehood (Kapla, 2001, p. 5). This was termed as “Till Death Do Us Parts”, where “one whose present state of couplehood is deeply embedded in his or her past marital history” (Kapla, 2001, p. 5). However, some spouses, despite having similar feelings of “We”, “also recognised that in some ways they were becoming spouses who no longer had mates who can participate in their marital relationship” (Kapla, 2001, p. 6). Therefore, they were labelled “We But…” (Kapla, 2001, p. 6). Some spouses, on the other hand, reported to perceive themselves as married but were uncertain about their marital status. They sometimes felt married, while sometimes they felt that they were uncertain regarding their partner’s presence in the relationship. This was labelled as “Husbandless wives/Wifeless Husbands” (Kapla, 2001, p. 6). Some spouses also reported feelings of “I” rather than “We”, where they “recognised that their married lives no longer included two people, but one” (Kapla, 2001, p. 7). However, they did not perceive themselves as completely alone and were labelled “Becoming an I” (Kapla, 2001, p. 7). On the other hand, some spouses strongly perceived themselves to be completely alone in the relationship. They were labelled “Unmarried Marrieds” since they reported to recognise themselves as “legally married, yet do not perceive themselves as married", even though "they loved their spouses and wished them no suffering" (Kaplan, 2001, p. 7).

4.1. Components of relationship continuity/discontinuity

A recent study was conducted to review qualitative studies in which relationship continuity/discontinuity had appeared as one of the themes (Riley et al., 2013). The review aimed to identify various components of the experience of continuity/discontinuity. They found five components which are described below (Figure 1.2).

Figure 2.2. Diagram representing components of relationship continuity/discontinuity in dementia (Riley et al., 2013)



4.1.1. Relationship redefined

Some couples perceive their relationship following dementia as a continuation of the marital relationship before dementia (Chesla et al., 1994; Kaplan, 2001; Walters, Oyebode, & Riley 2010). However, some perceived a change in their relationship where they felt that the marriage was over and the relationship with their partner has been 'redefined' in some form, for example, a relationship between a carer and a care-recipient (Kaplan, 2001; Walters et al., 2010).

4.1.2. Same/different person

Spouses often reported that they felt their partner with dementia is not the same person they once married (Walters et al., 2010). Since dementia brings changes in the personality of the injured, spouses often perceive their partner to be different following dementia and experience feelings of discontinuity in their relationship. On the other hand, some spouses noticed specific personality characteristics being intact in their partners and perceive the relationship as continuous (Chesla et al., 1994).

4.1.3. Same/different feelings

How the spouse feels regarding the injured partner also plays an essential role in how they perceive the overall relationship. The continuation of feelings of love and affection is part of what is involved in perceiving RC, in comparison to perceptions of discontinuity in which feelings of protection and care may be more prominent (Chesla et al., 1994; Walters et al., 2010).

4.1.4. Couplehood

Feelings of "we" define a strong bond between a couple (Kaplan, 2001); in continuity, spouses continue to feel like they are in a partnership. However, in discontinuity that feeling is replaced by an individualistic "I" (Hellström, Nolan, & Lundh, 2007).

4.1.5. Loss

When the changes that occur in a person and the relationship following dementia are experienced as radical (i.e., discontinuity), the spousal carer has feelings of loss and grief for the pre-dementia person and pre-dementia relationship (Riley et al., 2013).

These five different components of continuity/discontinuity are viewed as being closely interconnected (Riley et al., 2013; Riley, Evans, & Oyebode, 2018). For example, perceiving that the person with dementia is no longer the person one married (*different person*) could understandably undermine the feelings of love and intimacy (*different feelings*), and both might, in turn, contribute to a sense that the relationship has been transformed into a non-marital relationship between a caregiver and a care recipient (relationship redefined).

4.2. Relationship continuity in acquired brain injury

Studies have shown that specific continuity components are present in spousal experiences following ABI. For example, qualitative studies have reported that partners often perceive their injured partners as ‘strangers’, fitting in with the component of ‘same/different person’ (e.g., Bodley-Scott & Riley, 2015; Gill et al., 2011; Kratz et al., 2017). A study conducted to explore the emotional impact of TBI had on spousal relationships found that some non-injured partners perceived the relationship as a caregiver and care-recipient relationship, rather than husband and wife, fitting in with the component of same/different relationship (Bodley-Scott & Riley, 2015). Building on this evidence, Villa and Riley (2017) explored in more detail whether the various components of relationship continuity/discontinuity reported in dementia might be applicable in ABI. Their qualitative data showed some evidence of each of the various components of continuity/discontinuity in ABI.

4.3. Predictors and consequences of relationship continuity/ discontinuity

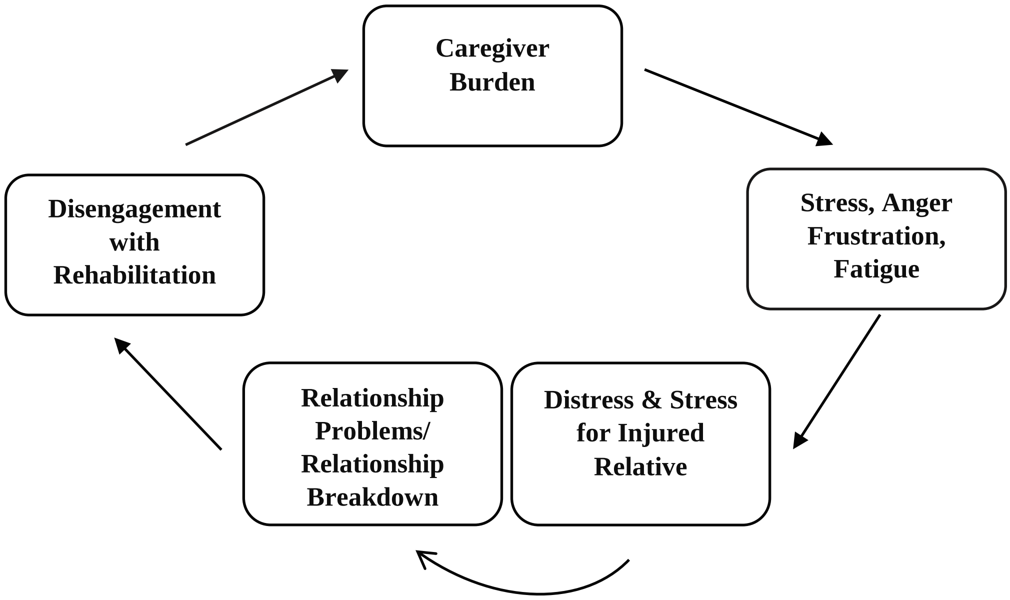
Qualitative studies in dementia have suggested that perceiving discontinuity in the relationship may be associated with increased adverse emotional reactions towards the caregiving role, while continuity is associated with deriving more positive meaning and satisfaction from the role (Riley et al., 2013; Walters et al., 2010). They have also suggested that continuity may be associated with a more person-centred approach to providing care and support (Chesla et al., 1994; Riley et al., 2013). A recent study provided quantitative support for the idea that discontinuity may contribute to a more negative emotional reaction to caregiving and continuity to deriving greater positive meaning from the role (Riley et al., 2018). Another quantitative study suggested that discontinuity may be influenced by the presence of more challenging behaviours in the person with dementia, but continuity/discontinuity was unrelated to a measure of the social cognitive abilities of the person with dementia (Poveda, Osborne-Crowley, Laidlaw, Macleod, & Power, 2017).

Recent qualitative research in BI similarly suggests that continuity may be associated with fewer negative emotional reactions to challenging behaviours in the caregiving role, and a more person-centred and effective way of understanding and dealing with those behaviours (Bodley-Scott & Riley, 2015; Villa & Riley, 2017). Discontinuity was also associated with more ambiguous feelings about staying in the relationship (Villa & Riley, 2017). A lack of emotional warmth on the part of the person with the BI also seemed to contribute to perceptions of discontinuity (Villa & Riley, 2017). These findings suggest the value of a more detailed investigation of why some spouses perceive RC, but others do not, what impact of continuity/discontinuity might have on the general features and long-term stability of the relationship, what effect it might have on the general psychological well-being of those involved, and what impact it might have on how spouses respond to the challenges of BI (Villa & Riley, 2017).

5. Impact of family functioning on survivors' rehabilitation outcomes

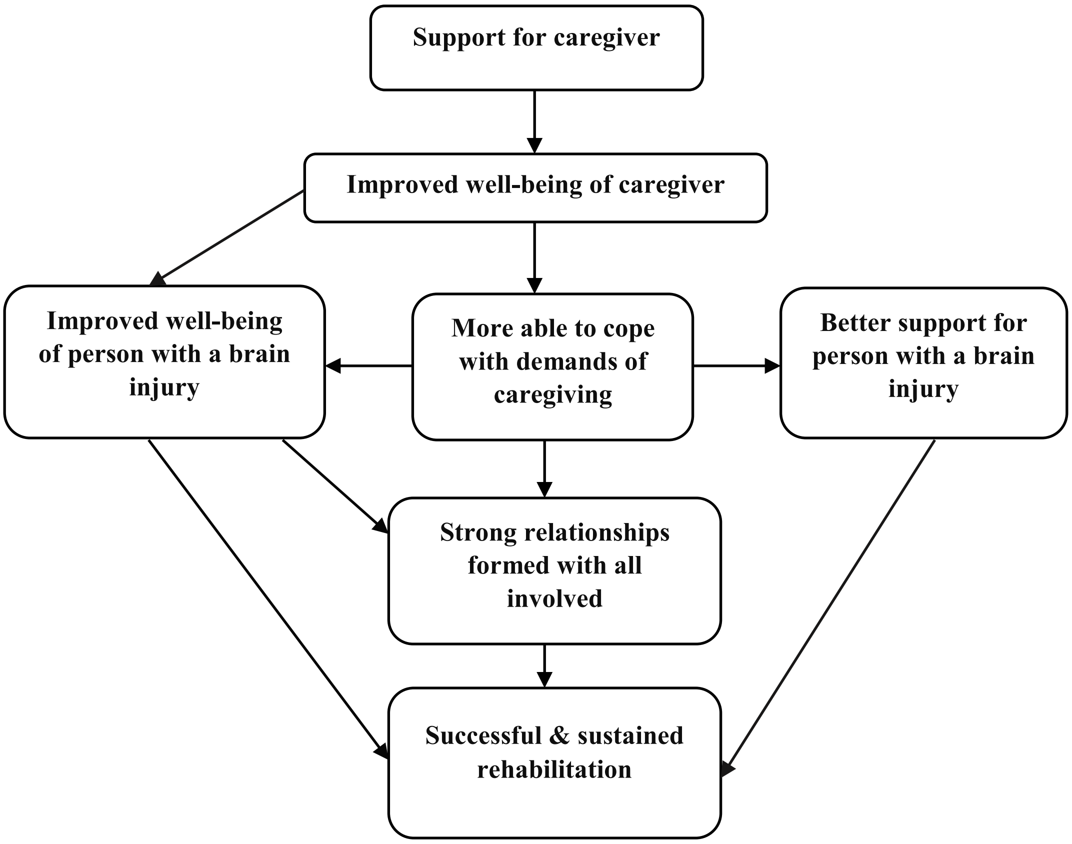
Family plays a crucial role in determining an individual's emotional health and well-being, as well as providing practical support (Mokomane, 2012). When in a crisis, be it emotional or physical, we very often turn towards our family for help. One might, therefore, expect that the quality of family relationships will have an impact on the survivor's general well-being and on how well they progress in rehabilitation (Foster et al., 2012).

Figure 2.3. The relationship between stress experienced by brain injury survivors and their caregivers (Evans-Robert, Weatherhead, & Vaughan, 2014)



The stress experienced by the survivor and the caregiver impacts on each other's well-being, their relationship, and the rehabilitation process (Evans-Robert et al., 2014) (Figure 1.3). Being a part of the difficulties post-injury, family members can "be a part of the solution" as well (Evans-Robert et al., 2014, p. 25). Studies have shown that variations in caregiver burden often affect the rehabilitation outcomes of the survivor (e.g., Degeneffe, 2001; Jumisko, Lexell, & Söderberg, 2007). The recovery process of the survivor, thus, depends on the well-being and quality of life of the family (Oddy et al., 2003; Tam, McKay, Sloan, & Ponsford, 2015; Wulf-Andersen & Mogensen, 2017). Figure 1.4 illustrates how caregivers' well-being positively affects the BI survivor.

Figure 2.4. Caregiver's well-being and its relationship with brain injury survivor (Evans-Robert et al., 2014)



6. Measuring quality of relationships following a brain injury

To advance research in this area, it is essential to measure the impact of BI on the marital relationship quantitatively, and in this context to measure relationship continuity/discontinuity quantitatively. Although qualitative studies are valuable, the small number of participants involved, and the subjectivity involved in the interpretation of the data can sometimes undermine confidence in the interpretation and make it difficult to draw general conclusions (Johnson & Onwuegbuzie, 2004). Corroborating the findings of qualitative studies with evidence from quantitative or mixed-methods studies can enhance generalisability and provide more robust conclusions (Johnson & Onwuegbuzie, 2004). Therefore, a quantitative measure of relationship continuity/discontinuity is needed.

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CHAPTER 3

EVALUATING THE PSYCHOMETRIC PROPERTIES OF THE BIRMINGHAM RELATIONSHIP CONTINUITY MEASURE FOR ACQUIRED BRAIN INJURY

1. Introduction

In Chapter Two, the concept of relationship continuity/discontinuity was discussed, and it was established that there was a need to develop a quantitative measure of relationship continuity/discontinuity for partners with brain injury (BI).

1.1. Birmingham Relationship Continuity Measure (BRCM)

Based on the five aspects of relationship continuity (RC), as mentioned in Chapter Three (p. 15), the BRCM scale was first developed for assessing relationship continuity/discontinuity in dementia. To establish the scale's reliability and validity, 84 spouses turned carers were assessed (Riley et al., 2013). Full-scale Cronbach's alpha was found to be 0.947, and the test-retest reliability was 0.932. The questionnaire was also validated with two other scales: The Closeness and Conflict Scale (CCS) (Schofield, Murphy, Herrman, Bloch, & Singh, 1997) and the Heartfelt Sadness and Longing subscale (HSL) of the Marwit-Meuser Caregiver Grief Inventory (Marwit & Meuser, 2002). HSL was found to be strongly correlated with the loss subscale of BRCM (-0.655; $p<0.001$) and the CCS had a strong correlation with the same/different feelings subscale of BRCM (0.551; $p<0.001$). Furthermore, exploratory factor analysis (EFA) was conducted on a combined sample of 135, and only one reliable factor was extracted, explaining 46% variance in scores, thereby establishing the BRCM as a unidimensional scale (Riley et al., 2013). Overall the BRCM was proven as a quality questionnaire quantitatively assessing RC among spouses with dementia.

The BRCM scale has so far been used in published studies on dementia. One study used the scale to assess the relationship between RC, social cognition, and behaviour in dementia and found that the BRCM correlated with the measure of behavioural disturbance but not the measure of social cognition (Poveda, Osborne-

Crowley, Laidlaw, Macleod, & Power, 2017). Another study used the scale to quantitatively assess the qualitative findings that suggested a link between RC and the emotional impact of a caregiving role (Riley, Evans, & Oyebode, 2018). It implies the adequacy of the scale in quantifying RC in partners with dementia.

2. Aim

Based on the need for a quantitative assessment of RC following a BI, the study adopted an existing scale the BRCM, in consultation with experts-by-experience and aimed to evaluate the scale and establish its psychometric properties for use in acquired brain injury (ABI). The study was divided into four stages:

Stage I: The original BRCM was adapted for use in ABI. The wording of the original measure needed altering to reflect its application to ABI rather than dementia. However, ABI and dementia are not equivalent, and the applicability of the items to ABI was also checked with a panel of experts-by-experience, and some alterations were made.

Stage II: The reliability, validity, and discriminative power of the scale were evaluated using an initial sample of 50 participants. Validity was assessed using the same method as in Riley et al. (2013). Riley et al. (2013) hypothesised that the heartfelt sadness and longing subscale of the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) would correlate most highly with the loss subscale of the BRCM and that Schofield Closeness and Conflict Scale (SCCS) would correlate most highly with the same/different feelings subscale. However, it was difficult to carry out an adequate statistical test of this because the scale was unidimensional and the differences between the correlations were relatively small. Because of the small difference, a very large sample would have been required to test whether the correlations were significantly different. In anticipation of similar unidirectionality and small differences in this study, a more modest hypothesis was tested- specifically, that the MM-CGI and the SCCS would both show at least a moderate correlation with the BRCM total (i.e. above 0.3).

Stage III: Further psychometric evaluation was carried out using a sample of extra 26 participants who were involved in a second study (described in Chapter Three). This sample and the initial sample were also combined to conduct a EFA. The expectation was that the scale would be unidimensional.

Stage IV: Further evidence about the validity of the scale was also collected on participants who were involved in a second study (described in Chapter Four), using Dyadic Adjustment Scale (DAS) and post-injury Relationship Assessment Scale (RAS). The hypothesis was that both the DAS and RAS would show at least moderate correlation with the BRCM total (i.e. above 0.3).

3. Stage I

A co-researcher conducted the study at this stage. The study included a focus group of five experts-by-experience to adapt the BRCM dementia version for use with spouses of those with ABI. Some of these experts were also spouses from a HEADWAY (the brain injury association) carers group. The focus group provided their feedback on the clarity of the instructions of the BRCM and the overall measure (Appendix 3a). To do so, they were shown the relevant items of each subscale of the BRCM separately and were asked the following questions:

- Is this statement clearly worded?
- Do you think it is a good way of asking about the (whatever the subscale aimed to measure)?
- From your own experience, can you imagine some partners of people with a BI may strongly agree with the statement, but others will strongly be disagreeing?

Once the responses were collected from the focus group, based on their feedback, specific changes were made to the BRCM. The most important feedback was that the group thought that all the statements were clearly worded, and it was an effective way to ask about the subscales. However, the group also thought that the instructions should be more precise. Therefore, a short introductory paragraph was then added to confirm that the measure is about changes in the spouse and the relationship since the ABI, and requesting spouses to think about how things were before the ABI, and how they are at present. Another critical feedback from the focus group was that they thought two statements did not reflect much of the experiences of spouses of those with an ABI. Therefore, those two statements were reworded. “He’s in a world of his own most of the time” was changed to “He is more interested in himself now that he is in me or our relationship” (Item 1; Subscale- Couplehood), and “He’s a shadow of his former self” was changed to “Since the brain injury, his personality is very different” (Item 7; Subscale- Same/Different Person).

4. Stage II

4.1. Methodology

4.1.1. Participants

A frequent practice is to use a minimum of 30 or more participants to conduct reliability and validity analysis of a questionnaire (Hobart, Cano, Warner, & Thompson, 2012; Rea & Parker, 2014). However, there is an ongoing debate about the right sample size for studies involving a psychometric evaluation of a measure. The number of participants needed varies across different studies, and there is no consensus (Hobart et al., 2012).

A simulation study conducted to assess sample size requirements in reliability and validity studies found that to assess reliability, a minimum sample size of 20 or more was adequate (Hobart et al., 2012). Another study, used simulation method, based on the bootstrap technique, to assess the minimum sample size requirements (Yurdugül, 2008). They found that a minimum sample of 30 participants was adequate to calculate Cronbach's alpha, provided that the first eigenvalue in a factor analysis be above 6.0. There is prior evidence about the original BRCM to suggest that it is unidimensional, and its first eigenvalue exceeded 6.0 (Riley et al., 2013), and therefore, a sample of 30 was found to be adequate for the reliability estimates.

The study conducted by Hobart et al. (2012) also found that 75% of the time, a sample size of 40 was adequate for establishing validity. The Riley et al. (2013) study reported a correlation of 0.6 between the BRCM and the MM-CGI scale, and 0.4 between the BRCM and the SCCS. Therefore, a power analysis calculation using G*Power (version 3.0.10) (Faul, Erdfelder, Lang, & Buchner, 2007) was conducted to check the required sample size. The analysis showed that, with the alpha set at .05 (two-tailed) and the power at .80, a sample of 44 would be required to detect a correlation of 0.4.

Based on the above-mentioned study findings and the G*Power calculation, a sample of at least 44 participants was targeted, and a total of 50 participants were finally recruited. The inclusion and exclusion criteria for selecting the participants have been mentioned below.

4.1.1.1. Inclusion criteria

a. Should be a husband, wife or partner of someone who has suffered a BI (e.g. traumatic BI, stroke, brain tumour) in the last ten years irrespective of their sexual orientation, religious or cultural beliefs, ethnicity, and nationality.

b. The BI happened at least nine months ago.
c. Husband, wife or partner had stayed in a hospital for at least a week because of the BI.
d. They lived with their husband, wife or partner for at least one year before their injury.
e. They are currently living with the person who had the BI and providing some degree of care and support.
f. They are at least 18 years of age.

4.1.1.2. Exclusion criteria

a. Carers of individuals with a BI who were not in a relationship before the injury, those who did not live together before the injury, and those not living together currently.
b. Cannot read or write.
c. Does not understand the English language.
d. Cannot give informed consent to participate.
e. Carers having a history of any form of psychological or neuropsychological illness for which they received treatment.

Participants were recruited from ‘Headway’ a charity organisation providing support for people with ABI and their families and from two other charitable BI carers’ support groups, ‘Carers UK’ and ‘Brain Injury Group’. All the participants with an ABI had received rehabilitation. None of the partners were in a same-sex relationship. Information was not collected about the severity of the injury, but since all the participants had received rehabilitation for at least nine months, they were considered to have had a moderate to severe BI rather than a mild one. Table 3.1 shows the demographic information of all the participants (caregivers) and care recipients.

Table 3.1. Demographic information of participants and their partners

(N= 50)	Participants (Caregivers)	Care recipients
Gender	Men= 30 (60%) Women= 20 (40%)	Men= 20 (40%) Women= 30 (60%)
Age	Mean= 59.4 SD= 12.3 Range= 33-81	Mean= 61.66 SD= 12.29 Range= 35-85
Ethnicity	White British= 32 (64%) British Asian=9 (18%) White and Black African= 8 (16%) Black Caribbean= 1 (2%)	White British= 36 (72%) British Asian= 6 (12%) White and Black African= 7 (14%) Black Caribbean= 1 (2%)
Religious belief	No religion= 16 (32%) Christian= 14 (28%) Muslim= 9 (18%) Hindu= 1 (2%) Missing data= 10 (20%)	No religion= 16 (32%) Christian= 14 (28%) Muslim= 9 (18%) Hindu= 1 (2%) Missing data= 10 (20%)
Employment status	Employed= 28 (56%) Unemployed= 11 (22%) Missing data= 11 (22%)	Unemployed= 100%
Type of BI		TBI= 14 (28%) Stroke= 13 (26%) Aneurism= 3 (6%) Brain Haemorrhage= 2 (4%) Missing data= 18 (36%)
Duration of partnership (in months)	Mean= 399.14 SD= 159 Range= 84-660	
Duration of caregiving role (in months)	Mean= 50.8 SD= 33.67 Range= 14-144	

4.1.2. Measures

The development of the BRCM has already been published (Riley et al., 2013) and in this study, it was assessed to evaluate the psychometric properties of a version adapted for use in ABI. For validation of the scale, two other questionnaires were used; the heartfelt sadness and longing subscale of the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) and Schofield Closeness and Conflict Scale (SCCS). Both these scales have also been used to validate the BRCM in dementia population (Riley at al., 2013).

4.1.2.1. Birmingham Relationship Continuity Measure (BRCM)

The BRCM scale for use in dementia was modified and adapted for use in ABI, as mentioned in Stage I of the study. It is a 23-item questionnaire, where participants are asked to express their view on changes in their partner following an ABI based on how things were before the injury and how things are at present. They answered on a five-point scale of agreement, where a higher score indicates a greater sense of RC (‘Agree a lot’ scored as one; ‘Agree a little’ as two; and so, on up to ‘Disagree a lot’ scored as five). It has both male and female versions, and items address each of the five components of RC described earlier.

4.1.2.2. Schofield Closeness and Conflict Scale (SCCS)

The SCCS was developed to assess both positive and negative caregiving experiences by measuring aspects of closeness and conflict (Schofield et al., 1997). It is a six-item questionnaire with three items about positive feelings towards the other person measuring closeness (e.g., compassion and love), and three items about negative feelings measuring the conflict (e.g., tension and resentment) (Schofield et al., 1997). The participants were asked to indicate the extent to which the feeling has occurred less, more or about the same since taking on a caregiving role. A low score on this scale shows a decline in positive feelings and an increase in negative feelings since taking on the caring role (for positive feelings, one = less, two = the same, and three = more; and for negative feelings, one = more, two = the same, and three = less). The scale has good validity and good internal consistency (closeness= .82 & conflict = .84) (Schofield et al., 1997). This scale was chosen since it measures similar caregiving aspects that same/different feelings subscale of BRCM does (Riley et al., 2013).

4.1.2.3. Marwit-Meuser Caregiver Grief Inventory (MM-CGI)

The MM-CGI was first constructed to assess caregiver grief in Alzheimer's (Marwit & Meuser, 2002), and later has been validated and used in dementia population (e.g., Holley & Mast, 2009; Marwit & Meuser, 2005; Sanders, Ott, Kelber, & Noonan, 2008). It is a 50-item scale with three sub-scales, 'Personal Sacrifice Burden', 'Heartfelt, Sadness and Longing', and 'Worry and Felt Isolation' (Marwit, & Meuser, 2002). The heartfelt, sadness and longing sub-scale is a five-point Likert scale consisting of 15 items measuring feelings of the caregiver's emotional reactions towards caregiving, specifically, loss and sadness (e.g., "I miss so many of the activities we used to share", "I feel terrific sadness") (Marwit & Meuser, 2002). The participants are asked to rate their experience carefully, and a high score predicts a higher level of loss and sadness ('strongly disagree' is scored as one, 'agree' scored as two, and so on up to 'strongly agree' scored as five). The sub-scale has good validity and good internal consistency (alpha .90) (Marwit & Meuser, 2005). This scale was chosen since it measures similar caregiver emotional reactions that the loss subscale of BRCM does.

4.1.3. Procedure

Opportunity sampling was used to recruit participants from a target population. As mentioned earlier, participants were recruited from charities and carer support groups, who were contacted using advertising posters, invitation letters or direct contacts with the organisation's coordinators.

Permission was first obtained from the co-ordinators of the charities and organisations for recruitment. The researcher then introduced herself to the carer groups where she delivered a short talk (approximately five minutes) about the research, stating who the researcher was, what the research was about and how it will be useful, who can participate, and the risks related to it, and other participation details. An invitation letter with similar information and the researcher's contact details was also provided (Appendix 3b). After the presentation, the researcher was present to answer potential recruits' questions and to provide an opportunity for people who were interested in the research to 'opt-in' by approaching the researcher and asking for the questionnaire package. In some cases, the coordinators displayed or distributed the invitation posters to caregivers themselves. If they wanted to find out more about the research, they were asked to contact the researcher.

Participation was voluntary, and people who expressed an interest in participating after a presentation (or at a later stage by contacting the researcher) were then screened against on the study inclusion and exclusion criteria as mentioned earlier. Once selected, they were provided with a participant information sheet (Appendix 3c), consent form (Appendix 3d), and a questionnaire pack (Appendix 3e). The questionnaire pack had a participation checklist, a socio-demographic information sheet, three scales (BRCM, MM-CGI, SCCS), and a support sheet at the end that had details of where they can find help if they were in distress. As mentioned above, Appendix 3e has details of the questionnaire pack. However, MM-CGI and SCCS have not been included in the appendix due to copyright issues.

Participants first went through the information sheets, asked any questions and then, if they wanted to participate, signed the consent forms. After this, in most cases, future appointments were made when the researcher personally met the participants and collected the data in the centres and helped them with queries they had during the process. However, due to the long distance at which they lived, the researcher was unable to meet 13 participants personally at the centre, so they were posted the participant information sheet, consent form, and questionnaire pack and were provided with a pre-paid envelope to return their completed questionnaires. The researcher’s contact number was also provided to them so that they could contact in case they had queries while filling in the questionnaires. A total of 99 participants were approached, and 50 participated. The overall response rate was 51%.

For BRCM test-retest reliability, the scale was re-administered within two weeks of its first administration. Information regarding the re-administration of the BRCM was provided to all the participants when they were first approached. They were informed that only those who gave consent to be contacted again for the test re-administration would be approached and that they could withdraw later if they wanted to do so. All the 50 participants gave their consent to be contacted again, and so the researcher met them again with the same set of participant information sheet, consent form, and just the BRCM questionnaire. For the 13 participants, whose questionnaires were posted, they were sent the retest questionnaire within a week of completion of first administration, and the participants were instructed to fill them in within a maximum of 8 days starting from when they received the package.

4.1.4. Ethical consideration

The study was approved by the University of Birmingham School of Psychology Human Research Ethics Committee (Appendix 3f). Since the retest of the BRCM questionnaire was conducted, the participant’s details like address or name were collected. However, once the retest scores were obtained, the paperwork containing the participant’s personal information was destroyed, and they were provided with a unique participation number to identify their test-retest responses in the future.

Due to the potentially sensitive nature of this research, with participants being asked to answer questions about their relationship with their care-receiver, it was possible that the participant might become upset when completing the questionnaire. In order to minimise such distress, the following measures were taken:

a. The information sheet explained to the participants that the questionnaires asks questions about the behaviours shown by their partner and their relationship with their partner, and if they find that distressing they could withdraw at any time, without having to give a reason.
b. All participants were provided with contact details for relevant support services on the information sheet. They were advised to contact their organisation from where they were recruited or their GP should they be upset by the questionnaires, or feel in need of further support.
c. All participants were provided with the contact details of the University of Birmingham, the school of psychology, if they were unhappy with the way the research was conducted and wanted to complain.

4.1.5. Statistical analysis

SPSS (Version 22) (2013) was used to analyse the data for both descriptive and inferential statistics. Pearson’s Product Moment Correlation Coefficient was used to assess the relationship between BRCM and its subscales with SCCS and MM-CGI. Intra Class Correlation (ICC) was used to measure test-retest reliability. Cronbach’s alpha was used to evaluate the internal consistency of the scale. The discriminative power of the scale was also calculated using Ferguson’s δ, using the formula provided by Hankins for scales with multiple response options (Hankins, 2007).

4.2. Results

4.2.1. Data Checking

Before any statistical analysis was conducted, the data from each stage was first analysed to check if there was any missing data, if there were any outliers, and to check the normality of the data.

4.2.1.1. Missing data

Missing data was found regarding the religious belief of the partners, caregiver employment status, and the type of BI of the care recipients (Table 3.1).

4.2.1.2. Outliers and normality of data

The recommendations of Tabachnick and Fidell (2013) were followed to check the normality of the data. For grouped data, outliers were sought separately for each group. To find outliers, scores were first transformed into standardised scores (z scores). Cases which had a standard score ± 3.29 (p<.001, two-tailed test) were considered as outliers (Tabachnick & Fidell, 2013).

Normality of scores was evaluated by evaluating the skewness and kurtosis values of each. A distribution is skewed when the mean score is not at the centre of the distribution, while distribution has kurtosis when the peak is too high or low compared to the normal distribution (Tabachnick & Fidell, 2013). Tabachnik and Fidell (2013) recommend, as a guide to evaluating whether the data are suitable for parametric analysis, dividing the skewness and kurtosis statistics by their respective standard error: If the result is below three, then data are assumed to be suitable for parametric analysis.

Outliers, skewness, and kurtosis were first assessed for the BRCM. The BRCM had no outliers but was found to have mild skewness and kurtosis. However, both skewness and kurtosis values were less than three times of their respective standard error which is within the acceptable range, thus indicating that the scores were relatively normally distributed and met the assumptions of parametric tests. The scale was found to be relatively normally distributed at all the stages.

Similarly, the other three scales, SCCS, MM-CGI, and DAS had no outliers, and both the skewness and kurtosis values were within the acceptable range, indicating that the scales were relatively normally distributed at all the stages (Tabachnick & Fidell, 2013).

For the post-injury RAS scale, there was no outlier, but the data were positively skewed and had kurtosis as well. Therefore, the post-injury RAS data-set was not normally distributed, and therefore, a transformation was conducted as per Tabachnick and Fidell recommendations (2013) so that parametric tests could be conducted. Since the data were positively skewed, a logarithmic transformation was conducted (Tabachnick & Fidell, 2013), and the data were found to have no skewness or kurtosis after the correction. Details regarding the DAS and post-injury RAS have been provided at Stage IV.

4.2.2. Data analysis

Table 3.1 shows the demographic information of the participants (caregivers) and care recipients. The relationship of the total BRCM score with the demographic variables were analysed. Mean score of men were found to be slightly higher on the total BRCM score than women, but the difference was not significant (mean for men= 61, mean for women= 55, t= 0.814, p= 0.422). The total BRCM score was found to have no significant relationship with age of the participants (r= 0.176, p= 0.327), age of the care recipients (r= 0.145, p= 0.420), duration of the partnership (r= 0.169, p= 0.347), and duration of caregiving (r= -0.107, p= 0.552). Due to missing data regarding religious belief of the partners, caregiver employment status, and the type of BI of the care recipients, an analysis of these variables with the BRCM total score was not conducted.

4.2.2.1. Reliability

Overall, the BRCM had a high internal consistency (alpha= 0.956) while the five study subscales also showed good internal consistency (Table 3.2). Similarly, the other two scales, SCCS and MM-CGI also had a high internal consistency (Table 3.2).

ICC was used to evaluate test-retest reliability using a two-way mixed effects model, single measure, and absolute agreement (Koo & Li, 2016). It was found to be 0.960 (95% Confidence Interval = 0.926 to 0.977, p< 0.001). Therefore, it can be stated that the participant's responses were similar over time, indicating the good reliability of the BRCM.

Table 3.2. Descriptive statistics

(N=50) Missing value=0	Mean	Possible Min/Max	Obtained Min/Max	SD	Skewness (Stand. Error)	Kurtosis (Stand. Error)	Cronbach's alpha
BRCM Total	63.2	23/115	23/112	22.1	.310 (.337)	-.630 (.662)	.956
BRCM Retest	61.5	23/115	29/97	20.5	-.040 (.337)	-1.216 (.662)	.956
BRCM subscale-Same/different feelings (7 items)	20.3	7/35	7/35	7.4	_	_	.897
BRCM subscale- Loss (3 items)	6.3	3/15	3/15	3	_	_	.759
BRCM subscale-Relationship redefined (3 items)	7.4	3/15	3/13	3.1	_	_	.671
BRCM subscale-Same/different person (6 items)	17	6/30	6/30	6.7	_	_	.876

BRCM subscale-Couplehood (4 items)	12.3	4/20	4/20	4.2	_	_	.819
SCCS	9.1	6/18	6/14	2.5	.047 (.337)	-1.412 (.662)	.793
MM-CGI	46.1	15/75	20/73	14.7	.236 (.337)	-1.146 (.662)	.953

4.2.2.2. Concurrent Validity

Concurrent validity of BRCM was assessed using Pearson's Correlation Coefficient and two established scales, SCCS and MM-CGI (Table 3.3). The overall BRCM score had a high positive correlation with SCCS (r= 0.911, p< 0.001) indicating that relationship discontinuity (RD) (low score in BRCM) is related with increased negative caregiving feeling (low score in SCCS). The BRCM score also had a negative correlation with the MM-CGI subscale (r= -0.732, p< 0.001) indicating that RD (low score in BRCM) is related to higher level of feelings of sadness and loss (high score in MM-CGI).

It was predicted that the MM-CGI and the SCCS would both show at least a moderate correlation with the BRCM total (i.e., above 0.3). For the sample of 50 participants, the 99% confidence intervals for the two correlations were; for 0.911 they were 0.821 to 0.957, and for 0.732 they were 0.506 to 0.863. It indicates that there is a 99% probability that the population correlation is a strong one (above 0.3).

Table 3.3 Correlations between the BRCM, SCCS, and MM-CGI

BRCM Subscale and overall total	SCCS	MM-CGI	BRCM Retest
Same/different feelings	Pearson=.849**	Pearson= -.643**	-
Loss	Pearson=.802**	Pearson= -.687**	-
Relationship redefined	Pearson=.824**	Pearson= -.661**	-
Same/different person	Pearson=.837**	Pearson= -.719**	-
Couplehood	Pearson=.757**	Pearson= -.573**	-
Overall total	Pearson=.911**	Pearson= -.732**	.965**

N=50; **p<0.01

4.2.2.3. Discriminative power

Discriminatory power is a measure of the degree to which a scale discriminates between individuals who are different in respect of the construct being measured (Ferrando, 2012). A scale in which lots of people scored zero (or lots scored high) would have poor discriminative power because the people who probably differ on the construct the measure is meant to assess, are receiving the same score (and so the scale is not discriminating between them).

Discriminatory power of the BRCM (N=50) was calculated using Ferguson's δ, as mentioned earlier (Ferguson, 1949; Hankins, 2007), and was found to be 0.964, which is above the 0.9 recommended score for satisfactory discriminative power (Kline, 2000). This finding should be interpreted in the light of the recent suggestion that the statistic is useful only when the measure is reliable and valid (Terluin, Knol, Terwee, & de Vet, 2009).

5. Stage III

5.1. Methodology

5.1.1. Participants

An additional 26 participants were recruited for another study (described in Chapter Four). Both these samples were combined, making a total number of 76 participants, to conduct further psychometric assessment and factor analysis of the BRCM. The inclusion and exclusion criteria were the same as it was in Stage II. Participants were adult partners turned carers who were recruited from HEADWAY and various other BI carers' support groups. All the participants with ABI had received rehabilitation. None of the partners were in a same-sex relationship. Table 3.4 shows the demographic information of the combined sample.

Table 3.4. Demographic information of participants and their partners

(N=76)	Participants (Caregivers)	Care receivers
Gender	Men= 43 (57%) Women= 33 (43%)	Men= 33 (43%) Women= 43 (57%)
Age	Mean= 57.3 SD= 12 Range= 33-81	Mean= 59 SD= 12 Range= 35-85
Ethnicity	White British= 49 (65%) British Asian= 16 (21%) White and Black African= 8 (11%) Black Caribbean= 1 (1%) Caucasian= 1 (1%) British Irish= 1 (1%)	White British= 52 (69%) British Asian= 14 (19%) White and Black African= 7 (9%) Black Caribbean= 1 (1%) Caucasian= 1 (1%) Irish= 1 (1%)
Religious belief	No religion= 27 (36%) Christian= 23 (30%) Muslim= 11 (15%) Hindu= 1 (1%) Missing data= 14 (18%)	No religion= 27 (36%) Christian= 23 (30%) Muslim= 11 (15%) Hindu= 1 (1%) Missing data= 14 (18%)
Employment status	Employed= 47 (62%) Unemployed= 12 (16%) Missing data= 17 (22%)	Employed= 8 (10%) Unemployed= 59 (78%) Missing data= 9 (12%)

Type of BI		TBI= 20 (26%) Stroke= 22 (29%) Aneurism= 3 (4%) Brain Haemorrhage= 2 (3%) Missing data= 29 (38%)
Duration of partnership (in months)	Mean= 366 SD= 152 Range= 60-660	
Duration of caregiving role (in months)	Mean= 45.2 SD= 30 Range= 12-144	

5.1.2. Measures

For the 50 participants who were recruited at stage II and whose data was used at this stage as well, the measures were the same. However, for the additional 26 participants, there was a battery of other questionnaires that were used along with the BRCM as they were involved in a second study. Only the BRCM data from that battery of questionnaires were used in this stage for analysis. Detailed information of this is in Chapter Four.

5.1.3. Procedure

The procedure for the first 50 participants was the same as in Stage II. For the remaining 26 participants, there were a few changes to the procedure, the details of which are in Chapter Four.

5.1.4. Ethical consideration

The ethical considerations were the same as mentioned in Stage II.

5.1.5. Statistical analysis

SPSS (Version 22) (2013) was used to analyse the data for both descriptive and inferential statistics. Cronbach’s alpha was used to evaluate the internal consistency of the scale. The discriminative power of the scale was also calculated using Ferguson's δ, using the formula provided by Hankins (2007) for scales with multiple response options. EFA was used to evaluate the BRCM.

5.2. Results

5.2.1. Missing data

Missing data were found regarding the religious belief of the partners, their employment status, and the type of BI of the care recipients (Table 3.4).

5.2.2. Data analysis

Table 3.4 shows the demographic information of the participants (caregivers) and care recipients. The relationship of the total BRCM score with the demographic variables were analysed. Mean score of men and women were found to be almost same on the total BRCM score, and, therefore, there was no significant difference (mean for men= 57.3, mean for women= 57, t= 0.064, p= 0.949). The total BRCM score was found to have no significant relationship with age of the participants (r= 0.086, p= 0.537), age of the care recipients (r= 0.086, p= 0.534), duration of the partnership (r= 0.139, p= 0.315), and duration of caregiving (r= 0.046, p= 0.742). Due to missing data regarding religious belief of the partners, their employment status, and the type of BI of the care recipients, an analysis of these variables with the BRCM total score was not conducted.

5.2.3. Reliability

Overall, the BRCM had a high internal consistency (alpha= 0.961) while the five study subscales also showed good internal consistency (Table 3.5).

Table 3.5. Descriptive statistics

(N=76) Missing value=0	Mean	Possible Min/Max	Obtained Min/Max	SD	Skewness (Stand. Error)	Kurtosis (Stand. Error)	Cronbach's alpha
BRCM Total	60.88	23/115	23/113	23.1	.556 (.276)	-.606 (.545)	.961
BRCM subscale- Same/different feelings (7 items)	20.1	7/35	7/35	7.5	_	_	.905
BRCM subscale- Loss (3 items)	6.06	3/15	3/15	7.5	_	_	.800
BRCM subscale- Relationship redefined (3 items)	7.1	3/15	3/15	4.6	_	_	.734
BRCM subscale- Same/different person (6 items)	16	6/30	6/30	6.9	_	_	.883
BRCM subscale- Couplehood (4 items)	11.6	4/20	4/20	4.6	_	_	.855

5.2.4. Discriminative power

Discriminatory power of the BRCM (N=76) was calculated using Ferguson's δ, as mentioned earlier (Ferguson, 1949; Hankins, 2007), and was found to be 0.990, which is above the 0.9 recommended score for satisfactory discriminative power (Kline, 2000). As mentioned earlier, this finding should be interpreted in light of the suggestion that the statistic is useful only when the measure is reliable and valid (Terluin et al., 2009).

5.2.5. Factor Analysis

One aim of the study was to assess the unidimensionality of the BRCM. First, the Kaiser-Meyer-Olkin measure was used to test the sampling adequacy which was found to be 0.870 (Table 3.6), indicating a moderate degree of factorability in the data (Kaiser, 1974).

Table 3.6. Kaiser-Meyer-Olkin (KMO)

Kaiser-Meyer-Olkin Measure of Sample Adequacy		.870
Bartlett's Test of Sphericity	Approx. Chi Square df Sig.	1684.957 253 .000

Next, to assess if the measures reflect a single underlying construct or a few distinct constructs, factor analysis was conducted. Since the BRCM has already been established as a measure with underlying correlated factors (Riley et al., 2013), EFA was conducted, to understand the underlying relationships between the measured variables (Fabrigar & Wegener, 2011).

Maximum likelihood was used as the extraction method as it computes a wide range of indexes of the model's goodness of fit and conducts statistical significance tests of factor loadings and correlations among factors (Costello & Osborne, 2005). Direct oblimin was used as a method of rotation as it allows the factors to correlate (Costello & Osborne, 2005). It was considered to be the best approach since the analysis was based on the findings that the factors were correlated (Riley et al., 2013). Pattern matrix is used to check the factor loadings when oblique rotation (direct oblimin) is conducted (Costello & Osborne, 2005), and therefore, was used in this study. Scree plot is used to decide the number of reliable factors to retain, and it involves checking the graph of the eigenvalues to find where the data line naturally bends (Costello & Osborne, 2005). The number of data points above the bend is the number of reliable factors that should be retained. It was checked by running multiple analyses to obtain the best possible factor solution (Costello & Osborne, 2005).

The first analysis was run without any fixed factor extraction number (based on eigenvalue greater than one) to allow the computation of the maximum number of factors, and a four-factor solution was obtained. Following Costello and Osborne recommendations (2005), repeated factor analysis was next run using a fixed number of factors which were less than the initial four-factor solution (i.e., three, two and one-factor analyses). The final analysis using one factor reveals good factor structure with high extraction values, all above 0.4, and no negative values (Table 3.8). The scree test showed the same results in every analysis where the curve flattened out after one point, indicating one factor to be retained in all the analysis, confirming the unidimensionality of the scale (Figure 3.1). Therefore, the first analysis where the number of factors were not fixed was considered to have provided the best factor solution, where the scree plot shows only one reliable factor to be retained, which explained 55% of the variance in scores (Initial Eigenvalues: Factor One = 12.68; Factor Two = 1.74; Factor Three = 1.44; Factor Four = 1.17). The goodness of fit test for the same analysis (factors based on eigenvalues greater than one) further showed that the model fits well with the expected factor model (Chi-Square = 390.578; df= 167; $p<.000$). The analysis was thus consistent with the previous findings in Riley et al. (2003), suggesting unidimensionality of the scale.

Table 3.7. Pattern Matrix

Item number	Factor (based on eigenvalue greater than 1)				Factor (based on fixed number of factors=3)			Factor (based on fixed number of factors=2)	
	1	2	3	4	1	2	3	1	2
1	.161	.207	-.052	.483	.172	-.087	.597	.298	.456
2	.021	.128	.799	.176	.147	.690	.277	-.115	.637
3	-.029	.599	.018	.235	.540	-.063	.239	.629	.127
4	-.053	.800	.243	-.052	.795	.150	-.072	.734	-.010
5	.219	-.005	.268	.672	-.018	.192	.841	.023	.828
6	.154	.820	.097	-.162	.975	.066	-.177	.948	-.161
7	.273	.179	-.170	.318	.234	-.167	.433	.319	.326
8	.060	.726	.152	.078	.756	.079	.093	.728	.121
9	.447	.192	.262	-.092	.462	.344	.063	.195	.403
10	-.037	.617	-.163	.306	.512	-.273	.317	.725	.031
11	.422	.525	.016	.027	.759	.019	.132	.754	.123
12	.487	.024	.147	.376	.214	.186	.577	.114	.730
13	.964	-.069	.010	.148	.440	.139	.416	.341	.552
14	.563	.413	-.068	-.076	.729	.004	.064	.689	.102
15	-.068	.019	.249	.770	-.173	.121	.864	-.078	.783
16	.347	.373	-.048	.267	.514	-.069	.378	.581	.288
17	.013	.388	-.345	.591	.238	-.458	.639	.582	.189
18	.258	.643	-.154	.070	.785	-.159	.096	.897	-.048
19	.022	.887	-.028	.060	.893	-.103	.039	1.007	-.111
20	.050	.463	-.188	.463	.383	-.284	.498	.633	.176
21	.200	.251	.535	.211	.342	.497	.345	.154	.598
22	.305	.107	.155	.417	.205	.115	.546	.231	.535
23	.306	.060	-.001	.568	.089	-.025	.741	.189	.638

Extraction Method: Maximum Likelihood
Rotation Method: Oblimin with Kaiser Normalization
*Highlighted items have low extraction values (<.4) and overlapping extraction values.

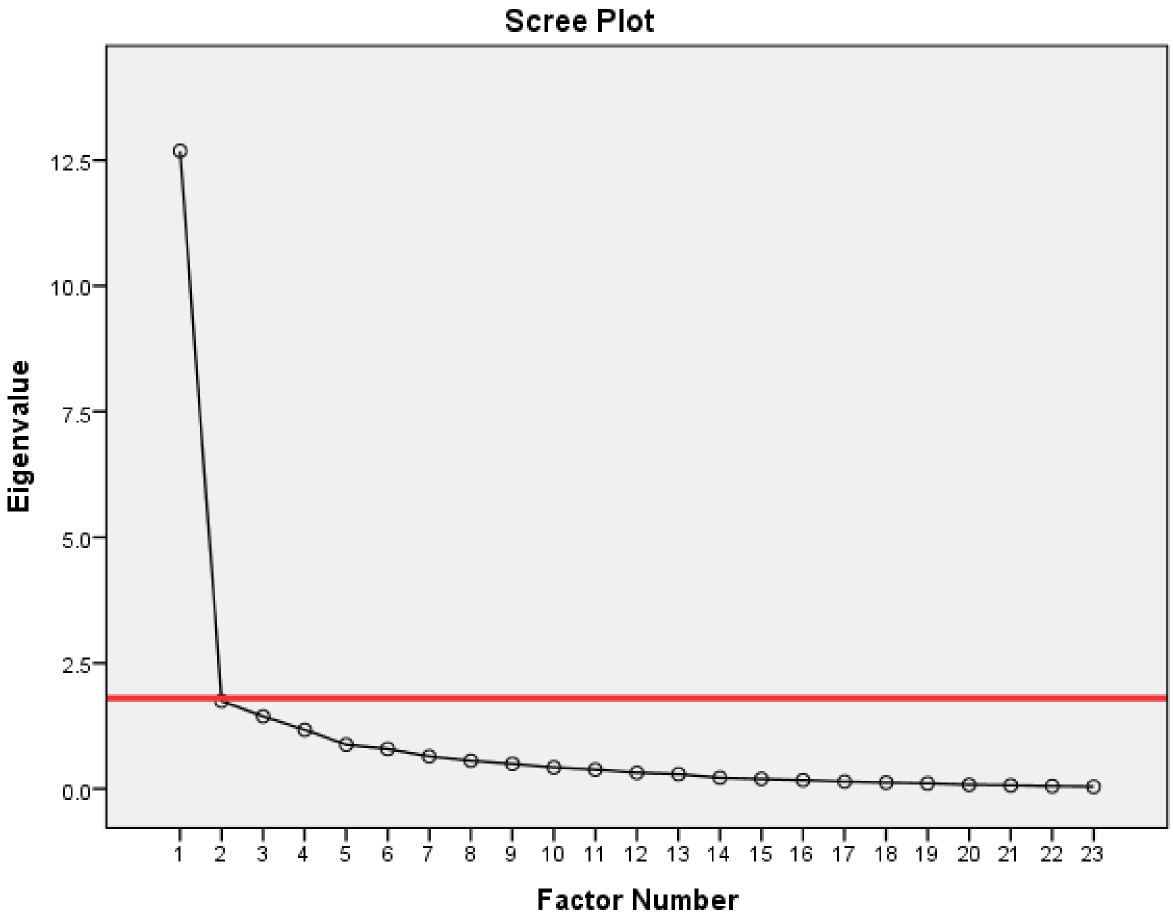
Table 3.8. Factor Matrix (based on a fixed number of factors=1)

Item number	Factor
	1
1	.681
2	.431
3	.721
4	.708
5	.729
6	.774
7	.600
8	.814
9	.544
10	.740
11	.850
12	.738

13	.813
14	.762
15	.590
16	.824
17	.737
18	.824
19	.871
20	.771
21	.663
22	.682
23	.730

Extraction Method: Maximum Likelihood

Figure 3.1. Scree Plot



The findings of the exploratory factor analysis should to be interpreted with caution. The study had a small sample size, based on the recommended minimum 2:1 subject to item ratio. As per Costello and Osborne (2005) recommendations, smaller sample size can yield good results in factor analysis provided that the data are “strong”. By strong data, they mean that the factors should have high communalities (0.8 or more) with no cross-loadings and there should be three or more variables loading strongly on each factor (Costello & Osborne, 2005). Pattern matrix in the current analysis revealed that two items (Item Seven and 16) had low communalities (<.4), and three items (Item Seven, 13, and 16) had overlapping extraction values as highlighted in Table 3.7. Moreover, only a few items had communalities of 0.8 or more (Table 3.7). However, as suggested by Preacher and MacCallum (2002), the present factor solution can be said to be reliable since only one factor was extracted and the communalities were not too low (Communalities ranged from 0.347 to 0.887).

6. Stage IV

6.1. Methodology

6.1.1. Participants

A total of 53 participants were recruited at this stage who participated in a second study. Detailed information of this, therefore, is in Chapter Four.

6.1.2. Measures

A battery of questionnaires was used that included the BRCM, DAS, and post-injury RAS.

6.1.2.1. Dyadic Adjustment Scale (DAS)

DAS is a self-report measure of relationship adjustment, constructed by Graham Spanier in 1976 (Spanier, 1976) (Appendix 4d). It is a 32-item questionnaire that measures four aspects of a relationship; dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression.

The scale has three different types of rating scales, and the total score (sum of all the items) is used to assess the overall dyadic adjustment. A higher score indicates a better relationship. It has good validity and good overall internal consistency, with an alpha of .96 (Spanier, 1987, 1989). It was expected that this scale would correlate with the BRCM because of some overlap in the underlying constructs. For example, dyadic cohesion and consensus in the DAS have some overlap with the notion of couplehood in the BRCM, and affectional expression has some overlap with same/different feelings.

6.1.2.2. Relationship Assessment Scale (RAS)

RAS is a brief measure of global relationship satisfaction, constructed by Hendrick in 1988. It consists of seven-items where participants are asked to answer each item on a five-point scale, ranging from one (low satisfaction) to five (high satisfaction). A higher score indicates higher satisfaction in the relationship. It has good validity and good overall internal consistency, with an alpha of 0.85 (Hendrick, Dicke, & Hendrick, 1998). The post-injury RAS measure was used for the present analysis (Appendix 4d). It was expected that RAS (post-injury) would show some correlation with the BRCM because those who experience a discontinuity in the relationship are likely to show less satisfaction with it.

6.1.3. Participants and Procedure

Detailed information about the participants and procedure has been provided in Chapter Four.

6.1.4. Ethical consideration

The ethical considerations were the same as mentioned in Stage II.

6.1.5. Statistical analysis

SPSS (Version 22) (2013) was used to analyse the data. Pearson's Product Moment Correlation Coefficient was used to assess the relationship between BRCM and DAS and RAS.

6.2. Results

Concurrent validity of BRCM was assessed using Pearson's Correlation Coefficient and two established scales, DAS and post-injury RAS (Table 3.9). The overall BRCM score had a high positive correlation with DAS (r= 0.669; p<.001) indicating that RD (low score in BRCM) is related to a poor overall adjustment in the relationship (low score in DAS). The BRCM score also had a positive correlation with the RAS subscale (r= 0-.849; p<.001) indicating that RD (low score in BRCM) is related with poor relationship satisfaction (low score in RAS).

It was predicted that the DAS and the post-injury RAS would both show at least a moderate correlation with the BRCM total (i.e. above 0.3). For the sample of 53 participants, both the DAS and post-injury RAS had a strong correlation with the BRCM total.

Table 3.9. Correlations between the BRCM, DAS, and RAS

	DAS	RAS (post-injury)
BRCM (Total Score)	.669**	.849**
DAS	-	.644**
RAS (post-injury)	.644**	-

N=53; **p<0.01

7. Discussion

Marital dissatisfaction and breakdown have been a common result of BI (Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007). It gave a platform to the formation of the concept of RD following a BI, where a partner loses the sense of partnership in their relationship, feels more like a carer and loses some of the love and affection previously felt. These experiences may be a potential cause of marital breakdown (Riley et al., 2013). It is important to assess this aspect of a relationship for better prognosis and rehabilitation of both the injured and their partners. There are very few caregivers/family measures that have been explicitly designed for use in ABI. The BRCM, a 23-item scale was developed for the same purpose but for partners with dementia (Riley et al., 2013). The current study evaluated the scale in the ABI population and found strong psychometric properties for future use.

The BRCM is based on the theoretical foundation of the following domains representing RC post dementia; relationship redefined, same/different person, same different feeling, couplehood, and loss (Riley et al., 2013). The current study was divided into four stages. At the first stage, the original BRCM was adapted for use on ABI population. At the second stage, the psychometric properties of the scale were assessed. At the third stage, the psychometric properties of the BRCM were assessed again using a larger sample size, along with assessing the factor structure of the scale. At the fourth stage, using another sample, the validity of the scale was assessed. No significant relationship was found at any stages between the total BRCM score and the demographic characteristics like gender, age, duration of the partnership, and duration of the caregiving role.

Overall, the BRCM was found to have high internal consistency and high test-retest reliability, indicating the scale's stability over time. Concurrent validity of the scale and the subscales was also found to be strong, with the BRCM showing the expected correlations with the SCCS, MM-CGI, DAS, and post-injury RAS.

The findings of factor analysis are in line with the findings of the evaluation of the BRCM scale in dementia population. It was argued that the five dimensions of the continuity construct, although conceptually distinct, were likely to show high correlations with one another because of their interrelated nature (Riley et al., 2013). Thus, the overall findings suggested that the scale has strong psychometric properties to be used for measuring relationship continuity/discontinuity experienced by partners following an ABI.

7.1. Limitations of the study

Though the evaluation of the scale has shown encouraging results, the study had some limitations. An important aspect is that the sample was self-selected. Thus, it is unclear how representative the sample was of the population of people with an ABI, and therefore, how generalizable the conclusions are about the psychometric properties of the scale. As mentioned earlier, the response rate in the second stage was only 51%. It is possible that those who did not take part may have characteristics that might affect the way in which they complete the BRCM. Moreover, the initial consultation with experts-by-experience (Stage I) was quite limited, and it may have been more useful to consult with a larger number of people.

The small sample size of the study has also created specific limitations. For example, the results of the factor analysis need to be treated with some caution due to the small sample size. Moreover, it was not possible to test a hypothesis that would have provided more robust evidence for the validity of the BRCM. Specifically, it was not possible to test hypotheses that the other questionnaires would show a higher correlation to some subscales of the BRCM compared to others.

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CHAPTER 4

PREDICTORS OF RELATIONSHIP CONTINUITY FOLLOWING A BRAIN INJURY

1. Introduction

Research has emphasised that social, emotional, and behavioural difficulties post-brain injury (BI) are strong predictors of partner distress, burden, and marital dysfunction in comparison to physical and cognitive impairments (Marsh, Kersel, Havill, & Sleigh, 2002; Weddell & Leggett, 2006; Wells, Dywan, & Dumas, 2005). For example, studies have found that among people with traumatic brain injury (TBI), aggression, irritability, depression, communication difficulties, and social disconnectedness are essential factors that create marital stress (Bracy & Douglas, 2005; Hora et al., 2012; Ponsford, Olver, Ponsford, & Nelms, 2003). As discussed in Chapter Two, there is a need for quantitative studies to investigate why some spouses perceive relationship continuity (RC), but others do not, since it might be useful in developing effective intervention strategies.

A handful of studies, mostly qualitative, have been conducted in this area. For example, a qualitative study conducted to explore how a partner's experience of various BI impairments affects their relationship, found that aggression, controlling behaviours, and lack of positive emotional responses like "loss of expression of care, love, and affection" were reported to be perceived as upsetting by partners of individuals with TBI (Bodley-Scott, & Riley, 2015, p. 215). The partners described that aggression and lack of positive emotions undermined their feelings of love and affection. The decline in these feelings of love and affection is one aspect of relationship discontinuity (RD).

Similar findings have been reported in other studies as well (e.g., Oddy, 1999; Peters, Stambrook, Moore, & Esses, 1990; Wells et al., 2005). A qualitative study conducted to explore how intimate relationships are affected following TBI from both survivors and their partner's perspective (Gill, Sander, Robins, Mazzei, & Struchen,

2011) found feelings like loss of expression of love and affection by the BI survivor creates a sense of loss of the partnership for the non-injured partners.

A study conducted to explore the experience of family members living with cognitive, emotional, and behavioural changes post acquired brain injury (ABI), used descriptive phenomenological method to analyse the family members experience (Braine, 2011). The study found aggression was a significant behavioural change that spouses found to be most distressing, alongside apathy and emotional volatility. In another study conducted by Villa and Riley (2017), participants reported that the lack of emotional warmth undermined their feelings of love and affection for their partner, but also contributed to the sense that the relationship itself was very different (another aspect of discontinuity).

Another qualitative study reported aggression to contribute to a perception of change towards a BI survivor in comparison to their pre-morbid personality (a distinct aspect of discontinuity) (Gibbons, 2016). It was because aggression was out of character and, therefore, a shock to the non-injured partners (Gibbons, 2016).

A quantitative study was recently conducted to explore the relationship between social cognition, behavioural difficulties, and RC in dementia of the Alzheimer type (Poveda, Osborne-Crowley, Laidlaw, Macleod, & Power, 2017). As mentioned in Chapter Three, the Birmingham Relationship continuity measure (BRCM) was used in this study to assess RC, while Awareness of Social Inference Test and Neuropsychiatric Inventory Test were used to assess social cognition and neurobehavioral difficulties. The measure of social cognition was a measure of things like the understanding of sarcasm in social interactions and was likely to have been insensitive to the lack of emotional warmth. The study findings show that there was no significant relationship between social cognition and partner's perception of RC. However, behavioural difficulties, like changes in apathy, disinhibition, and agitation were found to be significantly related with RC. Based on this finding the present study hypothesised that the BRCM would highly correlate with aggression and lack of emotional warmth.

2. Aim

The present study aimed to assess how various impairments arising from a BI are related to RC. As mentioned earlier, the hypothesis was that behavioural disturbances like aggression and lack of emotional warmth would be stronger predictors of the experience of RC (measured using the BRCM), compared to other impairments, such as cognitive deficits, physical disabilities, and problems with the activities of daily living.

3. Methodology

3.1. Participants

A power analysis calculation using G*Power (version 3.0.10) (Faul, Erdfelder, Lang, & Buchner, 2007) was conducted to check the required sample size for the study. The principal analysis involved a multiple regression with an expected eight predictor variables, with a focus on whether each of these variables made a significant unique contribution to the variance in the BRCM scores. To test the regression coefficients of eight predictor variables, 'multiple linear regression; fixed model, R^2 increase' on G*Power was used. The analysis showed that, with the alpha set at 0.05 (two-tailed) and the power at .80, a sample of 52 would be required to detect a large effect size (0.35). Accordingly, a sample of at least 52 participants (caregivers) was targeted, and a total of 53 participants were recruited.

The inclusion/exclusion criteria and recruitment procedure for participants were the same as study one (Stage II) (Chapter Three). None of the partners were in a same-sex relationship. Information was not collected about the severity of the injury. However, since all the care recipients had been in hospital for at least a week because of their ABI and had received rehabilitation, and since all the participants were still receiving some degree of support from the charitable organisation at least nine months since the injury, the care recipients (BI survivors) were considered to have had a moderate to severe BI rather than a mild one. Table 4.1 shows the demographic information of all the participants (caregivers) and care recipients.

Table 4.1. Demographic information of participants and their partners

(N= 53)	Participants (Caregivers)	Care recipients
Gender	Men= 28 (53%) Women= 25 (47%)	Men= 25 (47%) Women= 28 (53%)
Age	Mean= 57.11 SD= 12.70 Range= 36-81	Mean= 57.91 SD= 13.15 Range= 35-85
Ethnicity	White British= 35 (66%) British Asian= 10 (19%) White or Black African= 5 (9%) Black Caribbean= 1 (2%) British Irish= 1 (2%) Caucasian= 1 (2%)	White British= 32 (60%) British Asian= 14 (26%) White or Black African= 4 (8%) Black Caribbean= 1 (2%) Irish= 1 (2%) Caucasian= 1 (2%)
Religious belief	No religion= 20 (38%) Christian= 18 (34%) Muslim= 6 (11%) Missing data= 9 (17%)	No religion= 20 (38%) Christian= 18 (34%) Muslim= 6 (11%) Missing data= 9 (17%)
Employment status	Employed= 36 (68%) Unemployed= 8 (15%) Missing data= 9 (17%)	Employed= 8 (15%) Unemployed= 36 (68%) Missing data= 17%
Type of brain injury		TBI= 19 (36%) Stroke= 17 (32%) Aneurysm= 3 (6%) Missing data= 14 (26%)

Duration of partnership (in months)	Mean= 356.62 SD= 150.04 Range= 60-660	
Duration of caregiving role (in months)	Mean= 43.79 SD= 30.41 Range= 12-144	

3.2. Measures

Participants completed a battery of eight questionnaires. As mentioned in Chapter Three, the post-injury relationship assessment scale (RAS) and the dyadic adjustment scale (DAS) were included to provide further evaluation of the validity of the BRCM. The pre-injury RAS was included as a screening tool. Since the BRCM assumes that the pre-injury relationship was satisfactory (Riley et al., 2013), pre-injury RAS provided a check on whether this was the case or not. The remaining five measures were the BRCM, and measures of the impairments and changes in functioning shown by the care recipients, which were used as independent variables (IVs) in the present study.

3.2.1. Birmingham Relationship Continuity Measure (BRCM)

Detailed information about the BRCM has been provided in Chapter Three. The BRCM was used a dependent variable (DV) in the present study.

3.2.2. Relationship Assessment Scale (RAS)

Detailed information about RAS has been provided in Chapter Three. Two versions of this scale were used in the present study for two distinct purposes. A pre-injury RAS version was used in which the participants were asked to answer the questions based on how they perceived their relationship before the BI. A post-injury

RAS version was used in which the participants were asked to answer the questions based on how they perceived their relationship currently (after the BI).

3.2.3. Dyadic Adjustment Scale (DAS)

Detailed information about DAS has been provided in Chapter Three.

3.2.4. Intimate Bond Measure (IBM)

The IBM was developed to assess the dimensions of care and control among partners in intimate relationships (Wilhelm & Parker, 1988). Each dimension has 12 items with a total of 24 items in the scale that can be scored separately.

Only the care dimension was used in the present study. It was chosen as a measure of the emotional warmth of the care recipient. It includes items such as “Is affectionate to me”. All the items are on a Likert scale with four options ranging from “very true”, “moderately true”, “somewhat true”, to “not true at all”. The participants were asked to answer each question based how they perceived their partners’ attitudes and behaviours were towards them. A higher score indicates higher perceived care. The care scale has good validity and high internal consistency, with an alpha of 0.89 (Wilhelm & Parker, 1988).

3.2.5. Activities of Daily Living Questionnaire (ADLQ)

The ADLQ was first developed as an informant-based assessment to measure daily life functioning in six areas; self-care, household care, employment and recreation, shopping and money, travel, and communication (Johnson, Barion, Rademaker, Rehkemper, & Weintraub, 2004). It was first developed for use in dementia, but it has recently been used and validated for use in ABI (Johnson et al., 2004). It has 28 items measuring all six areas. The participants are asked to select the score for each question that suits them the most, ranging from zero-nine. A higher total score indicates severe functional impairment in activities of daily living. The questionnaire has good validity and high internal consistency, with an alpha of .86 (Johnson et al., 2004).

3.2.6. LaTrobe Communication Questionnaire (LCQ)

The LCQ was developed as an informant-based assessment to evaluate perceived communicative ability after BI (Douglas, Bracy, & Snow, 2007; Douglas, O'Flaherty, & Snow, 2000). It is a 30-item questionnaire, where participants are instructed to rate questions on aspects of communication on a Likert scale, ranging from one to four (One= never or rarely; Two= sometimes; Three= often, and Four= usually or always). The scale is divided into four sub-scales measuring different aspects of communication; initiation/ conversation flow (e.g., “need a long time to think before answering the other person”), disinhibition/ impulsivity (e.g., “gets side-tracked by irrelevant parts of the conversation”), communicational effectiveness (e.g., “knows when to talk and when to listen”), and partner sensitivity (e.g., “carry on talking about things for too long in his/her conversation”). Scoring is recorded separately for each sub-scale, where a higher score indicates a higher degree of impairment in communication abilities represented in the particular sub-scale (Douglas et al., 2000). A total score can also be calculated which was used in the present study analysis. The questionnaire has good validity and high internal consistency, with an overall scale alpha of 0.86 (Douglas et al., 2000).

3.2.7. Neurobehavioral Functioning Inventory (NFI)

The NFI was developed to evaluate various clinical-based symptoms related to BI. Its subscales are; depression (e.g., “Feels worthless”), somatic complaints (e.g., “Stomach bloated”), memory/attention (e.g., “Forgets people’s names”), communication (e.g., “Writes slowly”), aggression (e.g., “Argues”) and motor problems (e.g., “Weak”) (Kreutzer, Marwitz, Seel, & Serio, 1996). It is a 76-item inventory where participants/family are asked to rate the items based on a one to five Likert scale (One= never; Two= rarely; Three= sometimes; Four= often; Five= always). A higher score in each sub-scale states higher levels of impairment. The sale has good validity, an overall high internal consistency (0.97), and high internal consistency for all the sub-scales (depression= 0.93; somatic= 0.86; memory/attention= 0.95; communication= 0.88; aggression= 0.89; motor= 0.87) (Kreutzer et al., 1996). The family record form (informant-based form) was used in the present study, and each sub-scale was used individually as distinctive IVs.

3.3. Procedure

The procedure of the present study was the same as the first study (Chapter Three). The format and content of the invitation letter (Appendix 4a), participant information sheet (Appendix 4b), consent form (Appendix 4c), and a questionnaire pack (Appendix 4d) was little different based on the present study requirements. As previously mentioned, Appendix 4d has details of the questionnaire pack. However, LCQ and NFI have not been included in the appendix due to copyright issues.

A total of 143 participants were approached, and 53 participated. The overall response rate was 37%. In the later stages, after recruiting 30 participants, it was difficult to find more participants. Therefore, after receiving permission from the ethics committee, the last 23 participants were provided with a £10 Amazon voucher on completing the questionnaires as a token of gratitude.

3.4. Ethical Considerations

The study was approved by the University of Birmingham School of Psychology Human Research Ethics Committee (Appendix 4e), and the ethical considerations were the same as the first study (Chapter Three).

3.5. Statistical Analysis

SPSS (Version 22) (2013) was used to analyse the data. Pearson's Product Moment Correlation Coefficient was used to assess the relationships between the variables. Multiple regression analysis was used to assess which IVs made a significant unique contribution to the variance in the DV scores.

4. Results

4.1. Data checking

Before any statistical analysis was conducted, the data were analysed to check for any missing data, outliers, and the normality of the data.

4.1.1. Missing data

Missing data were found regarding the religious belief of the partners, their employment status, and the type of BI of the care recipients (Table 3.4). Moreover, nine missing data were found regarding pre-injury RAS measure.

4.1.2. Outliers and normality of the data

The recommendations of Tabachnick and Fidell (2013) were followed, as mentioned in Chapter Three. None of the measures was found to have any univariate outliers. Further, to meet the criteria for conducting a regression analysis, Mahalanobis distance was used to check multivariate outliers (Tabachnick & Fidell, 2013) and none were found.

Skewness and kurtosis were also checked for each measure. Except for the post-injury RAS measure, all the measures were found to have skewness and kurtosis values within the acceptable range of ‘-3 to 3’, indicating that the scales were relatively normally distributed (Tabachnick & Fidell, 2013). As mentioned in Chapter Three, the post-injury RAS scores were transformed before being used for further analysis.

4.2. Screening test

The cut-off point for RAS pre-injury screening score was a total of below 21, which indicates a mean of less than three on the seven items, i.e. the mean would be closer to the low than the high end of the five-point satisfaction score. The lowest actual score obtained was 24 (Table 4.2), and, therefore, no participants were excluded from further analysis.

Table 4.2. Descriptive statistics

(N=53)	Mean	Possible Min/Max	Obtained Min/Max	SD	Skewness (Stand. Error)	Kurtosis (Stand. Error)	Cronbach’s alpha
BRCM	57.85	23/115	23/113	23.37	.850 (.327)	-.180 (.644)	.963
IBM	15.17	0/36	1/36	10.75	.541 (.327)	-.901 (.644)	.964
ADLQ	79.42	0/300	48/102	12.81	-.640 (.327)	-.239 (.644)	.428
LCQ	37.06	30/120	32/97	15.14	-1.179 (.327)	.993 (.644)	.896
Depression	42.28	13/65	18/58	10.60	-.279 (.327)	-.980 (.644)	.915
Somatic	25.75	11/55	15/36	5.77	.112 (.327)	-1.000 (.644)	.591
Memory/ Attention	64.66	19/95	24/83	13.20	-.652 (.327)	.218 (.644)	.876
Communication	32.25	10/50	19/46	7..29	-.607 (.327)	.461 (.644)	.611
Aggression	23.13	9/45	12/43	7.29	.456 (.327)	.506 (.644)	.862
Motor	24.72	8/40	13/33	5.00	1.09 (.327)	-.838 (.644)	.617
RAS pre-injury (N= 44)	29.11	7/35	24/35	2.84	-.229 (.357)	-.721 (.702)	.849

RAS post-injury	12.21	7/35	7/28	4.84	.799 (.327)	.380 (.644)	.906
DAS	62.21	0/151	22/137	32.09	.681 (.327)	-.472 (.644)	.967

4.3. Correlational analysis

Correlations between the BRCM, RAS post-injury, and DAS were conducted to assess the validity of the BRCM, and the results have been reported in Chapter Three. Moreover, the BRCM and RAS pre-injury did not share any significant relationship (Table 4.3).

Table 4.3. Correlation between BRCM, RAS (pre- and post-injury), DAS

	BRCM	RAS (pre-injury)	RAS (post-injury)	DAS
BRCM	-	-.038	.849**	.669**
RAS (pre-injury)	-.038	-	-.078	.088
RAS (post-injury)	.849**	-.078	-	.644**
DAS	.669**	.088	.644**	-

N= 53; **p<0.01

Table 4.4. Correlations between BRCM, IBM, ADLQ, LCQ, and NFI sub-scales

	BRCM	IBM	ADLQ	LCQ	Depression	Somatic	Memory/ Attention	Communication	Aggression	Motor
BRCM	-	.829**	-.337*	-.703**	-.806**	-.477**	-.682**	-.401**	-.789**	-.050
IBM	.829**	-	-.458**	-.545**	-.694**	-.483**	-.610**	-.264	-.800**	-.006
ADLQ	-.337*	-.458**	-	-.027	.170	.078	.092	.221	.328*	.135
LCQ	-.703**	-.545**	-.027	-	.653**	.234	.615**	.373**	.467**	-.149
Depression	-.806**	-.694**	.170	.653**	-	.508**	.700**	.292*	.649**	.077
Somatic	-.477**	-.483**	.078	.234	.508**	-	.516**	.473**	.392**	.007
Memory/ Attention	-.682**	-.610**	.092	.615**	.700**	.516**	-	.512**	.519**	.008
Communication	-.401**	-.264	.221	.373**	.292*	.473**	.512**	-	.067	.175
Aggression	-.789**	-.800**	.328*	.467**	.649**	.392**	.519**	.067	-	-.074
Motor	-.050	-.006	.135	-.149	.077	.007	.008	.175	-.074	-

N= 53; **p<0.01

Since multiple tests were conducted to find the best regression model and due to the risk of high family-wise error rate, a more conservative alpha level of 0.01 was considered for analysing the correlations. The analysis (Table 4.4) shows that the results were consistent with the hypothesis, that discontinuity would be associated mainly with lack of emotional warmth and aggression, since IBM (highest correlation with the BRCM) and Aggression (third highest correlations with BRCM) were both strongly correlated with the BRCM.

For the IV's to be included in a regression model, it is vital that they share a strong significant relationship with the DV (Tabachnick & Fidell, 2013). Therefore, the motor sub-scale was eliminated from the regression analysis since it shared no relationship with the BRCM (see Table 4.4). Also, ADLQ did not meet the criteria of alpha 0.01 which is why it was eliminated as well (see Table 4.4).

The LCQ and the Communication sub-scale are both measures of communication impairments, and including two similar measures in the final regression model would cause problems with multicollinearity. Therefore, their respective correlations with the BRCM were compared, and the LCQ total score was included in the regression analysis since it shared a higher correlation with the BRCM in comparison to Communication (see Table 4.4).

4.4. Multiple Regression Analysis

Multiple regression analysis was conducted in two stages. At Stage I, the data were checked to meet all the necessary criteria (Tabachnick & Fidell, 2013), and at Stage II, the analysis was conducted.

4.4.1. Stage I

Specific theoretical considerations and assumptions must be fulfilled to conduct a multiple regression analysis. Therefore, at this stage, Tabachnick and Fidell, recommendations (2013) were followed to check if all the assumptions were met.

4.4.1.1. Theoretical considerations

The best regression model is the one where the IVs strongly correlates with the DV (Tabachnick & Fidell, 2013) which has already been established in the present study in the correlational analysis. However, another critical point to consider is that the IVs should not be correlated with each other. Table 4.4 shows that IBM correlates strongly with LCQ, and specific NFI sub-scales and so it was excluded from the regression analysis.

4.4.1.2. Practical assumptions

Sample size plays a vital role in finding an appropriate regression model. Appropriate sample size can be calculated based on the effect size (Tabachnick & Fidell, 2013), and the present study met the minimum sample size criteria. Minimum sample size was chosen since it works well in regression analysis if the DV is not skewed, and in the present study, the DV was not found to be skewed (Tabachnick & Fidell, 2013). Moreover, outliers should not be present in the DV or the IVs (Tabachnick & Fidell, 2013), and the present study did not have outliers.

Analysis of multicollinearity is vital before conducting regression, especially when IVs are correlated with each other (Tabachnick & Fidell, 2013). Multicollinearity was analysed by checking the conditioning index in the collinearity diagnostics (Tabachnick & Fidell, 2013). A collinearity problem occurs when the conditioning index for a specific dimension is higher than 30, and two of its variance proportions are higher than 0.50 (Belsley, Kuh, & Welsch, 2005; Tabachnick & Fidell, 2013). Therefore, five IVs that have been selected were entered to check the multicollinearity of the data (LCQ, Depression, Somatic, Memory/Attention, and Aggression).

Tolerance and Variance Inflation Factor (VIF) is also assessed to check multicollinearity. The data, to be free from multicollinearity, should have more than 0.10 tolerance values, and less than ten VIF values (Craney & Surles, 2002; Tabachnick & Fidell, 2013). The data obtained using the five IVs also met the tolerance and VIF criteria. It met the mentioned criteria, and so all the five variables were selected for the analysis.

Analysing normality, linearity, and homoscedasticity of residuals between predicted DV score and errors of prediction is also an essential assessment. It is checked using the residuals scatterplot, where the criteria were met if the scatterplot shows that none of the values falls beyond ‘-3 and 3’ in both the axis (Tabachnick & Fidell, 2013). The normal probability plot for regression standardised residual is also checked to assess if the points fall along the line to meet the normality criteria. Both the criteria were fulfilled in the present study (Appendix 4f).

4.4.2. Stage II

Once the data met all the necessary criteria, regression analysis was conducted where the selected five IVs were entered along with the DV. As mentioned earlier, in the correlational analysis, an alpha level of 0.01 was considered for the multiple regression as well. Communication difficulty (LCQ) and aggression (NFI sub-scale Aggression) were found to make a significant unique contribution to the variance in the BRCM scores (Table 4.5).

Table 4.5. Regression analysis for different measures of brain injury impairment predicting relationship continuity (BRCM)

Outcome variable (DV)	Predictors variable (IV)	β	T
BRCM ($R= .907$; $R^2= .823$) (Adjusted $R^2= .805$)	LCQ	.270	-3.094**
	Depression	-.266	-2.488
	Somatic	-.076	-.996
	Memory/ Attention	-.071	-.744
	Aggression	-.424	-5.204**

**p<0.01

5. Discussion

The purpose of the present study was to evaluate factors that predict relationship continuity/discontinuity following a BI. The results were supportive of the hypothesis in that emotional warmth and aggression were the variables that had the highest and third highest correlation with the BRCM (Table 4.4). In terms of the regression analysis, the IBM could not be entered because of problems with multicollinearity. However, again supportive of the hypothesis, aggression was one of only two variables (the other being the LCQ) that made significant contributions to the variance in BRCM scores in the regression (Table 4.5).

The findings thus state that discontinuity on the BRCM is associated with a lack of emotional warmth from the care recipient and their aggressive behaviours, and is consistent with previous literature as mentioned in the introduction (e.g., Bodley-Scott & Riley, 2015; Gill et al., 2011; Villa & Riley, 2017). A study conducted to explore how a partner's experience of various BI impairments affects their relationship found aggression in care recipients to be associated with caregivers' "fear and stress", while "lack of affection, emotional sensitivity and other positive attributes" were associated with “feelings of sadness and loss”, which are components of RC (Bodley-Scott et al., 2015, p. 20). Studies also state that due to the unpredictable nature of aggressive behaviours of care recipients, it is often difficult to control them, which increases caregiver stress (Connolly & Dowd, 2001; Wood, Liossi, & Wood, 2005). When such unpredictable behaviours have to be taken care of by partners or spouses, they often find it difficult to perceive love and affection for someone “who has become emotionally volatile and who shows little interest and few emotions in return” (Bodley-Scott et al., 2015, p. 3). Another qualitative study found that partners who experienced RC post-BI reported; “continued expression of love and affection from their partners” (Villa et al., 2017, p. 14). The study states that lack of love and affection from the care recipient makes it difficult for a partner to continue to feel love. It affects the essence of couplehood, where they might stop sharing enjoyable moments together, which makes the caregiver/partner perceive the relationship different than how a spousal relationship should be (Villa et al., 2017, p. 14).

The other measures, ADLQ, Depression, Somatic, and Memory/Attention, either had a lower correlation with the BRCM or did not make a significant contribution in the multiple regression. It is again consistent with previous literature, as mentioned in the introduction. For example, a study was conducted on spouses turned caregivers of individuals with TBI to understand the relationship between neurobehavioral difficulties, like physical and cognitive issues, caused due to TBI, stress among the non-injured partners, and family functioning, (Anderson, Parmenter, & Mok, 2002). Path analysis revealed that behavioural, communication and social problems caused by the TBI predicted disrupted family functioning and high spousal distress, more than cognitive difficulties. Behavioural problems were found to be the best predictor of decreased spousal psychological health. On the other hand, somatic difficulties were found not to predict family functioning.

In another study, conducted on family members and close relatives of people with TBI, they found behavioural (especially anger issues), emotional, and cognitive difficulties in the patients predicted a poor family functioning, increased depression, and increased anxiety (Ponsford et al., 2003). Other factors like physical impairments, severity of injury, social and occupational difficulties did not predict family functioning. The findings of these studies show that though cognitive and emotional factors are related to decreased family functioning and increased stress, they are not the most significant predictors when compared to other variables.

In the present study similar findings were observed, where cognitive, emotional, somatic, and activities of daily living correlated to a certain extent with RD (Table 4.4) but did not contribute much towards RD in comparison to behavioural and communication difficulties (Table 4.5).

Another important finding of the present study was that the LCQ scores (communication) were found to correlate with the BRCM highly and it also made a significant contribution to the regression model. BI affects communication abilities, like difficulties in speech and impairment in functional aspects of a conversation (Douglas et al., 2007; Murdoch & Theodoros, 2001; Sim, Power, & Togher, 2013). Difficulties in functional aspects of communication are often found to increase conversation breakdown leading towards marital stress (Bracy & Douglas, 2005; Tate, Lulham, Broe, Strettles, & Pfaff, 1989). Studies have often argued that those aspects that build and maintains an effective conversation get impaired in people with TBI, like initiating a topic of conversation, maintaining the topic over time, and responding to the other person appropriately, extreme talkativeness or presenting a disinterest, or an inappropriate comment (Bracy & Douglas, 2005; Coelho, Youse, & Le, 2002; McDonald, Code, & Togher, 2016). Studies also argue that these functional aspects of communication increases caregiver burden and affects family and marital relationships, as opposed to the "cognitive-linguistic impairments that generate confusion and result in reduced information transfer, but not necessarily in breakdown at an interactional level" (Bracy & Douglas, 2005, p. 2).

The studies mentioned above have not explained the specific difference between speech impairment and impairment in functional aspects of communication post-BI, nor any studies were found that explained which specific communication difficulties explicitly predict marital stress. However, it can be assumed that difficulty to follow a conversation and respond appropriately, difficulty in understanding humour or difficulty maintaining eye contact during a conversation would affect marital relationship more than the difficulty in reading or writing or inappropriately pronouncing words. Though such a conclusion cannot be drawn without any research evidence, it is an assumption, since studies have stated that couples need to rebuild their relationship post-BI by communicating effectively to understand each other's needs, which doesn't necessarily include ability to read and write efficiently (Bracy & Douglas, 2005; Wedcliffe & Ross, 2001).

Thus, from such an understanding of the effects of functional aspects of communication in couple relationships, it can be assumed that the present study findings implemented that RD post-BI is related to impaired functional communication abilities. Therefore, this could also have been a reason why the NFI sub-scale of communication shared a poor relationship with the BRCM in comparison to the LCQ measure (Table 4.4.). The LCQ measure assessed communication aspects like, "Find it hard to look at the other speaker", "Say or do things others might consider rude or embarrassing", "Know when to talk or when to listen", "Have difficulty in getting conversations started", which seems important to maintain a warm, effective conversation with a partner (Douglas et al., 2000). Therefore, difficulties in these aspects might cause a caregiver/partner inability to perceive positive feelings towards the care recipient. On the other hand, the NFI sub-scale measured aspects like, "Writes slowly", "Makes spelling mistakes", "Reads slowly" (Kreutzer et al., 1996), and such difficulties might not contribute much towards decreased satisfaction in partner interaction. However, as mentioned earlier, further studies need to be conducted in this area to understand the relationship in a useful way.

The Motor sub-scale assessed physical difficulties, for example, difficulty in balance, difficulty in lifting heavy objects, and muscle twitches (Kreutzer et al., 1996). In the correlational analysis, the motor sub-scale did not correlate with the BRCM. This finding can be corroborated with similar findings where studies have reported that physical disabilities are less often found to predict poor relationship quality, and caregiver burden in comparison to other disabilities caused post-BI (e.g., Marsh et al., 2002; Testa, Malec, Moessner, & Brown, 2006).

Physical difficulties are often found as a contributing factor towards caregiver burden at six months post-injury, but that does not necessarily remain to be an essential cause of caregiver stress at one-year post-injury (Marsh et al., 2002). Studies have argued that physical impairments are the easiest to deal with in rehabilitation as standardised strategies are available, and it is more socially acceptable than other impairments like behavioural and emotional difficulties (e.g., Marsh et al., 2002). Families have more opportunities and resources and learn to cope better with the physical impairments than the behavioural and emotional impairments that become more impaired and evident with time (Marsh et al., 2002). Physical difficulties, therefore, often don’t undermine the sense of the other person’s identity to the same extent as emotional changes (Landau, & Hissett, 2008). Such varied reasons can explain the findings of the present study, where physical difficulties did not have any relationship with RC.

Moreover, in western societies, personality is defined as a person’s tendency to think, feel and behave in patterns that are predictable, that is described in general terms (e.g., outgoing, moody) and that originate in what are thought to be underlying psychological processes concerned with needs, goals and desires (Allport, 1961). Personality is thus considered as a psychological concept. It is viewed as being tied to the physical body, but physical abilities are not part of it, nor are cognitive abilities. Therefore, it can be interpreted that loss of physical abilities does not undermine a carer’s sense of the personal identity of the person with the BI.

In the present study, RAS pre-injury was used as a screening tool to include participants who did not perceive any relationship difficulty before the BI. The scores obtained did not correlate with the BRCM measure, indicating that the quality of their current relationship did not appear to be dependent on the quality of the pre-injury relationship. However, the conclusion was made with a note of caution, since there were missing data. Moreover, the sample was biased in the sense that it was drawn from the population of couples who had stayed together after BI. Although the pre-injury relationship might not predict current relationship quality for those who remained together, it seemed quite likely that a poor-quality pre-injury relationship might predict which couples do or do not remain together.

5.1. Limitations

As mentioned earlier, certain study conclusions need to be evaluated with caution. For example, it cannot be assumed that the measures were appropriate. Using measures that would not correlate highly with the BRCM might be more effective. High correlations between the IBM and other predictive variables in multiple regression also prevented full analysis of the role of emotional warmth.

An essential aspect of the present study was that a limited range of BI impairments was measured. For example, executive functions were not assessed to explore its relationship with RC. Also, the sample was minimum and self-selected and had an unequal representation of cultural, ethnic, and religious groups. Thus, it was unclear how representative the sample was of the population of people with ABI and, therefore, how generalizable the conclusions were.

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CHAPTER 5

EFFECTIVENESS OF FAMILY INTERVENTIONS FOLLOWING BRAIN INJURY: A SYSTEMATIC REVIEW OF QUANTITATIVE AND QUALITATIVE STUDIES

1. Introduction

As previously discussed in Chapter Two, brain injury (BI) has detrimental effects on a family member, especially on partners/spouses (Bodley-Scott & Riley, 2015; Godwin, Chappell & Kreutzer, 2014). It often causes marital instability or even separation/divorce (Godwin et al., 2014; Kitter & Sharman, 2015). However, it should be noted, that the impact of BI varies greatly. Not all families experience adverse effects, and positive benefits have been reported as well (Villa & Riley, 2017). For example, a qualitative study was conducted to explore whether the framework of relationship continuity (RC) helps in understanding spousal relationships following an acquired brain injury (ABI) (Villa & Riley, 2017). One important finding was that few participants reported slight changes in their relationship post-injury, but despite those changes, they reported perceiving their partners as necessarily the same and that they were still sharing the same relationship they had pre-injury.

Understanding how to help families deal more effectively with the challenges of BI is essential not only because these challenges can have such a negative impact on the well-being of family members, but also because of the critical role that families may have on the well-being and effective rehabilitation of the person with the injury (as discussed in Chapter Two) (Wulf-Andersen & Mogensen, 2017). For example, a study conducted to evaluate the effectiveness of a “multi-family group treatment”, involved patients with traumatic brain injury (TBI) and their caregivers like spouses and parents (Rodgers et al., 2007). The study used both quantitative and qualitative strategies to analyse the findings. Quantitative data for the patients reported decreased depression and increased life satisfaction, and for the caregivers, it reported decreased caregiver burden. The qualitative data revealed that families, especially the patients reported to have increased feelings of closeness among themselves, and they reported that it helped them cope with issues like depression in an effective way. A few other qualitative studies have found similar results where involving the caregivers helped both them and the care-recipients (Butera-Prinzi, Charles, & Story, 2014; Straits-Troster et al., 2013).

There are a handful of studies that have involved family members in BI rehabilitation. Critical evaluation of those studies needs to be conducted to understand how best to support family members to come to terms with what has happened and maintain their well-being and also build a positive relationship with the BI survivor (Oddy & Herbert, 2003).

2. Aim

The aim was to review studies that evaluated the effectiveness of studies designed either to improve the ability of the family member to cope with the effects of brain injury, or to improve family dynamics.

3. Methodology

3.1. Data sources and search terms

The study used six databases, Embase, Medline, Ovid, PsycInfo, Proquest and Asia, to find articles published from 1984 till February 2018. There was a broad range of search terms used, which were divided into three main blocks (Table 5.1).

Table 5.1. Search Terms

BLOCK I	**BLOCK II**	**BLOCK III**	**BLOCK IV**
Injury Types	**Relationship**	**Intervention types**	**Intervention setting**
Head Trauma/ Head Injury/ Injuries/ Closed Head Injury/ Injuries/ Injured/ Brain damage/ Brain Injury/ Injuries/ Closed brain injury/ Open brain injury/ Brain haemorrhage	Family/ Families	Family counselling/ Therapy/ Intervention/ Family Centred care/ Family Coping/ Family Attitudes/ Family support/ Family health/ Caregiver support	Family/ Families
Concussion/ Contusion/ Coup-Contrecoup injury	Relative/ Relationship	Community Intervention/Counselling/ Community Programmes/Community services	Community/ Communities
Anoxic brain injury/ Anoxia/ Hypoxic brain injury/ Hypoxia/ Toxic brain injury/ Diffuse axonal injury	Spouse/ Spousal Relationship/ Partner/ Couplehood	Couple Intervention/ Therapy/ Counselling/ Spousal Intervention/ Marital intervention/ Marital therapy	Home/ In-home
Traumatic Brain Injury/Injuries/Injured/ FBI	Marriage/ Marital relationship/ Marital stress/ Marital Quality/ Relation quality	Person-centred Intervention/ Therapy/ Client Based Intervention/ Individual Intervention/ Individual therapy/ Symptom Based Intervention/ Therapy	
Acquired Brain Injury/Injuries/Injured/ Acquired brain disorder/ ABI	Caregiver/ Care Giver/ Carer	Cognitive Behaviour Therapy/ Behavioural Therapy/ Disruptive behaviour/Behavioural changes/Behaviour Modification/ Behaviour disorders/ Behaviour change/Behaviour problem/Behaviour disturbances/Neurobehavio(u)ral	
Stroke/ Ischemic stroke/ Haemorrhagic stroke/ transient ischemic attack/ TIA/ Aneurysm/ Arteriovenous malformations/ AVMs		Brain Injury Intervention/ Rehabilitation/ Recovery	
Brain tumour(s)/ Tumour(s)/ Meningitis/ Encephalitis		Intervention/Counselling/ Therapy	

3.2. Inclusion and exclusion criteria

The inclusion and exclusion criteria for selecting the studies have been mentioned below

3.2.1. Inclusion Criteria

a. Studies that evaluated a family-focussed intervention designed to improve the ability of family members to cope with the effects of brain injury and/or to improve family dynamics.

b. Studies that reported outcome data on the effectiveness of the intervention, either quantitative or qualitative data.

c. Intervention was provided after person with the BI had been released from hospital.

d. The person with the BI was 18 years or older.

3.2.2. Exclusion Criteria

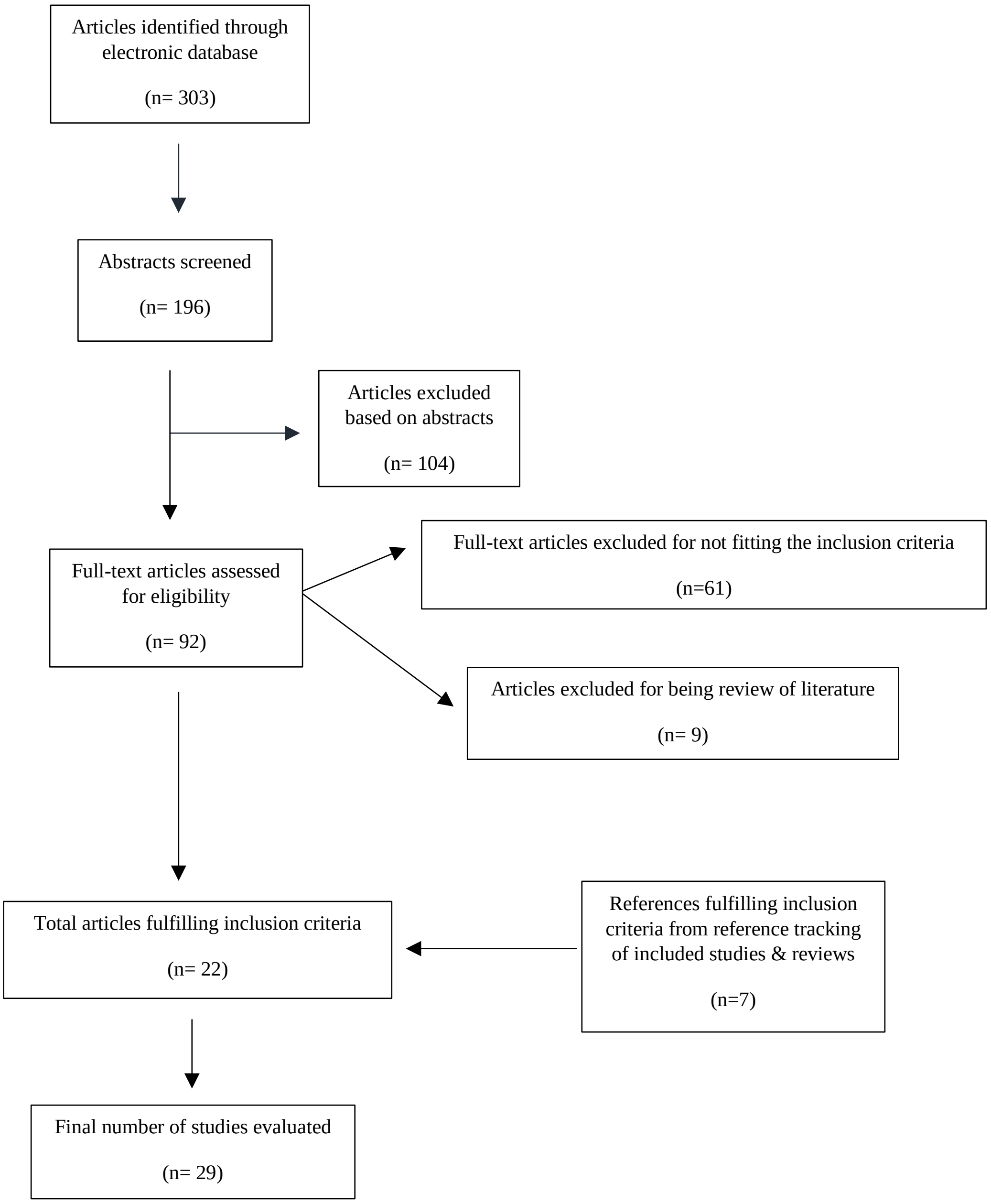
a. Articles not available in English.
b. Review articles or opinion pieces.
c. Interventions conducted in hospital/inpatient setting.
d. Interventions that focused on non-psychological outcomes (e.g., social work interventions focused on finance or housing).
e. Interventions that included only the BI survivors, which aimed to improve only the survivor’s well-being.
f. Interventions that included BI survivors living in long-term care homes.

3.3. Search strategy and data extraction

The mentioned search engines were used separately to find articles. In each search engine, a combination of all the search terms was employed, using ‘AND’, ‘OR’, ‘NEAR’ and ‘SAME’ search operators. Right-handed internal truncations were also used to find plural words, when applicable; the asterisk (*) was used to search a group of characters, and question mark (?) was used as a representation of any single character.

The search terms were used as keywords to identify suitable study titles, which were then transferred to the software Endnote. At the initial stage, 303 studies were collected in Endnote, and then 196 relevant articles were selected from the total number of articles based on the relevant study titles and excluding duplicate articles. Some articles did not provide a clear description of the study, and so their abstracts were reviewed. After reviewing the abstracts, 93 articles were selected for full-text review. Only 19 studies were finalised from the full-text review. Later, the reference lists of the 19 articles were hand searched, and seven more articles were included in the final list. A total of 29 articles were selected for the systematic review (see Figure 5.1).

Figure 5.1. Flowchart illustrating the selection process of the articles



3.4. Description of studies and quality assessment

Information was extracted from all the 29 papers on the study design, sample characteristics, intervention details, outcome measures, and the impact of the intervention. All these details were then arranged in three different tables. The first two tables have information about all the quantitative studies and the ones which used mixed methods. These were further divided into two categories; one that included both patients and family members in the intervention (Table 5.5) and one that included family members only (Table 5.7). The third table provides details of the qualitative studies (Table 5.9). Quantitative studies were further arranged according to the strength of design used, with randomised controlled trials (RCT) being listed first (see Figure 5.2).

Evaluation of the strength of evidence of each article was conducted using the quality assessment criteria provided by National Institute for Health and Care Excellence (NICE) Quality Framework for both quantitative and qualitative studies (NICE, 2009). NICE has developed checklist criteria to assess and rate studies for systematic reviews, and so a study was rated as superior quality if it fulfilled all the positive criteria and had good internal and external validity.

The quantitative studies were rated based on the criteria assessing the quality of evidence on the sample population, the methodology, analysis, and outcomes (Table 5.2). Each of these categories had subcategories and based on the evidence available for those subcategories, a final rating of the main category was done. Similarly, using checklist criteria for qualitative studies, they were rated based on their theoretical approach, study design, data collection, analysis and outcome (Table 5.3). Again, all the details of each category were assessed to provide a final rating. The rating for both qualitative and quantitative studies were based on one to five rating response criteria (Table 5.4).

Figure 5.2. Algorithm for classifying quantitative (experimental and observational) study designs (NICE, 2009)

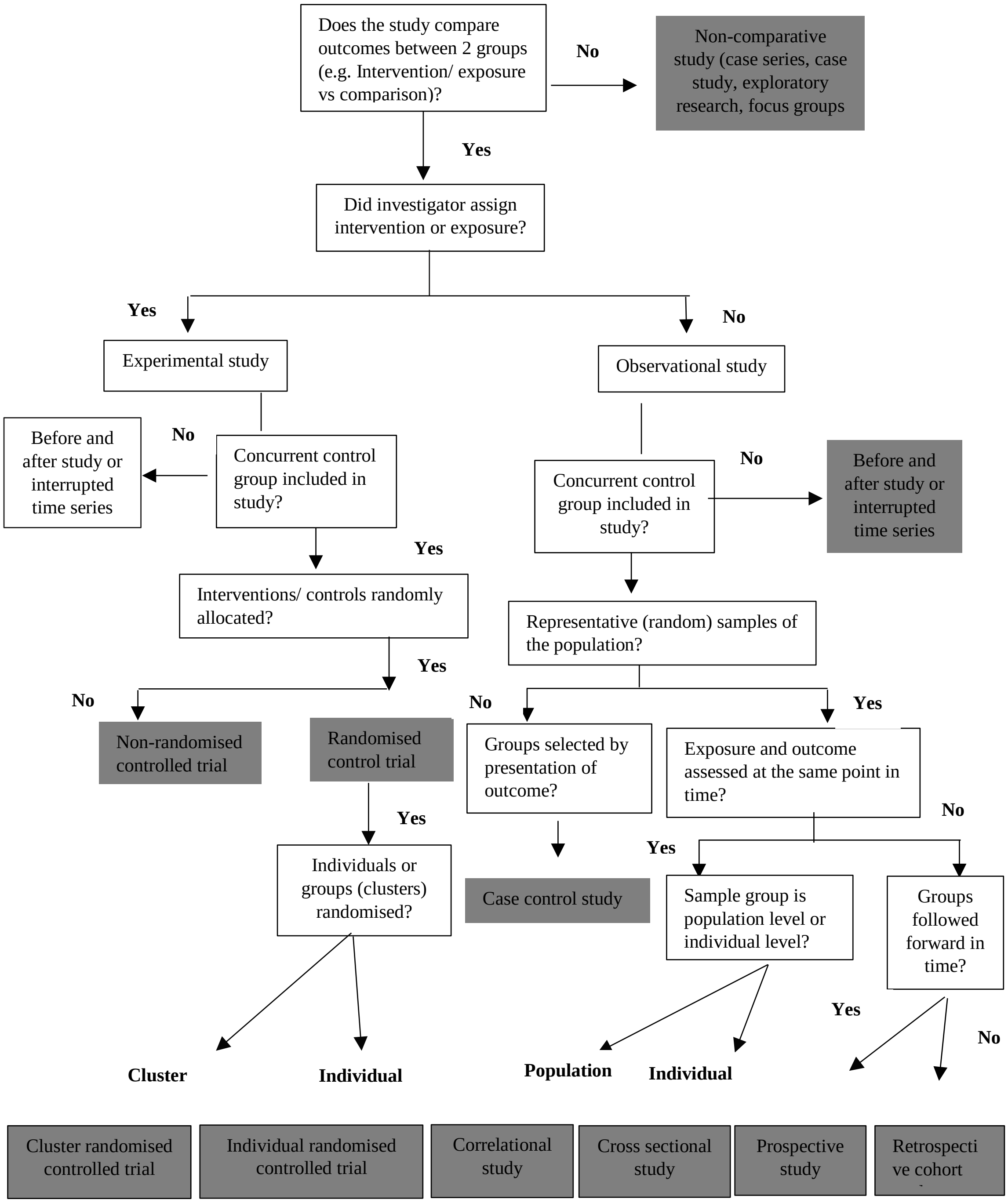


Table 5.2. Quality checklist criteria for quantitative studies (NICE, 2009)

Population	**Method of allocation of intervention**	**Outcomes**	**Analyses**	**Summary**
Is the source population or source area well described?	Allocation to intervention (or comparison). How was selection biased minimised?	Were outcome measures reliable?	Were exposure and comparison groups similar at baseline? If not, were these adjusted?	Are the study results internally valid (i.e. unbiased)?
Is the eligible population or area representative of the source population or area?	Were interventions and comparisons well described and appropriate?	Were all outcome measures complete?	Were intention to treat (IT) analysis conducted?	Are the findings generalizable to the source population (i.e. externally valid)?
Do the selected participants or areas represent the eligible population or area?	Was the allocation concealed?	Were all important outcomes assessed?	Was the study sufficiently powered to detect an intervention effect (if one exists)?	
	Were participants or investigators blind to exposure and comparison?	Were outcomes relevant?	Were the estimates of effect size given or calculable?	
	Was the exposure to the intervention and comparison adequate?	Were there similar follow-up times in exposure and comparison groups?	Were the analytical methods appropriate?	
	Was contamination acceptably low?	Was follow-up time meaningful?	Was the precision of intervention effects given or calculable? Were they meaningful?	
	Were other interventions similar in both groups?			
	Were participants accounted for at study conclusion?			

Table 5.3. Quality checklist criteria for qualitative studies (NICE, 2009)

Theoretical approach	Study design	Data collection	Trustworthiness	Analysis	Conclusion	Ethics	Overall assessment
Is a qualitative approach appropriate?	Was the research design/ methodology defensible / rigorous?	How well were the data collection carried out?	Is the role of the researcher clearly described?	Were the data analysis sufficiently rigorous?	Summary of the quality	How clear and coherent is the reporting of ethics?	As far as an be ascertained from the paper, how well was the study conducted?
Is the study clear in what is seeks to do?			Is the context clearly described?	Is the data 'rich'?			
			Were the methods reliable?	Is the analysis reliable?			
				Are the findings convincing?			
				Are the findings relevant to the aims of the study?			

Table 5.4. Rating response (NICE, 2009)

++	All or most of the checklist criteria have been fulfilled; where they have not been fulfilled the conclusions are very unlikely to alter
+	Some of the checklist criteria have been fulfilled; where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter
-	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter
NR	Not Reported
NA	Not Applicable given the study design under review

4. Results

Table 5.5. Summaries of quantitative studies where participants included both patients and their family

Study design	First author, Year	Patient characteristics	Family characteristics	Intervention details		Outcome assessment		Findings
				Setting	Description	Measures	Frequency of assessment	
Randomized Control Trials	Dennis, 1997.	**Injury type=** Stroke **Sample size** = 417 **Mean Age** = Not reported **Gender** = 209 males & 208 females.	**Sample size** = 417 **Mean Age** = Not reported **Gender** = Not reported Details about caregivers were not provided.	Community setting.	Both patients and their caregivers were randomly divided into an intervention and a treatment only control group. The intervention group received carer intervention along with usual patient rehabilitation, while the treatment only control group received just the standard rehabilitation services. The intervention was an **educational intervention** provided by a stroke care worker. The nature of the educational content depended on the unmet needs of the caregivers, and, therefore, varied among all the participants. The mean of number of sessions for each participant was 3.6. Intervention details were not provided.	Frenchay Activities Index; General Health Questionnaire; Hospital Anxiety and Depression Scale; Social Adjustment Scale; Mental Adjustment to Stroke Scale; Patient Satisfaction Questionnaire; Caregiving Hassles Scale; Carer Satisfaction Questionnaire.	Data were collected at baseline and at six-month follow-up.	The findings showed significant group differences at follow-up only for the Hospital Anxiety and Depression Scale, Caregiving Hassles Scale, and Carer Satisfaction Questionnaire. For the other measures there was no significant group differences. Similarly, within the intervention group, significant differences were only observed in the three measures mentioned above, and there was no difference in the scores of the other measures at follow-up. For the control group, there was no significant difference in the scores obtained in none of the measures at follow-up. **Analysis indicated that the intervention did not have a big impact on the caregivers as only a few outcome measures showed significant changes**.
	Sinnakaruppan, 2005.	**Injury type=** Head injury (moderate -severe) **Sample size** = 41 **Mean Age** = 42 **Gender** = 32 males & 9 females.	**Sample size** = 42 **Mean Age** = Not reported **Gender** = 9 males & 33 females. Caregivers included parents and partners.	Community setting.	Following pre-assessment, both patients and their caregivers were randomly divided into experimental and wait-list control groups. The intervention was an **educational programme** for both patients and their caregivers. It consisted of eight sessions (each lasting two and a half hours) and were provided separately for patients and caregivers. **The aim was to assess the impact of an educational programme, to improve their psychological health by reducing anxiety and depression and improving self-esteem and coping skills,**	Measures used for both patient and carers: The Hospital Anxiety and Depression Scale (HADS); The General Health Questionnaire (GHQ); The Rosenberg Self-Esteem Scale (RSE); The COPE Scale (COPE). Measures used for only carers: The Functional Independence Measure (FIM).	Data were collected at baseline and three-month follow-up.	No difference in levels of depression was found for neither patient nor carer groups (HADS). However, reduction in both carer and patient anxiety scores were reported for the experimental group, but when compared with the control group, no significant changes were reported (HADS). The general health was found to have significant changes at follow-up and between groups for both patients and carers (GHQ). About self-esteem, no difference was found at follow-up or between groups in the carers, but significant difference was obtained in the patient group at follow-up and between groups (RSE). The coping measure (COPE) showed a significant difference between groups for

					and to develop "user-friendly" materials for both the groups. The intervention addressed specific issues; memory, executive functioning, anxiety, depression, and anger. The programmes were compiled into handouts which were used for training through didactic presentations, group discussions and role play. Intervention details were provided.	Measures for only patients: Weschler Adult Intelligence Scale-Third Edition (WAIS-III); The Rivermead Behavioural Memory Test (RBMT); The Behavioural Assessment of Dysexecutive Syndrome (BADS).		patients, but no differences at follow-up. For carers, coping measure showed no difference at follow-up nor between groups. Functional measures (FIM, WAIS, RBMT, and BADS) showed a significant difference at follow-up and significant group differences, from both carers and patients' perspective. The study findings show that the intervention had some positive effect on the patient group, but **no significant effect on the carers.**
	Carnevale, 2006.	**Injury type=** Traumatic and other forms of acquired brain injury **Sample size** = 37 **Mean Age** = 40.5 **Gender** = 9 female, 28 males.	**Sample size=** 37 **Mean age=** 40.5 **Gender=** 9 female, 28 males. Demographic details caregivers were not provided.	Community setting.	Both patients and caregivers were randomly assigned into three groups; education only group, education and training group, and a no-treatment control group. **The intervention was aimed to investigate the efficacy of a behaviour management programme** (12 weeks' sessions, each lasting two hours). Group sessions for educational workshops were conducted, and individual sessions were conducted for behaviour management training, which focused on individual target behaviours. Intervention details were provided.	Questionnaire on Resources and Stress. (QRS); Maslach Burnout Inventory (MBI); Neurobehavioral Functioning Inventory-Revised (NFI-R).	Data were collected at baseline, in between session, post-intervention, and at three-month follow-up.	Change in individual target behaviours in education and training group in comparison to education only and the control group was reported. However, these changes were not significant until the three-month follow-up period. No group difference in the NFI sub-scales were found. For the carer group, no changes in caregiver stress (QRS) were found between the three groups. A significant difference in emotional exhaustion subscale of the MBI was found between the control group and the carer education only group, but not in the education and training carer group when compared with the other two groups. The other MBI sub-scales did not show any changes at any point for any carer group. Education only was found to have some effect on caregiver emotional exhaustion, but **the overall intervention was found to have no significant impact on the caregivers**.
	Backhaus, 2010.	**Injury type=** Traumatic brain injury, stroke, hypoxia, ruptured aneurysm, and metabolic	**Sample size=** 10 **Mean age=** 46.4 **Gender=** 2 males & 8 females. The treatment group had spouses, parents, and one sibling, while the control group had the same plus an aunt.	Community setting.	Both patients and caregivers were randomly assigned into two groups; a treatment group and a wait-list control group. The intervention aimed **to improve psychological functioning and self-efficacy** using a 12-session (two hours each) manualised module on coping strategies. It includes supportive psychotherapy, psychoeducation, stress	Brief Symptom Inventory-18 (BSI-18); Brain Injury Coping Skills Questionnaire (BICS).	Data were collected at baseline, post-intervention, and at three-month follow-up.	The findings showed no group difference in the BSI measure, between baseline, post-intervention and at follow-up. However, a significant group difference was observed in the perceived self-efficacy measure of the BICS. Concerning group satisfaction, 87% of participants reported feeling "very to extremely satisfied" with the group content; 88% reported it was what they expected or hoped to gain from the group, and 99% reported that they would recommend continuing to keep each module.

		encephalopathy **Sample size=** 10 **Mean age=** 43 **Gender=** 7 males & 3 females.			management, and problem-solving skills via the use of CBT approaches. Each group member was provided a 124-page Brain Injury Coping Skills workbook including PowerPoint handouts as well as appendices of in-session activities and homework. Intervention details were provided.			**The study showed increased caregivers perceived self-efficacy**, which might have been helpful in coping adequately with the challenges of brain injury.
	Bushnik, 2015	**Injury type=** Traumatic brain injury (mild-severe), aneurysm; brain abscess, stroke, or hypoxia. **Sample size=** 68 **Mean age=** 42.6 **Gender=** 58% males and 42% females.	**Sample size=** 68 **Mean age=** 51.4 **Gender=** 27.7% males and 72.3% females. Caregivers were spouses, partners, parents, significant others, and close friends.	Community setting.	Both patients and caregivers were randomly assigned into two groups; a treatment group and a wait-list control group. The intervention aimed to **assess the effectiveness of a newly developed family intervention.** The intervention was a manualised family intervention programme which included **educational, skill building, and psychological support components.** Participants had five sessions over a period of ten-weeks. Details of the intervention manual have been provided via a referenced article.	Family Needs Questionnaire (FNQ); Service Obstacles Scale (SOS); Zarit Burden Inventory (ZBI).	Data were collected at baseline, at fifth-week during intervention, post-intervention, and at three-month follow-up.	The findings showed significant group difference in all the measure at all-time points. With regards to the treatment group, significant difference in all FNQ sub-scale scores were found at all-time points, except for the emotional sub-scale. Significant differences in SOS and ZBI scores were found in the treatment group post-intervention but not at follow-up. With regards to the control group, significant differences in FNQ, SOS, and ZBI scores were not found across any time points. **Quantitative data analysis showed that the intervention had a significant impact on the caregivers.**
	Moriarty, 2016.	**Injury type=** Traumatic Brain Injury (mild-severe) **Sample size=** 81 **Mean age=** Not reported **Gender=** Males.	**Sample size=** 81 **Mean age=** 41.59 **Gender=** 76 females & 5 males. Caregivers were spouses and other immediate family members.	Home environment.	Veterans and caregivers were randomly divided into two groups. A control group where they were treated at an out-patient service, and a treatment group where they were both treated at an out-patient service and were additionally provided with the intervention. The intervention aimed **to improve caregiver depression, burden, and satisfaction**, and to assess the acceptability and efficacy of the in-home veteran program in comparison to out-patient services. **The intervention**	Center for Epidemiologic Studies Depression Scale (CES-D); Caregiver Appraisal Scale (CAS); Caregiver Burden; Caregiver Relationship Satisfaction Subscale; Acceptability tool.	Data were collected at baseline and three-month follow-up.	Comparison of baseline and follow-up data analysis showed significant changes in CES-D and caregiver burden scores between groups. However, caregiver satisfaction with the relationship did not show a significant effect for the intervention. 85.5% of family members answered that they would be willing to participate in another study on the same topic, indicating the acceptability of the intervention. **The study showed decreased caregiver depression and burden** and showed that in-home treatment might have a positive impact on caregiver well-being.

					included optimising the veteran's cognitive and daily functioning, strategies to regulate emotions, behaviour management and interpersonal difficulties. It included three-four months six in-home sessions & two telephone calls. Intervention details were provided.			
	Pitthayapong, 2017.	**Injury type=** Stroke.	**Sample size=** 61 **Mean age=** 79 **Gender=** 51 females & 10 males. Caregivers were partners, children, and relatives.	Community setting.	The patients and their caregivers were randomly assigned into an intervention group and in information only control group. **The intervention aimed to evaluate the effectiveness of a post-stroke family care program.** The intervention was a four-week **educational and motivational programme including emotional and stress management** and was based on information-motivation-behavioural skills model. The control group was provided with only suggestions relevant to the patient's condition or risks of developing complications, and suggestions related to physical rehabilitation. Intervention details were provided.	Modified Barthel Index (MBI); Post-stroke Care Skills Checklist; Complications checklist.	Data were collected at baseline, post-intervention, and at two-month follow-up.	The findings show statistically significant changes in activities of daily living (MBI) between groups and over time. Significant changes were also found in caregivers' post-stroke care skills between groups and over time. Statistically, significant difference was also found in complications between groups at the follow-up. No patients in the intervention group developed any complications at the end of the study, while the patients in the control group developed certain physical complications. **The study showed development in caregivers' care skill abilities over time.**
	Terrill, 2018.	**Injury type=** Stroke **Sample size=** 11 **Mean age=** 56.0 **Gender=** 6 females and 5 males.	**Sample size=** 11 **Mean age=** 55.9 **Gender=** 5 females, 6 males. Caregivers included spouses.	Home environment.	The patients and their spouses were randomly assigned into either an intervention group or a wait-list control group. **The aim of the intervention was to develop a dyadic intervention based on the theoretical framework of positive psychology for spouses post-stroke.** The intervention included one face to face training session and six-eight weeks of self-administered **dyadic positive psychology-based couple intervention**. The partners had to engage in two activities individually and two activities as a couple each week. Some details of the intervention were provided.	Quantitative measures: PROMIS-Depression Short Form 8b; Connor Davidson Resilience Scale (CD-RISC); Stroke Impact Scale (SIS, Version 3.0); Older People's Quality of Life Questionnaire (OPQOL); Social Relationships Index (SRI). Qualitative measure: Content analysis.	Data were collected pre-intervention, post-intervention, and at three-month follow-up.	Quantitative data analysis showed changes in all the caregiver outcome measures both between groups and across the different time points, but the changes were not significant. Qualitative analysis showed evidence of couples experiencing positive effects and benefits. Practicing acts of kindness and expressing gratitude was found to be most beneficial for the stroke survivors, while their partners turned caregivers found "fostering relationships" to be most beneficial. Doing things together as a couple that they stopped doing post-stroke was considered to very helpful for all the couples. **Qualitative evidence showed that engaging in different activities was perceived to be helpful by the couples, but significant quantitative changes were not obtained.**

Before and after designs	Perlesz, 1998	**Injury type=** Traumatic brain injury **Sample size=** 9 **Mean age=** 31.2 **Gender=** 5 females, 4 males.	**Sample size=** 13 **Mean age=** Not provided **Gender=** 5 females, 8 males. Caregivers were spouses, parents, siblings, and aunts.	Community setting.	**The intervention aimed to decrease burden and stress in families and improve marital relationships after brain injury.** The intervention consisted of an average of twenty-two counselling sessions that lasted for approximately nine and a half months. The duration and length of the sessions varied for each families. Intervention details were not provided.	General health questionnaire (GHQ); Profile of mood states (POMS); Subjective burden scale (SBS); The social adjustment scale-self report (SAS- SR); Family environment scale (FES).	Data were collected pre-intervention, post-intervention, and at twelve-month and twenty-four- month follow-up.	Quantitative data analysis showed significant changes in patient scores in GHQ, POMS, and SA-SR at all-time points. However, anger was found to have significantly increased post-intervention. With regards to family members, significant changes were found in GHQ, POMS, SBS, and SAS-SR at all-time points. FES also showed significant positive changes in family conflict, family cohesion, and adjustment across all time points. However, marital adjustment showed no changes post-intervention but was found to have significantly improved at follow-up. **The intervention was found to make significant changes in some respects but not for all outcome measures.**
	Rodgers, 2007.	**Injury type=** Traumatic Brain Injury **Sample size=** 16 **Mean age=** 39 **Gender=** 77.8% males and 22.2% females.	**Sample size=** 17 **Mean age=** 47 **Gender=** 14.3% males and 85.7% females. Caregivers were spouses, live-in-partners, parents, and friends.	Community setting.	**The intervention aimed to investigate a multi-family group treatment which was based on a family psychoeducation model. It provided educational and problem-solving workshops** using a manual guide to one group of patients and carers. The total duration was of 18 months and included bimonthly and monthly meetings. Each session lasted 90 mins. Intervention details were provided.	Measures for both patients and caregivers: Quality of Life Interview; Anger-Expression Inventory; Centre for Epidemiologic Studies Depression Scale–Global Distress. Measures for only caregivers: Interpersonal Support Evaluation List; Ways of Coping Checklist; Caregiver Burden Inventory. Qualitative methods were used to explore participants' experience through semi-structured interviews and focus groups.	Data were collected at the end of the intervention.	There was a significant change in survivor depression and life satisfaction scores. With regards to the caregiver measures, a significant decrease in the total Caregiver Burden Inventory score was obtained. However, there were no significant changes in any other caregiver measures. Qualitative analysis revealed that families reported having feelings of closeness within the family and a sense of re-established contact among themselves. All participants found it particularly helpful to gain an understanding of how brain injuries affect behaviour and to learn strategies of self-care. Caregivers stated that they learned to organise their lives more effectively and to express their feelings when frustrated effectively. Though qualitative data showed evidence of a positive impact of the intervention on caregivers, **quantitative data showed changes only in caregiver burden, but the intervention was found to have no impact on other caregiver measures.**
	Kreutzer, 2009.	**Injury type=** Acquired	**Sample size=** 17 **Mean age=** 47	Community setting.	**The intervention aimed to evaluate the manualized "Brain Injury Family Intervention".**	Family needs questionnaire (FNQ); Service obstacle scale	Data were collected post-	No significant changes post-intervention and at follow-up in family functioning (FAD) or family member's distress and life satisfaction (BSI &

		Brain Injury **Sample size=** 53 **Mean age=** 40.73 **Gender=** 58% males and rest females.	**Gender=** 14.3% males and 85.7% females. Caregivers included spouses, partners, parents, siblings, friends, and other relatives.		It included five two-hour sessions over ten weeks on **effects of brain injury, coping with loss and change, managing stress and intense emotions, practical problem-solving, setting reasonable goals and taking care of one's self**. The sessions were based on the theoretical foundations of cognitive behavioural therapy and family systems theory. Whether the sessions were provided to families separately or as a group along with the patients was not clearly mentioned. Details of the intervention manual have been provided via a referenced article.	(SOS); Family assessment device (FAD); Brief symptom inventory-18 (BSI-18); Satisfaction with life scale (SWLS).	intervention and three-month follow-up.	SWLS) were reported. The FNQ score was assessed separately as per its sub-scales. Only a few sub-scales showed statistically significant results. However, significant changes were found in the SOS. **The intervention was found to have no impact on the caregivers.**
	Kreutzer, 2010.	**Injury type=** Brain injury & non-degenerative brain disease **Sample size=** 76 **Mean age=** 43.2 **Gender=** 46 males & 30 females.	**Sample size=** 76 **Mean age=** 50.9 **Gender=** 53 females & 23 males. Caregivers included spouses, parents, and other family members/ relatives.	Community setting.	**The intervention aimed to describe and compare caregivers' and patients' helpfulness and goal attainment ratings of the Brain Injury Family Intervention (BIFI), and qualitatively evaluate their perceptions of the most important things learned**. The intervention was a structured family intervention program which **included educational, skill building, and psychological support components**. There were five two-hours intervention sessions for ten weeks. Whether the sessions were provided to families separately or as a group is not clearly explained, and little information about the interventions was provided.	The Session Report Form; Program Satisfaction Survey; Goal attainment. A qualitative method was also used to identify themes indicating the critical things learned by the participants during the sessions.	Data were collected pre-intervention, before the first intervention session, immediately post-intervention, and at three months follow-up.	Session report form revealed a substantial overlap between "most important things learned" and session goals. Analysis of Program Satisfaction Survey provided evidence that participants had positive perceptions of the intervention. Analysis of goal attainment data for individual sessions and the overall program indicated most participants perceived that program goals were met. Caregiver ratings in goal attainment were high post-intervention. The pattern of qualitative data suggests that the goals were achieved and perceived as valuable by both caregivers and patients. It provided evidence that the BIFI was perceived as helpful and that treatment methods facilitate the achievement of goals. Overall, **the BIFI was found to be useful for caregivers.**
	Edwards, 2013.	**Injury type=** Acquired Brain Injury **Sample size=** 4 **Mean age=** 55.7 **Gender=** Males.	**Sample size=** 4 **Mean age=** 55.7 **Gender=** Females. Caregivers were spouses.	Home environment.	**The intervention aimed to evaluate the efficacy of emotionally focused couples' therapy in increasing relationship satisfaction and decreasing individual distress in couples with brain injury.** The intervention started with a detailed discussion of post-brain injury experiences of the couple, and an average of 16 sessions was conducted among four couples separately. Details of the sessions were provided for each couple.	Dyadic adjustment scale (DAS); Hospital anxiety depression scale (HADS); Beck depression inventory-II (BDI); Beck anxiety inventory (BAI); Caregiver strain index (CSI).	Data were collected pre-and post-intervention.	Pre-post intervention comparison showed different results for each couple. For the first couple, significant differences in all the measures were observed, except for the DAS subscale Coherence. For the second couple, a significant change was found only in BDI and CSI. For the third couple, a significant change was found only in DAS subscale Coherence and BDI. The fourth couple showed a significant change only in CSI. Though the study did not mention using any qualitative methods, they reported qualitative

								feedback they received from the participants. The report stated that the sessions were perceived as helpful by the first three couples, both the patient and their partners, in bringing a meaningful change in their relationship. They stated that they perceived personal distress to have decreased and relationship connection and intimacy to have improved post-intervention. However, the fourth couple did not report any benefit from the intervention. **Both quantitative and qualitative data showed mixed results with no specific data to state that the intervention had any significant or reliable impact on the couples.**
	Backhaus, 2016.	**Injury type=** Acquired Brain Injury**.**	Combined details of participants were provided. There was a total of 18 participants with a mean age of 47.6 years. Participants/ caregivers were partners/ spouses of the patients.	Community setting.	**The intervention aimed to examine the feasibility of conducting a structured intervention for improving adjustment and satisfaction in the relationship with a partner with brain injury.** Intervention for the group went on for 16 weeks, two hours per session, focussing on aspects of relationships psychoeducation, and therapeutic support, including effective communication and interpersonal skills, emotional regulation and adaptation to circumstances, and strategies for addressing relationship needs. Group training sessions were conducted using in-sessions worksheets, activities, and homework assignments. Intervention details were provided.	Dyadic Adjustment Scale (DAS); Quality of Marriage Index (QMI); Four Horsemen of the Apocalypse Questionnaire; Session Evaluation form; Final Evaluation form.	Data were collected at baseline, at the end of each session, and at the end of the overall intervention.	Comparison between baseline and post-intervention results showed significantly improved relationship adjustment and satisfaction (DAS), improved QMI and improved communication skills (Four Horsemen of the Apocalypse Questionnaire). Both session and final evaluation forms provided positive information regarding the intervention acceptability and satisfaction. **The study showed significant improvement in relationship adjustment and satisfaction.**

Table 5.6. Study quality checklist of quantitative studies where participants included both patients and their family (based on the NICE framework)

Checklist	**First author, Year Study quality grading**													
	Dennis, 1997 (RCT)	**Sinnakaruppan, 2005 (RCT)**	**Carnevale, 2006 (RCT)**	**Backhaus, 2010 (RCT)**	**Bushnik, 2015 (RCT)**	**Moriarty, 2016 (RCT)**	**Pitthayapong, 2017 (RCT)**	**Terrill, 2018 (RCT)**	**Perlesz, 1998 (Before & After)**	**Rodgers, 2007 (Before & After)**	**Kreutzer, 2009 (Before & After)**	**Kreutzer, 2010 (Before & After)**	**Edwards, 2013 (Before & After)**	**Backhaus, 2016 (Before & After)**
Population	-	-	++	++	-	++	++	++	-	++	++	++	++	+
Is the source population well described?	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	N
Is the eligible population representative of the source population?	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	N
Do the selected participants represent the eligible population or area?	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	Y
Method of allocation to intervention (or comparison)	+	+	++	++	+	+	++	+	-	-	-	-	-	-
Was selection bias minimised?	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N
Were interventions well described and appropriate?	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	Y
Was the allocation concealed?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Were participants or investigators blind to exposure and comparison?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Was the exposure to the intervention and comparison adequate?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Was contamination acceptably low?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Were other interventions similar in both groups?	N	Y	N	Y	Y	Y	Y	N	NA	NA	NA	NA	NA	NA
Were all participants accounted for at study conclusion?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Outcomes	++	++	++	++	++	++	++	-	++	+	++	++	+	++
Were outcome measures reliable?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were all outcome measurements complete?	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y

Were all important outcomes assessed?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were outcomes relevant?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were there similar follow-up times in exposure and comparison groups?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Was follow-up time meaningful?	Y	Y	Y	Y	Y	Y	Y	Y	Y	NA	Y	Y	Y	Y
Analyses	-	-	+	+	-	+	+	-	-	+	-	-	-	-
Were exposure and comparison groups similar at baseline? If not, were these adjusted?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA
Was intention to treat (ITT) analysis conducted?	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Was the study sufficiently powered to detect an intervention effect (if one exists)?	N	N	N	N	N	Y	Y	N	NA	N	N	N	NA	N
Were the estimates of effect size given or calculable?	N	N	N	Y	N	Y	Y	N	N	N	N	N	NA	N
Were the analytical methods appropriate?	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Was the precision of intervention effects given or calculable? Were they meaningful?	N	Y	Y	Y	N	Y	Y	N	N	Y	Y	Y	N	Y
Summary	+	+	+	++	+	++	++	-	-	-	-	-	-	-
Are the study results internally valid (i.e. unbiased)?	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N
Are the findings generalisable to the source population (i.e. externally valid)?	N	N	N	Y	N	Y	Y	N	N	N	N	N	N	N

Note: Y= Yes; N= No; NA= Not Applicable

Table 5.7. Summaries of quantitative studies where participants included family members only

Study design	**First author, Year**	**Patient characteristics**	**Family characteristics**	**Intervention details**		**Outcome assessment**		**Findings**
				Setting	**Description**	**Measures**	**Frequency of assessment**	
Randomized Control Trial	Grant, 2002.	**Injury type=** Stroke.	**Sample size=** 74 **Mean age=** 57 **Gender=** 7 males & 67 females. Caregivers were spouses/ children, daughter-in-law, and other relatives.	Home environment.	Participants were randomly divided into three groups; an intervention group, a sham intervention group, and a no-treatment control group. **The intervention aimed to evaluate the impact of “social-problem-solving telephone partnerships” for stroke caregivers.** **The intervention consisted of educational sessions on using a positive problem orientation, social problem-solving skills training, and focused on individual caregiving needs**. The first three sessions were face-to-face interventions, and the rest were conducted over the telephone. The intervention was conducted over a period of 18-months. Intervention details were mentioned via a referenced article.	Medical Outcomes Study Short Form Health Survey (SF-36); Social Problem-Solving Inventory; Center for Epidemiological Studies Depression Scale; Preparedness for Caregiving Scale; Caregiving Burden Scale.	Data were collected pre- and post-intervention.	The intervention group showed significant differences post-intervention in the following sub-scales of SF-36 post-intervention; vitality, mental health, and role limitations related to emotional problems. The sham intervention group did not show any significant changes from pre- and post-intervention assessment in any outcome measures. The control group also did not show any changes over time except for the “mental health” sub-scale of SF-36, which was found to decrease the post-intervention period. Significant changes in problem-solving abilities were not obtained post-intervention for the intervention and sham intervention group, but the control group showed significant deterioration in problem-solving abilities. Significant changes in depression, caregiver preparedness, and caregiver burden were obtained for the intervention group over time but was not found for the other two groups. Comparison of the three groups showed that the mean of the intervention group for SF- 36, problem-solving abilities, depression, and caregiver preparedness were significantly different in comparison to the other two groups. However, there was no significant difference in the three groups regarding caregiver burden. **The data showed that vitality, mental health, role limitations related to emotional problems, depression, and caregiver preparedness significantly changed for the group who had received the intervention.**
	Schure, 2006.	**Injury type=** Stroke.	**Sample size=** 130 **Mean age=** 64.6	Community setting.	Participants were randomly divided into three groups; group intervention, home visiting program, and a no-treatment control group. **The intervention aimed to evaluate the strengths and weaknesses between family**	Mechanisms of change questionnaire; Short Form Utrecht Coping List-15.	Data were collected after a month following the intervention.	The findings showed that the caregivers in the group programme perceived specific intervention components, like informational and emotional support, as more helpful in comparison to the caregivers in the home visiting programme

			Gender= 34 males & 96 females. Details of caregivers' relationship with the patients were not provided.		**group support program and home visiting program following a stroke.** **Counselling and education strategies were provided to help the caregivers deal with emotional and practical problems, especially those related to a balanced lifestyle and role changes.** The home visiting programme consisted of four long sessions, while the group intervention consisted of eight shorter sessions. Separate intervention manuals were written for the individual and group program, but the content was the same. Intervention details were provided.			(Mechanisms of change questionnaire). Presence of active coping strategies and seeking social support was found to be more among the caregivers in the group programme in comparison to the home training programme. Qualitative data showed that most of the participants in both the groups reported lack of a follow-up session as an essential aspect. The data analysis procedure, however, was not complete. The study had a control group, but no evidence of the data from the control group has been mentioned, nor has it been included in the analysis. **Though specific quantitative data reports that group intervention was perceived to be more useful than the home visiting programme, the data analysis seems to be incomplete and, therefore, the impact of the intervention could not be evaluated appropriately**.
	Rivera, 2008.	**Injury type=** TBI.	**Sample size=** 67 **Mean age=** 36.85 **Gender=** 4 males & 63 females. Caregivers consisted of parents.	Home environment.	Participants were randomly divided into a problem-solving training group, and education only control group. **The aim was to evaluate the effectiveness of a problem-solving training program in lowering depression, health complaints, and burden, and increasing well-being in family caregivers.** **Problem-solving training** was conducted for the caregivers through monthly face-to-face sessions and telecommunication. The intervention was based on 5-basic principles of the social problem-solving model: identify the problem, brainstorm solutions, critique the solutions, choose and implement a solution, and evaluate the outcome. Worksheets were used for the sessions. For the education-only control group, monthly telephone sessions were conducted. Intervention details were provided.	Centre for Epidemiologic Studies Depression (CES-D) Scale; Satisfaction with Life Scale (SWLS); Pennebaker Inventory for Limbic Languidness (PILL); Caregiver Burden Scale.	Data were collected at baseline, and at three-time points post-intervention (four, eight, and 12 months).	The findings showed a significant change in depression (CES-D) for the training group in comparison to the control group, at all the three time-points. A significant linear increase in depression over time was observed in the control group, while a significant linear decrease in depression was observed for the training group. There was no statistically significant interaction between treatment and time on caregiver scores on the SWLS. The main effect for treatment was significant because caregivers in the control condition reported higher life satisfaction. The main effect for time was also significant since caregivers in both groups reported a significant linear increase in life satisfaction over time. There was a significant treatment by time interaction effect for caregiver scores on the PILL. The training group showed a decrease in health complaints over time, in comparison to the control group. No statistically significant interaction was found between treatment and time on caregiver burden. **The study showed that caregiver depression decreased over time through problem-solving training, while it increased with only education. However, education alone was also found to increase caregiver life satisfaction. Problem-**

								solving training was also found to decrease health complaints over time significantly. Moreover, neither education nor the training showed any change in caregiver burden.
	Pierce, 2009	**Injury type=** Stroke.	**Sample size=** 73 **Mean age=** 50 **Gender=** 18 males & 55 females. Caregivers were spouses, children, and other relatives and friends.	Home environment.	Participants were randomly divided into two groups, a web-based intervention group and a non-web-based group. **The intervention aimed to increase carer's well-being and decrease the patient's participation in healthcare services.** The intervention was an **educational intervention** that focused on individual carer needs and used both internet and email to remain connected to the carers. It went on for a year. Intervention details were not provided.	Centre for Epidemiological Studies Depression (CES-D); Satisfaction with Life Scale (SWLS); National Health Interview Survey (NHIS).	Data were collected at baseline, and at three, six, nine, and twelve-months.	The findings showed no significant group differences in CES-D and SWLS scores at any time points. With regards to the two groups, there were no significant differences within the groups in CES-D and SWLS scores across the time points. However, there was a significant difference in the NHIS sub-scales "emergency department visit" and "number of hospital readmissions" both between groups and across the time points. **The intervention was found to have no significant impact on most of the outcome measures.**
	Bakas, 2015.	**Injury type=** Stroke.	**Sample size=** 254 **Mean age=** 54 **Gender=** 55 males & 199 females. Further details about the caregivers were not provided.	Home environment.	Participants were randomly divided into two groups, an intervention group, and information only group. **The intervention aimed to evaluate the efficacy of a Telephone Assessment and Skill-Building Kit (TASK II), to help caregivers build skills based on an assessment of their own needs.** The intervention helped caregivers in **skill building** using weekly telephone sessions. Topics included strengthening existing caregiving skills, screening for depressive symptoms among the patients, maintaining realistic expectations, communicating with healthcare providers, problem-solving, stress management, and identifying and managing caregiver's needs and concerns. Training was provided using training manuals and podcasts, details of which were not provided.	The Patient Health Questionnaire Depressive Symptom Scale (PHQ-9); 15-item Bakas Caregiving Outcomes Scale (BCOS); Stroke-Specific Quality of Life Proxy (SS SSQOL proxy).	Data were collected at baseline, post-intervention, and at different time-points post-intervention (eight weeks, 12 weeks, 24 weeks, and 52 weeks).	The findings showed a statistically significant interaction between time and treatment, since PHQ-9 showed a significant reduction in depressive symptoms from baseline to 8 weeks, in the intervention group in comparison to the information only group. BCOS and SS SSQOL proxy showed significant improvement in the quality of life among the intervention group in comparison to the control group from baseline to eight, 12, and 24 weeks. **The study showed decreased caregiver depression and increased the quality of life over time, while information only was found to have no impact on the caregivers.**
	Fortune, 2016.	**Injury type=** Acquired brain injury.	**Sample size=** 113 **Mean age=** 52.38 **Gender=** 93 females, 20 males.	Community setting.	The participants were randomly assigned into an intervention and a wait-list control group. **The intervention aimed to evaluate the effectiveness of a multicomponent group programme in reducing carer distress and strain.**	Caregiver Strain Index (CSI); Hospital Anxiety and Depression Scale.	Data were collected at pre-and post-intervention, and at three-month follow-up.	The findings show that there were significant changes in CSI in the intervention group over time and in comparison, to the control group. However, there were no changes in anxiety or depression for the intervention group over time nor when compared to the control group.

			Caregivers were spouses, parents, children, and siblings.		The intervention consisted of six half-day core modules and three elective modules. All participants completed core modules and then chose electives if they perceived the content to meet their individual needs, which continued for two years. An overview of the intervention has been provided.			**The study showed that caregiver strain decreased over time following the intervention, but there were no changes in the caregiver's psychological distress.**
	Powell, 2016.	**Injury type=** Moderate-Severe TBI.	**Sample size=** 77 **Mean age=** 48.2 **Gender=** 64 females, 13 males. Caregivers were spouses/ partners, parents, and other family members.	Home environment.	The participants were randomly assigned into an intervention group and a no-treatment control group. **The aim was to evaluate the usefulness of telephone-based, individualised education and mentored problem-solving intervention on caregivers' outcomes.** A 12- topic **educational module was created**. **The intervention included acceptance, role management, i.e., creating new meaningful behaviour and life roles, and emotional management, i.e., adjusting to a situation that induces emotions such as depression, anxiety, and anger.** Details of the intervention were provided along with detailed examples.	Bakas Caregiving Outcomes Scale (BCOS); Brief Symptom Inventory (BSI); Brief COPE.	Data were collected at baseline and six-month follow-up.	The findings showed significant changes in all the outcome measures, from baseline to follow-up, for treatment group in compassion to the control group. The study showed increased caregivers well-being, active coping skills and less emotional venting. **The caregivers were found to be successful in gaining assistance and resources from health care providers and were better able to take care of themselves.**
Non-Randomized Controlled Trial	Wilz, 2007.	**Injury type=** Stroke.	**Sample size=** 124 **Mean age=** 63 **Gender=** 28% males & 72% females. Caregivers were spouses of the stroke patients.	Community setting.	Participants were divided into one intervention group and two control groups, without using randomisation. One of the control group was an informal support group, while the other was a standard care group. **The aim of the intervention was to reduce the prevalence of mental disorders and burnout among the caregivers.** The intervention was a **cognitive-behavioural group intervention programme** that consisted of 15 bi-monthly 1.5 hours sessions. The programme consisted **of education about stroke-related topics and social sharing, training in problem solving, and cognitive restructuring.** Limited intervention details were mentioned.	Beck Anxiety Inventory (BAI); Beck Depression Inventory (BDI); WHO Quality of Life Questionnaire.	Data were collected at baseline, post-intervention, and at six-month follow-up.	Significant group differences were found only in the WHO measure both at post-intervention and at follow-up. However, for the Beck Anxiety Measure and Depression Inventory, significant group differences were found only at follow-up. The intervention group also showed significant changes only at follow-up, while the two control groups showed no significant changes over time. **The intervention was found to have an impact on quality of life of the caregivers, and long-term effects, to some extent, on the mental health related variables.**
Before and after designs	Acorn, 1995.	**Injury type=** Head injury.	**Sample size=** 19 **Mean age=** 50	Community setting.	**The aim was to develop, implement and evaluate a community-based education/support programme.**	Jalowiec Coping Scale, Revised (JCS); Rosenberg's 10-item Self-esteem Scale	Data were collected at two-months and one-month pre-	The study findings showed that none of the outcome's measures were found to have any significant difference when compared at different time points.

			Gender= 5 males & 14 females. Details about the caregivers were not provided.		The intervention was a 10-module **manualised intervention, focused on carers to provide them with information regarding the injury and how to better understand and care for the survivors**. Topics in the programme were effects of a head injury, management of cognitive and behavioural problems, communication, impact on the family system, impact on the caregiver, community resources and advocating for services, legal and financial issues, and group maintenance and follow-up. Weekly sessions of two hours per week or monthly three weekend sessions, five hours per day was conducted. Intervention details were mentioned via a referenced article.	(RSES); Life Satisfaction Index Z (LSIZ); Dupuy General Well-Being Scale (GWB).	intervention, immediately before and after the intervention, and at one-month and two-month follow-up.	**The intervention was found to have no significant impact on the caregivers.**
	Man, 1999.	**Injury type=** Stroke, brain tumour, arteriovenous malformation, and traumatic brain injury.	**Sample size=** 50 **Mean age=** 35-44 **Gender=** 41 females & 9 males. Caregivers were spouses, parents, siblings, children, and cousins.	Community setting.	**The intervention aimed to evaluate a community-based development programme. The intervention focused on helping family members to better cope with their situation** regarding reducing caregiver burden and increasing their psychological well-being so that they can provide better care to the survivors. The intervention was delivered in groups of eight-ten family members. Intervention details were provided.	Empowerment questionnaire (Part I and II); General Health Questionnaire (GHQ).	Data were collected pre-intervention, post-intervention, and at three-month follow-up.	The study findings showed significant changes in all the empowerment components (Part I and II) when compared at all the different time points. However, when compared with pre-intervention scores, the GHQ was found to change post-intervention but not at the follow-up period significantly. **The study showed that caregivers learned new information and new coping skills with the onset of brain injury. There were changes in general health, but the change was not consistent on a long-term basis.**

Table 5.8. Study quality checklist of quantitative studies where participants included family members only (based on the NICE framework)

Checklist	**First author, Year Study quality grading**									
	Grant, 2002 (RCT)	**Schure , 2006 (RCT)**	**Rivera , 2008 (RCT)**	**Pierce, 2009 (RCT)**	**Bakas, 2015 (RCT)**	**Fortun e, 2016 (RCT)**	**Powell , 2016 (RCT)**	**Wilz, 2007 (Non-Randomized Controlled Trial)**	**Acorn, 1995 (Before & after)**	**Man, 1999 (Befor e & after)**
Po7pulation	++	-	++	++	++	++	++	++	-	++
Is the source population well described?	Y	N	Y	Y	Y	Y	Y	Y	N	Y
Is the eligible population representative of the source population?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Do the selected participants represent the eligible population or area?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Method of allocation to intervention (or comparison)	+	+	++	+	+	++	+	-	-	-
Was selection bias minimised?	Y	Y	Y	Y	Y	Y	Y	N	N	N
Were interventions well described and appropriate?	Y	Y	Y	N	N	Y	Y	Y	N	Y
Was the allocation concealed?	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA
Were participants or investigators blind to exposure and comparison?	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA
Was the exposure to the intervention and comparison adequate?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA
Was contamination acceptably low?	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA
Were other interventions similar in both groups?	N	N	N	N	N	Y	N	N	NA	NA
Were all participants accounted for at study conclusion?	N	N	Y	Y	Y	Y	Y	Y	Y	Y
Outcomes	++	-	++	++	+	++	++	++	++	+
Were outcome measures reliable?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were all outcome measurements complete?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were all important outcomes assessed?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Were outcomes relevant?	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Were there similar follow-up times in exposure and comparison groups?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA
Was follow-up time meaningful?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Analyses	-	-	+	+	+	++	-	-	-	-
Were exposure and comparison groups similar at baseline? If not, were these adjusted?	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA
Was intention to treat (ITT) analysis conducted?	N	N	N	N	N	Y	N	N	N	N
Was the study sufficiently powered to detect an intervention effect (if one exists)?	N	Y	Y	Y	Y	Y	N	N	N	N
Were the estimates of effect size given or calculable?	N	Y	Y	Y	Y	Y	N	N	N	N
Were the analytical methods appropriate?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Was the precision of intervention effects given or calculable? Were they meaningful?	Y	Y	Y	Y	Y	Y	Y	N	Y	N
Summary	+	++	++	++	++	++	+	-	-	-
Are the study results internally valid (i.e. unbiased)?	Y	Y	Y	Y	Y	Y	Y	N	N	N
Are the findings generalisable to the source population (i.e. externally valid)?	N	Y	Y	Y	Y	Y	N	N	N	N

Note: Y= Yes; N= No; NA= Not Applicable

Table 5.9. Summaries of qualitative studies

Study design	**First author, Year**	**Patient characteristics**	**Family characteristics**	**Intervention**		**Analysis**	**Findings**
				Setting	**Description**		
Focus group	Straits-Troster, 2013.	**Injury type=** Traumatic Brain Injury Veterans **Sample size=** 8 **Mean age=** 34.5 **Gender=** 2 females and 6 males.	**Sample size=** 8 **Mean age=** 37.9 **Gender=** 6 female spouses, 1 mother, and 1 sister.	Community setting.	**The intervention aimed to evaluate the effectiveness of multi-family group treatment for veterans.** The intervention included family meetings with a clinician, and **an educational workshop focused on problem-solving and communication skills building**, for a year. Intervention details were not provided.	Data were analysed using content analysis.	Multiple codes were reported which were grouped into different themes; exploring everyday struggles and reducing isolation, skill-building and problem-solving, restoring relationships by developing communication skills, understanding the connection between brain injury and post-traumatic stress disorder, and increasing family engagement. **Both patients and caregivers reported a better understanding of the effects of the injury. They also reported that the educational workshop and communication skills training helped them to change their communication pattern which they perceived to have helped in their relationship.**
	Butera-Prinzi, 2014.	**Injury type=** Acquired Brain Injury **Sample size=** 1 **Mean age=** 41 **Gender=** male.	**Sample size=** 4 **Mean age=** Age of spouse= unknown. Age of son=14. Age of daughters=9 & 12 **Gender=** 1 female(spouse), 1 son & 2 daughters.	Community setting.	The intervention was conducted on one family which was conducted over a period of two years. **The intervention aimed to evaluate the effects of narrative family therapy following an acquired brain injury.** It included narrative family therapy **to enhance the family members' skills and knowledge**, **to reconnect with what they value in each other, and to explore ways to minimise the impact of acquired brain injury on their lives**. Intervention details were provided.	The analysis procedure of the data was not clearly described.	**Qualitative data states that family members reported to have benefitted by reconnecting with the family and embracing the complexities they were facing, and by finding ways to live their lives in line with their values and what is meaningful for them, despite the ongoing challenges. The children were reported to have benefitted with narrative tools like "The Tree of Life".**
	Couchman, 2014.	**Injury type=** Acquired Brain Injury **Sample size=** 29 **Mean age=** 39.4 **Gender=** 20 males and nine females.	**Sample size=** 30 **Mean age=** 53.3 **Gender=** 22 females, 8 males Caregivers were spouses/ partners, friends, and	Community setting.	**The intervention aimed to understand the process and factors influencing the success of Multifamily Group Therapy programmes.** Some patients attended with more than one caregiver/ family members, while three individuals with brain injury and two caregivers attended on their own. The intervention included **educational and problem-solving workshops** for two years (12 sessions over 12 weeks). The intervention was conducted in the form of group sessions. Intervention details were provided.	Thematic analysis of the data were conducted.	Themes that emerged were: connectedness, identity, knowledge and understanding. Both patients and family members reported a perceived increase in self-confidence and wellbeing after the intervention. **Increase in connection with others within their intervention group, sharing experiences, development of self and family identity, and gaining of knowledge and understanding were the specific perceived impact of the intervention as reported by the participants.**

			other family members				
	Damianakis, 2016.	**Injury type=** Traumatic Brain Injury **Sample size=** 10 **Mean age=** 20 **Gender=** 7 Male, 3 females.	**Sample size=** 10 **Mean age=** Not provided **Gender=** 8 females (mothers), 2 males (sons).	Home environment.	**The aim was to explore the effects of supporting families using video-conferencing.** The intervention was a web-based ten weekly 1-hour session on a website named “Caring for Others (CFO)”. The website included a TBI Information Handbook, an e-mail link with a pull-down list of group member e-mails, a text-based discussion forum, and a video conferencing link for both individual and group meetings. There were group sessions attended by only caregivers, and individual sessions attended by both patients and caregivers. The group intervention provided brain injury information, behaviour management, problem-solving, and communication skills training. The individual sessions focused on the development of empathic understanding and support, identifying and working on individual problems/goals. Intervention details were provided.	Content analysis was conducted on transcripts of each session, coded with the “NVivo Quality Software Programme”.	Caregiver burden, stress, and difficulty managing the caregiving process emerged as the main themes. **Participants reported perceived usefulness of the intervention in the following areas: availability of resources; increased self-efficacy; increased acceptance of the changes and managing the emotional impact of caring for the patient; sharing the emotional effects of perceived loss of their loved ones, and identifying ways to re-connect.**
Case study	Evans-Robert, 2014.	**Injury type=** Traumatic Brain Injury **Sample size=** 1 **Age=** late 20’s **Gender=** female.	**Sample size=** 2 **Age=** Not provided **Gender=** 1 female (mother) and 1 male (father).	Home environment.	**The intervention aimed to understand the impact of family intervention post-injury on both the patient and their family members**. It was a **clinical therapeutic intervention** on one family. Some information about the sessions were provided, but not in detail.	Method of analysis was not mentioned.	**The study stated that the patient and her mother reported a gradual increase in self-confidence and well-being post-intervention. The mother reported that she felt she was supporting the patient but not at the expense of her health & happiness. However, the impact that has been reported was solely based on the clinician’s judgement, and much detail about the case was not reported to have an in-depth understanding.**

Table 5.10. Study quality checklist of qualitative studies (based on the NICE framework)

Checklist	**First author, Year Study quality grading**				
	Straits-Troster, 2013 (Focus group)	**Butera-Prinzi, 2014 (Focus group)**	**Couchman, 2014 (Focus group)**	**Damianakis, 2016 (Focus group)**	**Evans-Robert, 2014 (Case study)**
Theoretical approach	++	++	++	-	++
Is a qualitative approach appropriate?	Y	Y	Y	N	Y
Is the study clear in what it seeks to do?	Y	Y	Y	Y	Y
Study design: Was the research design/ methodology defensible/rigorous?	++	+	+	-	-
Data collection: How well was the data collection carried out?	++	++	++	+	-
Trustworthiness	+	+	++	+	+
Is the role of the researcher clearly described?	Y	N	Y	Y	Y
Is the context clearly described?	Y	Y	Y	Y	Y
Were the methods reliable?	N	Y	Y	N	N
Analysis	++	-	+	+	-
Is the data analysis sufficiently rigorous?	Y	N	Y	Y	N
Is the data 'rich'?	Y	Y	N	Y	N
Is the analysis reliable?	Y	N	Y	Y	N
Are the findings convincing?	Y	Y	Y	N	N
Are the findings relevant to the aims of the study?	Y	Y	Y	Y	Y
Conclusions	++	+	++	+	-
Ethics: How clear and coherent is the reporting of ethics?	-	-	-	-	-
Overall assessment: As far as can be ascertained from the paper, how well was the study conducted?	++	+	++	+	-

Note: Y= Yes; N= No

5. Findings

This review summarises evidence of interventions provided to family members of BI survivors. It evaluated 21 quantitative studies (Table 5.5 & Table 5.7), five qualitative studies (Table 5.9), and three mixed methods study (using both quantitative and qualitative measure) (Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010; Rodgers et al., 2007; Terrill et al., 2018) (Table 5.5). Among the quantitative studies, 14 studies included both the survivors and their family members in the intervention process, while ten studies included only the family members. The articles were heterogeneous concerning their study designs, patient and family characteristics, sample size, intervention setting, duration, content, mode of delivery, outcome measures, and data analysis.

5.1. Target of the intervention

Most of the studies were multi-component intervention and so they had various targets. For example, the study conducted by Pitthayapong et al. (2017) focused on both educating the patients and caregivers about BI and its effects, and at the same time it also aimed to help the caregivers cope better with the emotional and behavioural challenges they have to face post-BI. Another example is the study conducted by Sinnakaruppan et al., (2015), where the study intervention aimed to not only provided educational information about BI to the patients and their caregivers, but it also focused on improving the caregiver’s emotional well-being, self-esteem, and coping skills by providing them with separate training. Only four studies had intervention that focused on improving only one aspect (Acorn et al., 1995; Edwards et al., 2013; Man et al., 1999; Terrill, et al., 2018). For example, in the study conducted by Terrill et al. (2018) the intervention focused on helping the couples re-engage into activities they used to do together as a couple previous to the injury. Another example was the study conducted by Acorn et al. (1995) where the intervention solely focused on educating the caregivers about different aspects of brain injury.

The studies have been grouped below according to the targets of the interventions, but, because so many of them were multi-component, the same study could be placed into more than one of the categories.

5.1.1. Increasing the knowledge of the family member about the effects of BI.

Ten studies used interventions that focused on providing information about BI, its effects on both the survivors and their family members/caregivers, and other related information. (Acorn et al., 1995; Damianakis et al., 2016; Dennis et al., 1997; Grant et al., 2002; Kreutzer et al., 2009, 2010; Pierce et al., 2009; Powell et al., 2016; Rodgers et al., 2007; Schure et al., 2006). For example, the study conducted by Kreutzer et al. (2009) provided information to both patients and their family members on the effects of BI, on how to cope better with the BI changes and challenges, how to set individual goals, and how they should take individual care. Among these ten studies, five studies provided interventions to both patients and their family members (Damianakis et al., 2016; Dennis et al., 1997; Kreutzer et al., 2009, 2010; Rodgers et al., 2007), while the rest five studies provided interventions only to the family members. Moreover, nine studies were quantitative studies while only one study (Damianakis et al., 2016) was a qualitative study. Though all the educational interventions provided information to the participants on various different topics, the most common outcome assessment conducted were to analyse if the intervention had any effects on the participants emotional well-being (anxiety, depression, stress), caregiver burden, caregiver satisfaction, and their adjustment and satisfaction with life.

5.1.2. Improving the problem-focused coping skills of the family members.

Five studies used interventions that focused on helping the caregivers develop skills to better cope with the BI challenges like challenging patient behaviour, cognitive impairments, and communication difficulties using various problem-solving strategies (Backhaus et al., 2010; Carnevale et al., 2006; Couchman et al., 2014; Straits-Troster et al., 2013; Wilz et al., 2007). For example, the study conducted by Carnevale et al. (2006) used intervention to help the caregivers develop problem-solving strategies to manage individual patient behavioural issues like aggression. Two among these studies were qualitative studies (Couchman et al., 2014; Straits-Troster et al., 2013) while the rest were quantitative studies. All of these studies focused on different outcome measures.

5.1.3. Improving the emotion-focused coping skills of the family members.

Seven studies used interventions that focused on helping the family members develop skills to better manage their emotional difficulties like anxiety, depression, and stress management, caregiver burden, and caregiver satisfaction (Bakas et al., 2015; Fortune et al., 2016; Man et al., 1999; Moriarty et al., 2006; Pitthayapong et al., 2017; Rivera et al., 2008; Sinnakaruppan et al., 2005). For example, the study conducted by Sinnakaruppan et al. (2005) used an intervention to improve the family member’s psychological health by reducing their anxiety and depression, and by improving their self-esteem and coping skills. All the studies were quantitative studies and the majority of them had similar outcome measures. The most common outcome assessments focused on quality of life of the participants, anxiety, depression, stress, caregiver burden, and caregiver satisfaction.

5.1.4. Improving family functioning and dynamics among the family members and the person with the BI.

Seven studies used interventions that focused on improving various aspects of family functioning such as communication (Backhaus et al., 2016; Bushnik et al., 2005; Butera-Prinzi et al., 2014; Edwards et al., 2013; Evans-Robert et al., 2014; Perlesz et al., 1998; Terrill et al., 2018). For example, the study conducted by Backhaus et al. (2016) used an intervention that aimed to improve adjustment and satisfaction among couples where one partner had an ABI, by helping them develop effective communication skills, interpersonal skills, and by addressing to their individual relationship needs. Two among these studies were qualitative studies (Butera-Prinzi et al., 2014; Evans-Robert et al., 2014) while the rest were quantitative studies. All of these studies focused on different outcome measures.

5.2. Content of intervention

Detailed information about the content of their intervention was provided by 21 studies. Four studies provided the intervention details via a referenced article (Acorn, 1995; Bushnik, Kreutzer, Marwitz, Sima, & Godwin, 2015; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Kreutzer et al., 2009). Five studies did not provide any information on the content of their interventions (Bakas et al., 2015; Dennis, Slattery, Staniforth, & Warlow, 1997; Perlesz & O'loughlan, 1998; Pierce, Steiner, Khuder, Govoni, & Horn, 2009; Straits-Toster et al., 2013), making it difficult to replicate such studies. Only eight studies mentioned the theoretical framework on which their intervention was based (Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010; Backhaus et al., 2016; Butera-Prinzi et al., 2014; Edwards, Murray, Creamer, Mahadevan, & Yeates, 2013; Evans-Roberts, Weatherhead, & Vaughan, 2014; Kreutzer et al., 2009; Terrill et al., 2018; Wilz, & Barskova, 2007). For example, the study conducted by Backhaus et al. (2010) was based on Cognitive Behavioural Therapy approach.

5.3. Mode of delivering the intervention

The majority of the studies used face-to-face contact between the researcher and the participants to deliver the interventions. However, five studies used telephone-based intervention (Bakas et al., 2015; Grant et al., 2002; Moriarty et al., 2016; Powell et al., 2016; Rivera et al., 2008), while two study conducted a web-based intervention (Damianakis et al., 2016; Pierce, 2009). Ten studies conducted group intervention (Acorn, 1995; Backhaus et al., 2016; Backhaus et al., 2010; Couchman et al., 2014; Fortune et al., 2016; Man, 1999; Pitthayapong et al., 2017; Rodgers et al., 2007; Sinnakaruppan et al., 2005; Wilz, 2007), 16 studies conducted individual sessions (Bakas et al., 2015; Bushnik, 2015; Butera-Prinzi et al., 2014; Damianakis et al., 2016; Dennis, 1997; Edwards et al., 2013; Evans-Robert et al., 2014; Grant et al., 2002; Moriarty et al., 2016; Perlsez, 1998; Pierce, 2009; Powell et al., 2016; Rivera et al., 2008; Straits-Troster et al., 2013; Teasdale et al., 2009; Terrill et al., 2018), and three studies used both group and individual sessions (Carneval et al., 2006; Geurtsen et al., 2011; Schure et al., 2006). However, for two studies, it was not clear if they used group interventions or individual sessions (Kreutzer et al., 2009, 2010).

Only ten studies used some form of handouts, presentations, or manuals to deliver the interventions (Acorn, 1995; Backhaus et al., 2010; Bakas et al., 2015; Bushnik, 2015; Damianakis et al., 2016; Kreutzer et al., 2009; Rivera et al., 2008;

Rodgers et al., 2007; Schure et al., 2006; Sinnakaruppan et al., 2005). For example, while Backhaus et al. (2010) used workbooks and power-point handouts, Bakas et al. (2015) used training manuals and podcasts to conduct their sessions. Majority of the studies conducted their interventions in a community setting while only ten studies conducted it in the participants home environment which includes web-based and telephone-based studies (Bakas et al., 2015; Damianakis et al., 2016; Edwards et al., 2013; Evans-Robert et al., 2014; Grant et al., 2002; Moriarty et al., 2016; Palmisano & Arco, 2007; Pierce, 2009; Powell et al., 2016; Rivera et al., 2008; Terrill et al., 2018).

5.4. The timing of the intervention

Most of the studies mentioned details regarding when the intervention was conducted post-injury, i.e., the gap between the injury and the intervention. However, nine studies have not mentioned these details (Bakas et al., 2015; Couchman et al., 2014; Edwards et al., 2013; Man, 1999; Pitthayapong et al., 2017; Powell et al., 2016; Rivera et al., 2008; Sinnakaruppan et al., 2005; Straits-Troster et al., 2013).

5.5. Economic information

None of the studies reported the cost of conducting the intervention, nor conducted any economic analysis.

5.6. Follow-up and longitudinal studies

Majority of the studies conducted follow-up sessions, while only nine studies did not, which mostly includes the qualitative studies (Backhaus et al., 2016; Butera-Prinzi et al., 2014; Couchman et al., 2014; Damianakis et al., 2016; Edwards et al., 2013; Evans-Robert et al., 2014; Grant et al., 2002; Rodgers et al., 2007; Straits-Troster et al., 2013). There were no longitudinal studies.

5.7. Quality ratings

The study quality of all the articles was assessed based on the NICE framework, for both quantitative and qualitative studies (NICE, 2009) (Table 5.6, 5.8, & 5.10). Mixed ratings were obtained and the RCTs were found to have the highest number of "++" rating. However, most of the RCT studies also got a few negative ratings in some categories since some studies had limitations, for example, some did not provide evidence of power or effect size calculations. None of the studies got a rating of "++" in all the categories. However, seven studies did not get any negative ratings, and rather got a mixture of "++" and "+" rating in their categories (Backhaus et al., 2010; Bakas et al., 2015; Carnevale et al., 2006; Fortune et al., 2016; Moriarty et al., 2016; Pitthayapong et al., 2017; Rivera et al., 2008).

The effectiveness of an intervention depends on numerous factors, most importantly the research design. RCT's are considered as the most desirable study design (Shekelle, Maglione, Luoto, Johnsen & Perry, 2013). However, only 15 studies were RCT (Backhaus et al., 2010; Bakas et al., 2015; Bushnik, 2015; Carnevale et al., 2006; Dennis, 1997; Fortune et al., 2016; Grant et al., 2002; Moriarty et al., 2016; Pierce. 2009; Pitthayapong et al., 2017; Powell et al., 2016; Rivera et al., 2008; Schure et al., 2006; Sinnakaruppan et al., 2005; Terrill et al., 2018). Four were focus group studies (Butera-Prinzi et al., 2014; Couchman et al., 2014; Damianakis et al., 2016; Straits-Toster et al., 2013), one was a case study (Evans-Roberts et al., 2014), eight studies were before and after studies (Acorn, 1995; Backhaus et al., 2016; Edwards et al., 2013; Kreutzer et al., 2009, 2010; Man, 1999; Perlesz, 1998; Rodgers et al., 2007), and one was a non-randomized controlled trial (Wilz, 2007).

The quality of the RCT studies also depended on the type of groups they had. Five studies had wait-list control groups (Backhaus et al., 2010; Bushnik, 2015; Fortune et al., 2016; Sinnakaruppan et al., 2005; Terrill et al., 2018), three studies had no-treatment control groups (Carnevale et al., 2006; Powell et al., 2016; Schure et al., 2006), and four studies had information only or placebo control groups (Bakas et al., 2015; Moriarty et al., 2016; Pitthayapong et al., 2017; Rivera et al., 2008). One study was found to have a mixture of an intervention group, a placebo group, and a no-treatment control group (Grant et al., 2002), while two studies had both intervention and a control group that received usual rehabilitation treatment services (Dennis, 1997; Pierce, 2009).

Among the 22 quantitative studies, four papers failed to describe their source population (Acorn, 1995; Backhaus et al., 2016; Schure et al., 2006; Sinnakaruppan et al., 2005).

5.8. Inter-rater reliability of quality ratings

A random selection of seven studies, both quantitative and qualitative, were rated by two reviewers to check the inter-rater reliability of the quality ratings. Table 5.11. illustrates how the NICE quality ratings were graded, and Table 5.12 illustrates the individual grades given for the individual items of the articles by the two raters. The intra-class correlation coefficient (ICC) was calculated using SPSS (version 22, 2013). A high degree of reliability was found between the two raters: The average measure ICC was .934 with a 95% confidence interval from 0.880 to 0.964 (F (43, 43) = 15.341, $p<0.001$) (Table 5.13). The raters agreed on most of the quality ratings and did not differ more than a single grade.

Table 5.11. The grading system for the NICE quality ratings (NICE, 2009)

Quality ratings	Grades
++	4
+	3
-	2
NR	1
NA	0

Table 5.12. Agreement between two raters for the individual items of the selected articles

	Rater 1		Rater 2	
	Quality ratings	**Grades**	**Quality ratings**	**Grades**
Article 1	++	4	++	4
	++	4	++	4
	++	4	++	4
	+	3	+	3
	+	3	+	3
Article 2	++	4	+	3
	+	3	+	3
	-	2	+	3
	+	3	+	3
	-	2	+	3
Article 3	+	3	+	3
	-	2	-	2
	+	3	+	3
	+	3	+	3
	-	2	+	3
Article 4	++	4	++	4
	-	2	-	2
	+	3	+	3
	-	2	-	2
	+	3	+	3
Article 5	+	3	+	3
	+	3	+	3
	++	4	++	4
	+	3	+	3
	+	3	++	4
	++	4	++	4
	++	4	++	4
	+	3	+	3
Article 6	++	4	++	4

	+	3	+	3
	++	4	++	4
	++	4	++	4
	+	3	+	3
	++	4	++	4
	NR	1	NR	1
	++	4	++	4
Article 7	++	4	++	4
	+	3	+	3
	++	4	++	4
	+	3	+	3
	-	2	+	3
	+	3	-	2
	NR	1	NR	1
	+	3	+	3

Table 5.13. Reliability statistics for quality rating between two raters

	Mean	**SD**
Rater 1	3.09	.83
Rater 2	3.12	.77

6. Discussion

6.1. Overview of the evidence

The review aimed to summarise the type of interventions, involving family members that have been conducted following a BI and to evaluate their methodological quality and effectiveness. Twenty nine articles were reviewed among which 13 studies used intervention to focus on improving some individual difficulty arising from the BI while involving family members in the treatment process, while ten studies focused solely on helping caregivers. However, even those ten studies might be expected to have an impact on individual difficulties experienced by the person with the brain injury. As it has been mentioned so far, throughout every chapter, that BI affects family members and their relationship with the survivors, it was essential to explore studies that focused on these aspects as well. However, only six studies were found that focused on interventions to help improve different aspects of family functioning that were affected because of the injury.

6.2. Quality of evidence and impact of interventions on caregiver outcomes

As mentioned earlier, only seven studies got a mixture of “++” and “+” study quality rating and no negative rating. However, even though these studies got moderately good ratings, it cannot be firmly stated that the studies fulfilled all the checklist criteria to state that the interventions were valid and the findings can be generalised in a specific clinical population (NICE, 2009). Thus, overall, the quality of the evidence is weak.

One of the positive findings of the review was that all the studies used relevant and reliable outcome measures. However, most of the measures were self-report measures which were subject to response bias.

The review found that, of the ten studies that focused on providing educational information about BI, there were five RCTs, four Before and After Design, and one Focus Group. Only three studies out of the ten focused solely on providing educational workshops to the participants, whereas the other studies focused on various other aspects of BI along with providing educational sessions. Moreover, only two studies showed significant impact of the interventions on the outcome measures. They were RCTs (Grant et al., 2002; Powell et al., 2016) and their outcome measures showed significant differences post-intervention. However, there were two more studies that used mixed methods (Kreutzer et al., 2010 & Rodgers et al., 2007) and their qualitative findings showed positive changes post-intervention, but their quantitative findings did not show any significant changes. The two RCTs (Grant et al., 2002; Powell et al., 2016) did not evaluate an intervention that was focused exclusively on education, and both contained other elements of intervention such as problem-focused skills training. It is therefore difficult to draw any conclusions about the effectiveness of education alone.

The five studies that focused on helping the caregivers develop different problem-focused coping skills involved two RCTs, one Non-Randomized Controlled Trial, and two Focus Groups. Among these five studies, only two studies focused solely on what the intervention intended to do, while the rest of the studies focused on different aspects as well like conducting educational workshops or working on caregiver stress. Moreover, only three studies showed significant impact of the interventions on the outcome measures. Among the two RCTs, only one study focused solely on what it intended to do (Backhaus et al., 2010). The study findings showed that the intervention had a significant impact on the participants. However, the other RCT study (Carneval et al., 2006) findings showed that the intervention had no impact on the participants. These findings make it important to understand the effect of intervention aims, and to replicate such intervention studies that focuses only on what it intends to do, to establish the efficacy and generalisability of such interventions. Moreover, the Non-Randomized Controlled Trial (Wilz, 2007) findings stated that the intervention had a significant impact on the outcome measures when assessed both post-intervention and at a six-month follow-up. Since the intervention had a lasting positive impact, it can be suggested that future research should focus on developing this intervention to assess its effectiveness and usefulness further.

The seven studies that focused on improving the emotional coping of family members included six RCTs and one Before and After Design. Four among those studies focused solely on what the intervention intended to do, while three studies also focused on training the family members in other aspects like behaviour management or communication skills training. However, only two studies out of the seven showed a significant impact on their respective outcome measures. This suggests that these interventions may be of limited effectiveness.

The seven studies that focused on family functioning involved two RCTs, three Before and After design, one Focus Group, and one Case Study. Moreover, all of the seven studies focused on what the aim of the intervention was. However, only four studies were found to make significant positive impact on family functioning. A RCT study that used both quantitative and qualitative outcome assessment to assess a couple intervention post-BI, though there were no significant quantitative changes, had qualitative evidence indicating the usefulness of the study (Terrill et al., 2018). Again, the evidence to support the effectiveness of this kind of intervention is limited. It can be recommended that more such family focused interventions should be conducted in future to assess their usefulness and effectiveness.

6.3. Directions for future research

6.3.1. Design issues

One of the most critical aspects of developing an effective intervention that can have an impact on patient and family outcomes and can be generalised in a clinical setting is to develop studies with appropriate research designs. RCT’s are considered the ‘gold standard’ since they minimise bias and therefore provide the most valid and reliable evidence of the effect of interventions (Kaptchuk, 2001). With a smaller number of good quality RCT studies, it is, therefore, important to develop more RCT’s with a stronger methodology. Future studies should also focus on using power calculations and effect sizes to detect significant differences and also use stronger control groups. There were studies found to use no treatment control group. It can be suggested that future research studies should use alternative treatment groups, for example, an intervention group along with a treatment group that receives standard rehabilitation services. Moreover, there is a need to develop longitudinal studies or studies with more extended follow-up periods to evaluate the long-term effects of interventions.

As it has been mentioned earlier, all the quantitative studies used reliable outcome measures, but more consistency is required in what outcome measures are being used. The inclusion of more objective measures and not just self-report ones is an essential factor to be considered. Moreover, the effectiveness of using a mixed methods study (both quantitative and qualitative methods) needs to be evaluated and replicated more.

6.3.2. Demographic, family and injury-related variables

An area that needs to be investigated is the impact on responsiveness to family interventions of demographic, family and injury-related variables. None of the studies considered these factors while developing or evaluating the effectiveness of the intervention. Demographic factors such as gender, age, race/ethnicity may well impact on the effectiveness of interventions. For example, we may need to develop culturally sensitive interventions rather than assume that a general intervention style will be suitable for all (Griffin et al., 2014). It is also essential to consider the kind of relationship family members shared pre-injury and how much that has been affected post-injury. A pre-and post-injury assessment of the relationship, assessment of family dynamics, and personality characteristics of the individual members need to be included. Moreover, the type, severity and symptoms of BI may also have an impact on the ability to participate, assess, and appropriately respond to interventions, and that should be taken into account in designing and evaluating interventions.

6.3.3. Intervention details

Studies need to provide details of the content of the intervention and especially the theoretical framework on which it is based. Interventions that focus on working with families along with the survivors and aim to improve their relationship need to be based on theoretical understandings of how family's function and on what happens to these relationships following a BI (Oddy & Herbert, 2003). Eight studies have explored certain theories and based the framework of their interventions on them. However, other theories like interdependence theory, developmental contextual theory, social support theory, and social control theory can also be used to design family interventions post-injury, as they provide predictions about aspects of family functioning that if changed, should improve family functioning (Berg & Upchurch, 2007; Shields, Finley, & Chawla, 2012). Also, the specific impacts of BI on family and their shared relationship (such as denial, objective and subjective burden, coping, bereavement and loss) should be considered when designing interventions. For example, in the study conducted by Straits-Troster et al. (2013), one of the participants reported having feelings of loss, and that the nature of the intervention gave her an opportunity to share the feeling which helped her in her relationship with the injured. Without such details, replication of useful studies becomes difficult.

It is also essential to know which type of intervention setting works for which situation, and future research should compare the effectiveness of interventions in different settings. Conducting therapy in a home environment is more consistent with the "person-environment fit model", that states that an individual's ability to perform successfully gets affected according to physical, social and environmental circumstances (Edwards, Cable, Williamson, Lambert, & Shipp, 2006). With all the complications a person suffers from an injury, it might be essential to keep the surrounding constant to enable better participation in therapy, primarily if it focuses on specific relationship difficulties.

Ten studies used handouts, presentations, or manuals to conduct the interventions. Due to various cognitive deficits arising from BI, it is difficult to assume that just one mode of presenting information will be adequate (Fleminger & Ponsford, 2005). For example, following a manual rigidly may not always be an appropriate approach because of its insensitivity to the specific needs of injured individuals. Some studies have recommended that information should be provided to brain injured individuals and their families through both written and verbal formats to ensure better understanding and retention (Oddy & Herbert, 2003). This suggestion needs to be properly evaluated in future research.

People who have less mobility due to physical impairments arising from BI or have difficulties with transport, usually benefit from interventions that use telecommunication (Griffin et al., 2014). Moreover, studies have often stated that given the caregiving demands and the time invested in the caregiving role, drop-outs might be lower if the delivery methods of the intervention were via telephone. The current review found six studies that used telecommunication and two study used web-based technology as a mode of delivering the intervention. Therefore, further research needs to be conducted in the development and evaluation of these electronic-based interventions because of their potential value to those who may have difficulty attending therapy in person.

6.3.4. Timing

The timing of when the interventions are conducted, specific variables like the time since injury, the time since the survivor returned home and the point the survivor has reached regarding recovery, may have a significant impact on the intervention outcome. However, only ten studies were found to have considered and mentioned this variable in developing their intervention.

Sometimes, intensive interventions during early stages of recovery may promote faster recovery and more chances of maintenance for a longer duration (Cifu, Kreutzer, Kolakowsky-Hayner, Marwitz, & Englander 2003; Wright, 2006). However, in the earlier stages, families are emotionally sensitive which may make it difficult to start a family intervention (Degeneffe, 2001). For example, it has been suggested that families sometimes are unable to grasp information about the BI in the earlier stages of recovery because of their emotional state and anxiety and that they filter out specific information that makes them vulnerable to stress (Oddy & Herbert, 2003). Family needs might also change with time, and so it is crucial to know what kind of intervention would work best at what time (White, Cantu, & Trevino, 2015). For example, it has been previously mentioned that providing a one-off educational session to families just after the injury is not sufficient, but preferably such sessions should be carefully embedded throughout the rehabilitation process to keep the family updated and provided information that they need at different stages of recovery (Oddy & Herbert, 2003).

Future research, therefore, should focus on evaluating the importance of the timing of interventions. Longitudinal comparisons between the effectiveness of interventions offered at different stages of the recovery process might prove beneficial.

6.3.5. Cost of intervention

It was also found that none of the studies mentioned or addressed the costs associated with the administration of the interventions in question. It is an important aspect to be considered while designing and implementing future interventions. Family interventions need to be cost-effective (Griffin et al., 2014; White et al., 2015). Treatment of BI involves much expenditure during hospitalisation and rehabilitation (Humphreys, Wood, Phillips, & Macey, 2013) and so interventions need to be affordable to families and the services provided them. Comparisons between the cost of the intervention and the costs involved in the absence of the intervention are also required. For example, family interventions that prevent family breakdown and the institutionalisation of people with ABI may turn out to be more economical than not providing the interventions.

6.4. Limitations of the review

As it can be seen from the findings section, a few relevant information’s was missing from some studies, and so their study quality was rated accordingly. However, since no attempt was made to contact the authors for further information, such evaluations of study quality cannot always be validated. Moreover, though inter-rater reliability was assessed to ensure appropriate study quality rating, chances of the raters being biased still remains a factor. Therefore, with all these limitations, and the evidence being poor in quality, it was difficult to draw any firm conclusion.

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CHAPTER 6

STRENGTHENING RELATIONSHIP QUALITY FOLLOWING A BRAIN INJURY: A CASE STUDY ON THERAPEUTIC INTERVENTION

1. Introduction

The review described in Chapter Five suggested that there are only a handful of studies that have worked with couples and their dyadic relationship following acquired brain injury (ABI) and that even fewer have been guided by theories about the specific impact of ABI on the relationship. Interventions need to be developed that address these particular impacts. The literature reviewed elsewhere in the thesis suggests that the perception of relationship continuity (RC) may have beneficial consequences and perceptions of relationship discontinuity (RD) may have adverse effects for those involved. For example, Riley, Evans and Oyebode (2018) reported that discontinuity was associated with higher stress and burden. This chapter describes a pilot study exploring the initial development of an intervention to promote perceptions of RC. The chapter describes therapeutic work with a couple that used Integrated Behavioural Couple Therapy (IBCT) as a general guide. The therapy addressed goals identified as necessary by the couple and by the formulation of their difficulties, alongside the goal of promoting continuity. Before and after measures were taken to evaluate whether there was an increase in perceptions of continuity and improvement in other aspects of the relationship and the stress felt by the carer.

1.1. Integrated Behavioural Couples Therapy (IBCT)

1.1.1. Principles and techniques

IBCT is an extension of traditional behavioural couple therapy, developed to increase engagement in couples' therapy and promote behaviour change and emotional acceptance (Jacobson, Christensen, Prince, Cordova, & Eldridge, 2000; Roddy, Nowlan, Doss, & Christensen, 2016).

The first step of IBCT is to use validated measures and structured/semi-structured interviews to understand the relationship and current difficulties of the client (Roddy et al., 2016). Detailed information about what kept the marriage/partnership together, helps in understanding their relationship strengths, and to make a clinical formulation. The case formulation focuses on aspects like external stressors that cause relationship difficulties, and disruptive interactional patterns that negatively affect emotional and behavioural reactions in relationships (Gurman, Lebow, & Snyder, 2015; Roddy et al., 2016).

The theory behind IBCT states that problems in relationships are caused due to challenging situations (external stressors) that trigger undesirable behaviours which, in turn, create and maintain difficulties (Christensen & Doss, 2017). Relationship issues are addressed by changing the stressors, changing the behaviours of the partners, and promoting emotional acceptance of the situation and one another (Christensen &Doss, 2017). Various treatment techniques are used. Building mutual acceptance through empathetic joining is an important technique that focuses on promoting emotional acceptance (Jacobson et al., 2000). It encourages partners to use non-blaming language when discussing conflict situations, and to refer to ‘soft’ emotions like hurt, sadness, and fear, rather than ‘hard’ emotions like anger, defensiveness, and resentment (Gurman et al., 2015). Building tolerance towards the partner’s behaviours helps the spouse to ‘let go’ and decreases their experience of negative emotions (Jacobson et al., 2000). Self-care (i.e., each partner ensures that their own needs are acknowledged and met within the relationship) is also considered an important way of building tolerance (Gurman et al., 2015; Jacobson et al., 2000). Communication and problem-solving training are also some important techniques used in IBCT, specifics of which are mentioned later while describing the intervention. Other behavioural techniques that are commonly used includes providing between-session homework, in-session tasks, and role-playing (Gurman et al., 2015).

1.1.2. The rationale for using IBCT in the intervention

Chapter Four suggested that behavioural difficulties, and the emotional reaction to them, maybe a significant contributor to relationship discontinuity (RD) following a brain injury (BI). A therapeutic approach that focuses on behaviour and the emotional reactions to behaviour, therefore, seemed appropriate. Moreover, difficulties arising from BI like communication and fatigue, and difficulties experienced by the non-injured partners like increased responsibilities and decreased social network are appropriately addressed using an approach that focuses on specific behaviours.

1.2. The impact of the intervention

The intervention was expected to have three primary outcomes:

a. An increase in carer perceptions of continuity.
b. Given the link between continuity and relationship satisfaction and the general functioning of the relationship (Chapter Three), an improvement in continuity was expected to be associated with improvement in these more general aspects of the relationship.
c. Given the link between discontinuity and caregiver stress (Chapter Two), an improvement in continuity was expected to be associated with reduced caregiver strain and stress.

2. Aim

The study aimed to explore whether it is possible to support a partner to experience greater continuity within the relationship, and what benefits such a change might have. To do so, a single case study was conducted. A couple where one partner has gone through an ABI was provided with a therapeutic intervention addressing issues within the relationship that the couple wanted to work on in the context of also trying to enhance the experience of RC. The focus was on the five components of RC, as mentioned in Chapter Three:

a. Same person: The aim was to help the spouse appreciate important aspects of the person that have remained the same despite the changes.

b. Same relationship: The aim was for them to experience their relationship as essentially continuous with the previous relationship, and experience it as a spousal relationship rather than like one between a carer and a person being cared for, or a parent-child relationship.

c. Couplehood: The aim was for them to experience their relationship as a couple working together, rather than two individuals.

d. Same feelings: The aim was for them to regain some of the feelings of love and affection that characterised their previous relationship.

e. Loss: The aim was for them not to feel a loss for the person and relationship that has gone before.

3. Methodology

3.1. Design

This is a case study that compared pre- and post-intervention assessments.

3.2. Participants

The inclusion and exclusion criteria for selecting the participants have been mentioned below.

3.2.1. Inclusion criteria

a. One of the partners should have suffered from an ABI (specifically, traumatic BI or stroke) in the last six-twelve months.

b. The person with the injury had stayed in a hospital for at least a week because of the BI and had been discharged at least three months prior.

c. They have lived as a couple for at least one year before the injury.

d. They did not have relationship difficulty before the BI (will be assessed quantitatively, using the pre-injury Relationship Assessment Measure (RAS)).

d. They were, at the time of recruitment, living together.

e. They were at least 18 years of age or more.

f. The partner of the person with the injury experienced some degree of RD (assessed by the Birmingham Relationship Continuity Measure (BRCM)).

3.2.2. Exclusion criteria

a. Cannot read or write.

b. Does not understand the English language.

c. Cannot give informed consent to participate.

d. Have been through couple/marital therapy before.

e. Either one of them has severe physical, cognitive or emotional difficulties that may restrict their participation in therapeutic sessions or that may pose a risk to the health and wellbeing of themselves, their partner, or the researcher (will be assessed both qualitatively and quantitatively using Depression Anxiety Stress Scales (DASS-21).

f. Any other concern that there can be a risk to the health or wellbeing of the participants or the researcher if a couple took part (e.g., if there are concerns regarding aggression in the person with the BI)

Opportunity sampling was used to recruit a couple from a target population of individuals receiving services from the Department of Neurosurgery, AMRI Hospital Salt Lake, Kolkata, India. Participation was voluntary, offering travel and subsistence expenses reimbursement at the end of each session. The demographic details of the couple have been provided in the results section (5.2. Phase 2. Interview).

3.3. Measures

A battery of six questionnaires was completed by the wife (who was the caregiver) (BRCM, pre-injury RAS, post-injury RAS, DAS, CSI, DASS-21) and one questionnaire was completed by the husband (the care recipient) (DASS-21). A session evaluation questionnaire (SEQ) was also used. The BRCM was used to measure if the therapy improved the caregiver's experience of RC. It was expected that improvements in continuity would lead to improvements in the relationship generally (e.g., greater sense of satisfaction), and the RAS and DAS were used to assess whether this occurred. Based on the research linking discontinuity and carer burden (Riley et al., 2018), it was expected that improvements in continuity would also lead to a reduction in the caregiver’s sense of burden and stress; and the CSI and DASS21 were used to assess this.

3.3.1. Birmingham Relationship Continuity Measure (BRCM)

The scale was administered pre-and post-intervention. Details of this scale were provided in Chapter Three.

3.3.2. Relationship Assessment Scale (RAS)

First, this scale was administered to the partner/carer from a pre-injury perspective to measure her degree of relationship satisfaction before taking the role of a caregiver. The purpose was to assess whether the couple met the inclusion/exclusion criteria (i.e., that there were no major problems with the relationship before the ABI). Next, the scale was administered to the partner/carer from a post-injury perspective to assess the same relationship aspect, pre- and post-intervention. Details of this scale were provided in Chapter Three. The post-injury RAS was selected because of the evidence, described in Chapter Three, of the association between the BRCM and the RAS.

3.3.3. Dyadic Adjustment Scale (DAS)

The scale was administered pre-and post-intervention. Details of this scale were provided in Chapter Three. It was selected because of the evidence, described in Chapter Three, of the association with the BRCM.

3.3.4. Caregiver Strain Index (CSI)

CSI is a screening instrument developed by Robinson (1983) to identify carer strain, to assess carer ability to go on caring and to identify areas where the carers might require support. It consists of 13 questions with a ‘yes’ or ‘no’ answer format, helping in identifying difficulties faced by a caregiver, where a high score indicates higher caregivers stress. The scale has good validity and good reliability of 0.86. The scale was administered pre-and post-intervention.

3.3.5. Depression Anxiety Stress Scale (DASS-21)

DASS-21 is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress, developed by Lovibond and Lovibond (1995). Each of the three DASS scales contains 14 items, divided into subscales of two-five items with similar content, which needs to be answered with a ‘yes’ or ‘no’. The Depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia (Lovibond & Lovibond, 1995). The Anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect (Lovibond & Lovibond, 1995). The Stress scale is sensitive to levels of chronic non-specific arousal. It assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient (Lovibond & Lovibond, 1995). Each scale provides a specific range of scores that can be categorised as normal, moderate, and severe. The depression scale has a reliability of 0.91, anxiety scale has a reliability of 0.81, and the stress scale has a reliability of 0.89. It was used on both the partners to assess their level of clinical depression and anxiety, to ensure whether the couple met the inclusion/exclusion criteria (the partners should not have any significant emotional difficulties), and to assess post-intervention changes as mentioned earlier.

3.3.6. Session Evaluation Questionnaire (SEQ)

The questionnaire was used at the end of the intervention to assess clients' evaluations of sessions and the impact it had on them (Osgood, Suci, & Tannenbaum, 1978). The questionnaire has three sections, but the one section with five questions that evaluated the client's feedback was used in the present study, which had greater reliability of 0.89. The answers provided by the clients were used as qualitative evidence.

3.4. Procedure

The Department of Neurosurgery, AMRI Hopsital, assessed the eligibility of the clients they had at the time based on the study's inclusion and exclusion criteria and the client's physical and cognitive status. After careful consideration, one couple was identified who was expected to be eligible for the study and might benefit from it. They were then sent a letter of invitation and a consent-to-contact form to complete if they were interested in finding out more about the study (Appendix 6a). The first couple who was contacted did not respond, and after waiting for an appropriate amount of time, the department then contacted another couple who met the eligibility criteria. The second couple responded by expressing an interest in participating, and then the researcher met them. A copy of the participant information leaflet was provided to the couple, and the study was explained to them along with the confidentiality of the study (Appendix 6b). The researcher emphasised the inclusion/exclusion criterias and asked for verbal confirmation that the couple met those criteria. The researcher gave them time to think and re-read the information sheet at home, and then contacted them after 24 hours to confirm if they still wanted to take part. The couple agreed to participate, and another meeting was arranged where further questions were answered, written consent to participate was obtained from both the participants (Appendix 6c), and all the quantitative measures (Appendix 6d) were administered. The purpose was to gather the pre-intervention measures, as well as to check their eligibility to participate. Both participants were informed of their right to withdraw at any point during the intervention if desired and the possibility to contact another clinical psychologist or their GP if they were unhappy with the sessions (Appendix 6b). Dates were then finalised to conduct the sessions weekly as per the participants' choice and comfort.

The researcher is a registered clinical psychologist in India. She had the required training to conduct the therapeutic intervention. Moreover, she also obtained weekly supervision from her supervisor at the University of Birmingham who is registered to practice as a clinical psychologist in the UK, to ensure the effectiveness of the sessions.

3.5. Ethical considerations

Ethical permission was given by the University of Birmingham School of Psychology Human Research Ethics Committee, and the AMRI Hospital's internal research committee (Appendix 6e). The study involved one to one therapeutic session about a couple's relationship. Such sessions are sensitive, and can potentially evoke anxiety and stress among partners. Other risks include the possibility of verbal or physical aggression because of the upsetting nature of the sessions. In order to minimise risks and to ensure that the research was conducted ethically, the following measures were taken:

a. Potential recruits were excluded if there were concerns that there might be a risk to the health or wellbeing of the participants or the researcher if the couple took part (e.g., because of concerns about aggression in the person with the BI).

b. The participants were provided signed consent-to-contact and consent-to-participate forms before taking part in the research. These forms had their name and their contact details so that the researcher could contact them if required throughout the intervention process. They were, therefore, stored separately from other data to protect the couple’s anonymity. The couple did not consent to audio recording the session but gave consent to take written notes to enable the researcher to produce written summaries of the content of the sessions. To minimise further risks, on the questionnaires and the session summaries, participant information like their names or any other identifying information was not recorded.

c. The sessions were always conducted in a private room within the hospital. There were other staff present at the hospital to help the researcher manage any problematic situation (if required).

3.6. Statistical analysis

The data collected from the pre- and post-intervention assessments were further analysed using the Reliability Change Index (RCI) (Jacobson & Truax, 1991; Maassen, 2004).

4. Results

The study was divided into four phases. Phase one was about conducting pre-intervention quantitative assessments. Phase two was an interview stage to gather information regarding the partners and their relationship which eventually helped in therapeutic conceptualisation. Phase three was the therapeutic intervention. Phase four consisted of the post-intervention quantitative assessment.

4.1. Phase 1. Pre-intervention assessment

A pre-intervention quantitative assessment was conducted to evaluate the couple's relationship and the need for intervention (Table 6.1). The couple were given a set of questionnaires as mentioned in the measures section. It was conducted in one separate session.

The BRCM score showed a higher perception of RD. The RAS pre-injury score suggested a relationship satisfaction, indicating that the couple fulfilled the inclusion/exclusion criteria. The RAS post-injury score suggested relationship dissatisfaction. The DAS score suggested a poorly functioning relationship and impairment in dyadic cohesion, dyadic consensus, and affectional expression. The CSI score suggested that the wife (caregiver) experienced a higher stress level. The DASS-21 scale scores suggested that neither the wife nor husband had clinical depression or anxiety. However, the stress scale suggested that the wife and husband were undergoing a moderate and mild level of stress, respectively.

Table 6.1. Pre-intervention quantitative scores

Measures	Scores (Interpretation)
BRCM	42 (Perceived relationship discontinuity)
RAS Pre-injury	31 (Relationship satisfaction)
RAS Post-injury	19 (Relationship dissatisfaction)
DAS	27 (Difficulty in dyadic adjustment)
CSI	12 (High level of stress)
Depression (Wife/caregiver)	5 (Normal)
Anxiety (Wife/caregiver)	0 (Normal)
Stress (Wife/caregiver)	21 (Moderate)
Depression (Husband/care recipient)	6 (Normal)
Anxiety (Husband/care recipient)	0 (Normal)
Stress (Husband/care recipient)	16 (Mild)

4.2. Phase 2. Interview

Semi-structured interviews were conducted to obtain an overall understanding of the participants and their relationship on both an individual level and as a married couple. It was a lengthy session which first started as two separate individual interviews and then a joint session.

4.2.1. Characteristics of the selected couple

The participants were a male who was in his early 60's and a female who was in her late 50's. Both were Indian and strictly followed Hinduism. They had been married for more than 35 years. They live as a joint family, with the husband's brother and his family. They have two sons, both of whom were married with children. The elder son lives with them while the younger son lives in a different part of the country with his family. The husband was an entrepreneur and was not working when the intervention started, while the wife was always a homemaker.

4.2.1.1. Husband

The husband had a stroke nine months before the intervention was conducted. He was at home watching TV with his family when it happened. Immediately after, he was admitted to a hospital where he had a surgery for a subdural haemorrhage during the same time. Post-surgery he was found to have speech difficulty and movement issues. There was numbness in his left arm and muscle weakness in his left leg leading to inability to walk. After the surgery, he had to remain in the hospital for approximately one month. When the intervention was conducted, he was under regular medical supervision and was undergoing rehabilitation. At the time of the intervention, his arm movement had improved a little, but he was still unable to walk. He was using a wheelchair and had been home for approximately six-months. His speech difficulty had improved a little with rehabilitation, but he still had difficulties in functional aspects of communication like showing a disinterest in initiating conversations. With further exploration, he expressed that he did not feel like talking for too long and sometimes it felt more comfortable for him to nod than to speak. He was also found to experience fatigue when the intervention started. For example, he would often say that he feels tired all the time although he acknowledges the fact that he does not do much physical activity throughout the day.

The husband owns his own business where he works with his younger brother and his elder son. As soon as he completed his bachelor's degree, he started his business and was actively involved in it before he had the stroke. However, following the stroke, he has stopped working. When the interview was conducted, he stated that he wished to return to work soon and feelt positive about it.

He was a quiet individual but was very open about his difficulties. He was optimistic and motivated to work towards his physical recovery and to get back to his earlier life as soon as possible.

4.2.1.2. Wife

The wife was a homemaker who got married early in life. She was actively involved in taking care of the household chores and raising their children. In the past, she was involved in helping her husband with the administrative aspects of his business. She felt the need to do so since her husband was getting old and since she did not have much to do at home. She decided to help him during the afternoon or evenings which would, in turn, keep her active as well.

She was a vocal person and was found to be deeply affected by the changes in their life following her husband's medical condition. She was eager to help her husband so that he could recover soon.

4.2.2. Relationship of the couple

The couple went through an arranged marriage when they were both relatively young. They had a short conversation before the wedding, and both expressed that they liked each other at that time. However, their relationship blossomed post-wedding as they started getting to know more about each other. The wife revealed that the husband was very talkative at the time and always had a beautiful smile which made her feel positive about him. The husband revealed that the wife was always a very traditional person and he liked that aspect of her.

4.2.2.1. Relationship before stroke

Both the partners talked about having a peaceful married life pre-stroke. They both stated that sometimes they used to have little arguments over certain things, but nothing was ever too big to affect their relationship.

The husband expressed that he felt proud and happy to see her get involved in the household responsibilities and in raising their sons as that helped him to have enough time to focus on his work. The wife always had a good sense of responsibility and being in a joint family it was important to be respectful towards the other family members which she always did.

The wife stated that she always loved him as he has been caring and has always been there for her whenever she needed his help. It was a little difficult for her to adjust in a joint family environment post-marriage where she had less personal space and had to share most of the things around the house, but since her husband was very understanding and supportive, she could cope with ease.

As a couple, they stated how they always enjoyed each other’s company as they had remarkably similar needs and hobbies. They both liked classical music and listened to the radio together while having breakfast. They liked watching television together after dinner or sometimes going out for movies. They were both deeply religious people and liked to visit temples often and organise religious events at their house. Having their meal together, especially dinner and Sunday lunch, is something they both enjoyed doing together.

4.2.2.2. Relationship after stroke

From both partners’ perspective, their relationship has changed post-stroke in many aspects that previously defined them as a couple. The husband talked about a few changes he had noticed in his wife, while the wife talked about many changes that have affected her individually and their overall relationship.

According to the husband, the wife had developed irritability following his stroke. She gets angry very quickly and has frequent outbursts. They also were not able to do many things they enjoyed doing in the past, like having a meal together or visiting the temple due to his physical restrictions and her time constraints.

According to the wife, she has added responsibility following the stroke that has affected her both psychologically and physically. Her routine had drastically changed and besides doing her usual household chores she now had the added responsibility of taking care of her husband's daily activities like helping him to have a shower, getting dressed, helping him with his meals, taking care of his medication and appointments, and also ensuring that he follows his rehabilitation plan correctly. She talked about having less time for herself, had noticed increased anger more than love towards her husband, showing a change in the RC component of same/different feelings. However, her anger and frustration often made her feel guilty since she felt she was not as supportive as she should be towards him since she believed it was her responsibility to take care of him at this challenging phase of his life. However, she felt the transition to her new role could have been smoother if her husband was the same as he was before the stroke. She stated that she had noticed a fundamental change in her husband's personality, showing a change in the RC component of same/different person. For example, he does not talk properly anymore and doesn't share his feelings, which makes it more difficult for her to understand his needs, which is inconsistent with his pre-morbid personality. It makes her feel that she has lost her partner, showing a change in the RC component of loss. They also don't engage in activities they used to enjoy doing together, and she has to do everything post-stroke on her own, showing a change in the RC component of couplehood. She felt the relationship had become less of a partnership, less like a spousal relationship and more like a carer relationship. It showed a change in the RC component of same/different relationship.

From the wife's perspective, there was qualitative evidence that exhibited a change in all the five components of RC. The quantitative evidence also showed a change in the relationship and increased carer strain and individual stress. The findings, thus, indicated fulfilment of the study eligibility criteria and a need for an intervention to help them re-establish the lost connection.

4.2.3. Case conceptualisation

The conceptualisation of the relationship difficulties of the couple was based on the IBCT approach (Gurman et al., 2015). The IBCT perspective for this couple was centred on external stressors, interactional problems, emotional sensitivities, acceptance and change, understanding the needs and desires each of the partners, and on flexibility and adaptability in an intimate relationship.

The husband had an ABI that functioned as an external stressor. Lack of knowledge regarding the effects was causing individual and relationship difficulties. The wife was unable to understand the causes of those difficulties, especially communication difficulties since the husband had stopped interacting with her which was not consistent with his pre-morbid personality. It made the wife attribute it to 'laziness' that led to frustration and stress. She ended up having anger outbursts often, and that, in turn, made the husband interact less, leading towards loss of communication and creating interactional problems. They also failed to understand each other's perspectives. Their negative emotions regarding the sudden change in their lives hindered emotional sensitivity towards each other. For example, they never shared how the changes post-stroke had affected them. They failed to understand each other's needs and what the other felt to be desirable/undesirable behaviours. For example, the husband did not realise that the wife’s sudden anger issues were due to the frustrations created by extra responsibilities that she needs to take care of on her own.

The sense of couplehood had disintegrated in their current relationship. They did not share their problems as they used to before the stroke, nor did they do things together that used to define them as a couple and made them happy, like praying together.

The stroke had also caused long-term physical disability and difficulties like fatigue, but the couple had not accepted those changes particularly well. For example, the husband still felt shame when going out in his wheelchair.

4.3. Phase 3. Therapeutic intervention

Once all the required information was collected, the therapeutic intervention was started. It consisted of 12 sessions, one session per week, where each session lasted for one and a half to two hours. Each session always started with a review of their current status, a summary of what was discussed during the earlier session, and what had been planned to work on in the current session. Written notes were taken during each session with the partners’ consent.

The intervention was based on the individual and relationship difficulties that were highlighted during the assessment, on the wishes of the couple, and on the aim of promoting perceptions of continuity. The goals were not exclusively focused on promoting continuity; it was considered essential that the work addressed the needs of the couple, and not just the needs of the research. Continuity was promoted in two general ways. First, when opportunities arose in the course of the therapy, the researcher explicitly highlighted similarities and continuities between the pre-stroke and current situation. For example, when discussing the effects of ABI (Goal One), it was highlighted that the changes that frustrated the wife were symptoms of the ABI, not changes to her husband’s feelings towards her.

While working on empathic understanding (Goal Two), it was highlighted that many of these behaviours were motivated by the same caring feelings that he always had towards her. Second, the aim of promoting continuity also influenced the choice of specific therapeutic goals within the broader goals that had been identified. For example, within the general goal of promoting desirable interactive behaviours (Goal Five), behaviours were chosen that characterised their interactions before the stroke in order to emphasise the continuity between their pre-stroke and current life. Similarly, for Goal Three (improving communication), efforts were made to re-establish the communication patterns that were the same as those in their life before the stroke.

Goal 1. To increase their understanding of the effects of an acquired brain injury

An educational session was first provided to give the couple an overview of the emotional, cognitive and behavioural changes that follow after an ABI, and how spousal relationships can be affected by those changes. At the end of the session, a handout was provided for them to refer back to their convenience (Appendix 6f).

Having an educational session was important for two reasons. Firstly, studies state that BI survivors lack an awareness of the nature and effects of impairments they have sustained, and knowledge about it helps them to understand their current self, better, leading towards a higher degree of positive rehabilitation outcome (Fleming & Ownsworth, 2006; Prigatano & Klonoff, 1998). Educating the family about the consequences of a BI also helps in decreasing their stress level (Khan, Baguley, & Cameron, 2003).

Secondly, from the interview session, it was clear that the husband had specific difficulties, like communication and fatigue, which was a significant concern for the wife and it affected their relationship due to lack of awareness of it being an effect of BI.

Below is a quote based on the written notes that were made by the researcher during their sessions. The sessions were not audio-recorded, and so the written notes do not provide a verbatim account of what was said, but they capture the essence of what was said.

> He has become so dependent on me. He thinks that I will do everything for him. However, how can I do things if he does not tell what he needs? Even though I ask him often, he does not respond. It is frustrating. Of course, he can talk, but he chose not to nowadays. I do not understand why he does not reply and sometimes he will make gestures assuming I will understand. He has become so lazy that he nods instead of saying a proper yes or a no. (Wife)

Similarly, in terms of fatigue, it was discussed how it is a common effect of BI, and even primary activities of daily living can be exhausting for the person, affecting their mood, ability to return to work, and decreasing quality of their intimate relationships (Malley, Wheatcroft, & Gracey, 2014). At a later stage, strategies were discussed to help them effectively deal with it.

The communication issue may have contributed to the sense of discontinuity in relation to perceiving the husband as a different person. The wife felt it was very unlike her husband to be so uncommunicative, and also unlike him that it seemed like he did not care/couldn’t be bothered to talk back to her. Similarly, the fatigue may have contributed because the wife attributed it to laziness which was, again, very unlike his pre-injury personality. The session may have promoted a sense of continuity by giving the wife an understanding of these issues regarding the BI; the behaviours could be seen as symptoms of the BI rather than a fundamental change in his identity as a person (*same person*).

Goal 2. Empathic understanding

Related to the aim of improving their understanding of the symptoms of the BI, another goal focused on increasing their empathic understanding of each other’s situation. The wife was encouraged in the sessions to talk about how she felt about the experience.

Opening up using soft emotions like sadness instead of hard emotions like anger made the discussion easier and helped the husband to understand her struggles as well (Gurman et al., 2015). Using soft emotions in future daily interactions was also encouraged. They were encouraged, especially the wife, not to assume their partner's feelings and behaviour, but to encourage her husband to express his feelings and emotions, and then to discuss it in a supportive way. They were encouraged to express their emotions and thoughts in a way that could help the other partner understand if they are hurt or sad, instead of showing it through anger.

> It makes me sad seeing him like this… I am scared about what will we do if he does not recover. (Wife)

Similarly, when the husband was asked to share his thoughts, he opened up about feeling responsible and guilty since his wife has added responsibilities after his stroke.

> I feel that I have brought this hard time on my family and my wife. She has all these responsibilities now, and I am unable to help her even if I want to do so… She has become this angry person she was not before. (Husband)

Having a heart-to-heart discussion of their experiences was useful for empathetic joining (Gurman et al., 2015; Jacobson et al., 2000). The revelation made by the husband regarding his guilt and concern made the wife realise that the husband still thinks about her and cares for her as he used to before the BI.

Empathic understanding may help promote continuity. Sharing emotions may have helped the couple appreciate that they were in the experience together (*couplehood*). Empathy for the other's situation may also promote feelings of closeness (*same feelings*). Understanding the positive and caring feelings behind some of her husband's behaviours and feelings may have helped the wife see him more in the context of the loving person she knew him to be before the BI (*same person*).

Goal 3. To improve communication

The importance of developing better communication strategies was evident. There was a repetitive dysfunctional cycle of communication that led the wife to interact with the husband anxiously, and that led the husband to move further away from the wife by shutting down to avoid such dysfunctional interaction. The couple were aided with communication strategies like actively listening while the other partner in speaking, increasing patience, paraphrasing, and reinforcing positive communication (Gurman et al., 2015). They were also encouraged to re-enact specific difficult interactions during the session. They were encouraged to discuss issues by first focusing on one problem at a time, defining and acknowledging the problem, brainstorming solutions about it, and then trying to use the most promising solution (Gurman et al., 2015; Jacobson et al., 2000).

Before the stroke, the couple used to have a regular conversation especially during or after dinner, but the pattern changed following the stroke. They were, therefore, given the task to start discussing their everyday life after dinner. The aim was to restore a previous pattern of communication to help them feel connected again with their life before the BI (*same relationship*). In the beginning, it was difficult for the couple to practise this as often the husband did not communicate well, and that made the wife angry. However, the emphasis was placed on the effectiveness of using better communication strategies repeatedly during sessions, and role-play was conducted where the couple discussed current issues. Eventually, towards the end of the intervention, it was noticed that the husband had started communicating more often and took the initiative during sessions to discuss things without being asked to do so. There was a change in the wife's communication pattern. For example, she started giving the husband enough time to respond back when they had a conversation, and she listened patiently when the husband had to talk about something instead of interrupting him.

The communication issue may have contributed to the sense of discontinuity. The wife felt it was very unlike her husband to be so uncommunicative, and also unlike him that it seemed like he did not care/couldn't be bothered to talk back to her (*different person*). Because they were not talking, this may have undermined the sense of being a partnership, working together to deal with the problems caused by the stroke (*couplehood*). Instead, the wife felt as if it was all down to her to deal with everything. The feeling that he had withdrawn may also have undermined the bonds of affection and closeness (*different feelings*). Along with the after-dinner conversations, working on improving their communication may have enhanced the sense of continuity.

> Yes, he has started talking comparatively more than he used to before we started the sessions… At least now I do not have to ask him something several times to get a nod. He now responds to my question like a normal human being! (Wife)

> I have seen a lot of changes in her after we started this therapy. She was so aggressive in the beginning, but now she reacts normally to conversations like she used to. It seems like she does not feel much stressed as she was experiencing and that makes me happy to see her happy! (Husband)

Goal 4. Reducing dependence and increasing activity levels

The aim was to develop the husband's ability to participate in daily activities effectively and thereby become less dependent on his wife. Much of this work focused on helping them develop more effective ways of managing the fatigue that was a significant reason for his reduced activity.

Actively participating in minimal work like bathing and getting changed often feels like hard work for people post-stroke, causing tiredness, exhaustion, and lack of energy (Annoni, Staub, Bogousslavsky, & Brioschi, 2008; Flinn & Stube, 2010). It happened to the husband as well, and some strategies were incorporated to decrease it. A graded approach was taken to set daily goals. They were asked to set everyday tasks for him that he felt he could manage, and once he has achieved it and felt confident about it, to set a slightly more difficult goal; rather than starting out with a challenging goal that might feel too difficult so that he felt unable to tackle it. The wife was asked not to be forceful in trying to get him to do things. They were asked to provide him with rest in between tasks, and he was encouraged to take a nap in the daytime/afternoon if he needed to.

Towards the end of the intervention, the husband started actively participating in daily activities like taking phone calls, pouring his water, and folding his laundry. Over the course of the therapy, the husband's tiredness reduced. He started feeling more involved. The change helped the husband to participate in activities, thus increasing his independence and quality of life. It is possible that seeing her husband more active and engaged may have helped the wife see him as close to his old self (*same person*). The reduced dependency on herself may also have helped her feel that the relationship was more similar to what it had been before the stroke (*same relationship*). Co-operating on daily tasks may also have fostered a sense of togetherness (*couplehood*).

Goal 5. To develop effective problem-solving strategies

After the assessment session, it was clear that they had difficulties in effectively handling demanding situations as a couple, and that these situations often created conflict between them. To address this, the IBCT technique of problem-solving training was used (Gurman et al., 2015).

They were trained in specific problem-solving strategies that they could use in any daily life situations. The emphasis was on discussing current difficulties and finding solutions during the sessions, and also doing it on their own time at home and then discussing the results at sessions. The steps were to start by defining the issues or difficulties, acknowledging them, brainstorming ideas, evaluating the pros and cons of the workable solutions, negotiation and mutual agreement on one solution, implementing it and assessing if it made any positive and productive change (Gurman et al., 2015; Jacobson et al., 2000).

The intervention may have enhanced the wife's sense of continuity by helping her feel that they were still a couple who work together to solve problems as they used to pre-stroke (*couplehood* and *same relationship*).

Goal 6. To promote desirable relationship-focused behaviours

One aspect of IBCT involves the couple identifying behaviours towards one another which are perceived as positive and desirable by the other partner, so that the frequency of such behaviours can be increased. These behaviours were, in turn, hypothesised to improve the positive feelings the couple had for each other.

For example, before the stroke, whenever one partner was busy with work, the other partner took the initiative to get some household work done. It always made them feel loved and cared for. However, since the injury, the husband was unable to help, and it was the wife who always did everything. Therapy involved encouraging them to identify housework that the husband could manage within his physical limitations, like folding the laundry while still sitting on the couch. The wife found this helpful and felt she was still being cared for by her husband.

The intervention may have helped the wife to perceive continuity by providing evidence that her husband's positive feelings towards her (like love and care), which was a big part of their relationship, were still there (*same relationship*). Perceiving these feelings again in him may have helped her to reciprocate those feelings (*same feelings*). These behaviours may also have strengthened the feeling of working together again (*couplehood*) and helped her feel that their current life together was closer to what their pre-injury life was like (*same relationship*).

> I now feel closer to him and feel more love for him than ever. My feelings for him, of course, have not changed which is why I still keep trying every day to help him out and it is the same for him. (Wife)

Goal 7. To increase his engagement in valued roles and activities

Work was an essential part of the husband's life before the stroke, and he expressed a desire to return to it. However, he had taken no steps towards this goal. It became clear that one of the major obstacles to this was the embarrassment he felt about being seen in a wheelchair. Addressing this embarrassment was an important step in working towards helping him return to his workplace.

The husband's feelings about people he met in his rehabilitation centre who were using wheelchairs were discussed. He said that he thought they were 'ok' using a wheelchair and seeing them sometimes made him feel that some people are more disabled than he is.

> They seem to be ok with it. Most of them have an advanced one where they can move on their own and do not need someone else's help. However, some can't even move their hands or cannot control thing. It makes me think that there are people who are more disabled than I am. (Husband)

His feelings were further discussed with the perspective that if people with severe disability can go on with their lives without feeling ashamed, there is no shame for him to do the same. A research article was shared with him where it says that due to different disabilities, more than 67 million people in the world use a wheelchair (World Health Organization, 2011). Moreover, it was discussed how a wheelchair could help him get back into his work which he wanted, and that it would make him more independent.

He was encouraged to start by just going out for a few minutes in his wheelchair in the immediate neighbourhood. A graded approach was used whereby he started by going out to a nearby place he wanted for a short period, and then gradually increasing the distance and time.

After his confidence about using the wheelchair improved, he started going out to the park with his wife. He also used it in the house more to get some work done on his own without his wife's assistance. Using the graded approach, he also eventually started spending some time at work. He started going to work in the afternoon or sometimes in the evening for two-three hours, and was involved in checking the financial aspects of his business.

The return to work, as well as helping the husband feel of more value again, may also have helped continuity in the relationship. Seeing him engaged again in a role that was such an essential part of his life before the stroke, may have helped the wife see that he was not so radically different and changed (*same person*).

Goal 8. To re-establish valued shared activities

The couple were encouraged to think about things they did together before the stroke which created happiness and defined them as married partners. They were then encouraged to start doing all the things that mattered to them as partners, and what is still doable within the physical and cognitive limitations of the husband, using a graded approach. They were also asked to note difficulties they might perceive during the process which were then discussed during the sessions to help them develop practical solutions.

For example, the wife enjoys fast food, and the husband used to surprise her often with food that they used to enjoy together. It was an aspect that had changed following the stroke. Initially, they felt that this was something that could not be done anymore. However, when encouraged to think about possible options, they decided that the wife could now instead get the fast food so that they still can enjoy it together. They were encouraged to realise that, even if the surprise element is missing, they can still enjoy the experience together. Towards the end of the intervention, they were doing more such things together such as once again listening to the radio on weekend mornings, having evening tea together, spending time with other family members, and watching a show they both loved in the evening. Also, they organised a small prayer at their house to help the family deal with the current situation in a better way.

These activities may have helped them appreciate the strength and positive qualities they still had in their relationship, things that still worked well between them, things they still liked about each other, and things they still enjoyed together. They may have reduced the wife's perception of discontinuity by rekindling the positive feelings she had towards her husband (*same feelings*), enhancing the sense of togetherness (*couplehood*), reducing the feelings of difference about his identity when she sees him doing these old familiar activities together (*same person*), and making it feel like a more normal relationship between spouses (*same relationship*).

The intervention also focused on other therapeutic goals, besides the ones mentioned so far. The researcher worked on helping the couple come to terms with the likelihood that there would be some permanent physical disability, in promoting the wife’s self-care strategies, and in increasing their tolerance of annoying behaviours. However, those intervention specifics have not been described in detail in this chapter because they did not have any direct bearing on the promotion of continuity.

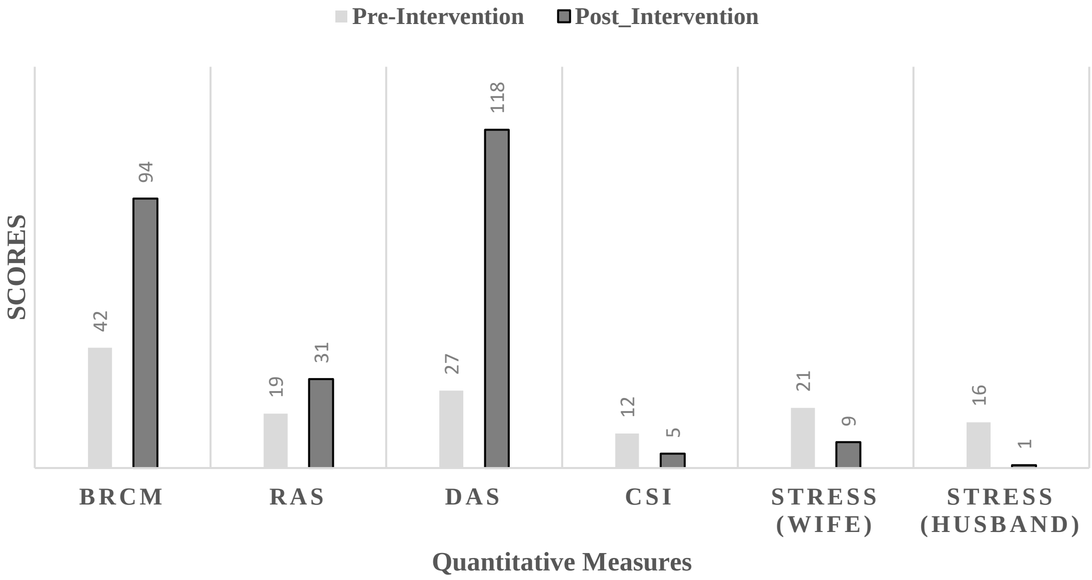
4.4. Phase 4. Post-therapy assessment

A post-intervention quantitative assessment was conducted in a different session at the end of the intervention (Table 6.2). The couple were given the same set of questionnaires as they were provided with before the intervention started. It was done in a separate session, and it helped to quantify if there were any changes in their relationship following the therapeutic intervention. Interpreting the raw scores showed that there was a change in the perceived RC, relationship satisfaction, caregiver strain, and both the partners' stress level (Figure 6.1).

Table 6.2. Comparison of pre- and post-intervention quantitative measure

Measures	Pre-Intervention Scores (Interpretation)	Post-Intervention Scores (Interpretation)
BRCM	42 (Perceived relationship discontinuity)	94 (Perceived relationship continuity)
RAS Post-injury	19 (Relationship dissatisfaction)	31 (Relationship satisfaction)
DAS	27 (Difficulties in dyadic adjustment)	118 (Improved dyadic adjustment)
CSI	12 (High level of stress)	5 (Low level of stress)
Depression (Wife/caregiver)	5 (Normal)	2 (Normal)
Anxiety (Wife/caregiver)	0 (Normal)	0 (Normal)
Stress (Wife/caregiver)	21 (Moderate)	9 (Normal
Depression (Husband/care recipient)	6 (Normal)	6 (Normal)
Anxiety (Husband/care recipient)	0 (Normal)	0 (Normal)
Stress (Husband/care recipient)	16 (Mild)	1 (Normal)

Figure 6.1. Pre- and post-intervention quantitative measures assessing the impact of the intervention on the relationship and individual stress



As mentioned earlier, the data collected from the pre- and post-intervention assessments were further analysed using the RCI. This index is commonly used in clinical research to assess whether pre-test post-test change in individual scores are reliable or not (Jacobson & Truax, 1991; Maassen, 2004). The concept was first introduced by Jacobson and Truax (1991) but has been criticised and have evolved over the years (Maassen, 2004; Temkin, 2004). The index is calculated by subtracting the pre-test and post-test scores and dividing it by the standard error of the scale (Jacobson & Truax, 1991). The debate on conceptualising the appropriate way to calculate the standard error has led towards several different formulas. In the present study, both the classical formula and the most recent formula that has been published with statistical evidence have been followed (Jacobson & Truax, 1991; Maassen, 2004). Both ways yielded similar results (Table 6.3). The RCI should be 1.96 or more (equating to the 95% confidence interval); in other words, the difference between the pre-test and post-test scores should be more than 1.96 times the standard error of the scale to establish a significant change (Heaton et al., 2001; Jacobson & Truax, 1991; Parsons, Notebaert, Shields, & Guskiewicz, 2009).

Table 6.3 shows the actual difference in pre- and post-intervention scores, with regards to their standard error, along with the difference required to conclude that is a reliable difference. The scores obtained in the study from the BRCM, RAS, DAS, CSI, and Stress scale fulfilled the criteria for a reliable change. The depression and anxiety scores from the DASS-21 were not assessed. The husband obtained low scores on the depression and anxiety subscales pre-intervention, and these scores showed no change post-intervention (Table 6.1 & 6.2). The wife similarly scored zero on anxiety both pre and post-intervention. There was a change of score in depression subscale for the wife, but since both the pre- and post-intervention scores were under the normal range, the RCI was not calculated (Table 6.1 & 6.2). The stress scores, on the other hand, were assessed for both the partners as both had a moderate/mild level of stress in the pre-intervention phase (Table 6.1 & 6.2). The RCI showed a decrease in stress for both the wife and the husband providing evidence that the intervention had a significant effect on reducing their stress level (Table 6.3). However, for the husband, the significant change was shown only by the Jacobson way, and not when calculated using the Maassen (2004) way.

Table 6.3. Reliable difference between pre- and post-intervention scores based on Reliability Change Index (RCI)

Measures	**Actual difference (Required difference) (Jacobson & Truax, 1991)**	**Actual difference (Required difference) (Maassen, 2004)**
BRCM	11.399 (8.942)	14.428 (7.064)
RAS	34.384 (0.684)	22.222 (1.058)
DAS	17.491 (11.094)	21.864 (8.875)
CSI	16.820 (2.564)	11.236 (3.838)
Stress (Wife/caregiver)	5.213 (4.512)	3.930 (5.986)
Stress (Husband/care recipient)	6.516 (4.512)	4.912 (5.986)

4.4.1. Qualitative feedback

Findings from the quantitative measures were supported by qualitative comments made by the couple in the SEQ that indicated less stress, more continuity in the relationship and a better relationship generally.

> Last week we had a religious festival, and so we decided to organise a small prayer session at our house. We hoped to pray that this positive change we are experiencing after the stroke and all the difficulties lasts forever and God bestows his blessings on our family… **We felt like a family again.** We both organised the prayer session on our own just like we used to do earlier. **I think it helped us re-connect again as a married couple.** (Wife)

Below are quotes based on the written feedback provided by the wife on SEQ.

> We progressed from feeling anxious to being excited to come to the sessions. Every time we came with so many things. We always wanted to share and change. Moreover, especially when he started going back to work and when we organised the prayer at home, we felt it was an

> achievement and motivation to come back for the sessions. **The best part is how the sessions helped us to do things together and share our responsibilities as much as we can.** It gave us the strength to **share our emotions with each other** that we had not done in months. It helped us feel connected again. It **changed the present us and our relationship to what it was before the stroke to some extent**. (Wife)

> Honestly, there are still daily life things that are stressful as they were even before the stroke. However, we now realise that that basic level of stress is inevitable in anyone's life. However, we were experiencing unwanted stress due to the changes we have experienced since the stroke, and that has reduced after completing the session. Instead, we feel we are a little more confident now than stressed to handle our present situation. (Wife)

5. Discussion

The study aimed to explore the possibility that perceptions of RC can be improved by therapy, and that improving these might have a beneficial impact on the stress felt by the carer, their satisfaction with the relationship and overall levels of conflict and closeness within the relationship. The outcomes were consistent with these possibilities. RC was improved after the therapy, as were the measures of stress and other aspects of the relationship. The stress felt by the person with the BI also showed some evidence of improvement. Overall, the study suggests that developing interventions to enhance continuity within a relationship merits further investigation.

5.1. Limitations of the study

Because of the study design issues, it is not possible to conclude that the improvements that occurred were due to the intervention. Also, one cannot conclude that the enhancement of the wife's experience of continuity contributed to the general improvements in their relationship or their emotional responses to the situation. For example, the change in individual stress and caregiver strain could have been due to other reasons like their participation in rehabilitation or just an effect of being a part of a therapeutic process. Further development and evaluation of efforts to enhance continuity within relationships after BI will require stronger experimental designs.

Another challenge for future development and research on this issue is to develop and evaluate an intervention that is specifically focused on promoting RC. The intervention in this study involved many components, some of which were not directly relevant to continuity. Even for those components that were directly relevant, it was not easy to distinguish them from components that might be included in many kinds of couple intervention that are not focused on promoting continuity. The two distinctive ways of promoting continuity were to explicitly highlight to the couple similarities and continuity when the opportunity arose, and, in the behaviourally-focused goals, to select specific behaviours that replicated patterns of life before the ABI. These may provide the basis for developing a more distinct continuity-focused therapy in the future.

There were also limitations on how generalizable the findings of the present study were. One of the exclusion criteria was that the husband should not have severe cognitive and emotional impairment. The findings, therefore, cannot be generalised to a wider population where couples would have different profiles and level of impairments. Moreover, the study was conducted in India, and its applicability across cultures is unknown at this stage.

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CHAPTER 7

STUDY IMPLICATIONS AND FUTURE DIRECTIONS

1. Introduction

The thesis aimed to explore the impact of a brain injury (BI) on spousal relationships, with a specific focus was on the concept of relationship continuity (RC), its assessment, predictors of RC, and its treatment. A systematic review was also conducted to have an overview of the existing literature on family/couples intervention following a BI. The findings and implications of the empirical studies and the systematic review have been summarised in this chapter, followed by a few points on future research.

2. Summary of the studies

2.1. Study one

The first empirical study was based on developing and establishing the psychometric properties of The Birmingham Relationship Continuity Scale (BRCM) (Chapter Three). The BRCM is a validated and reliable measure in assessing RC from a carer's perspective in dementia. It has also been used as a measure in dementia studies. The present study evaluated a modified version of the measure for use in ABI and found promising results. It showed a high internal consistency (alpha= 0.956), and good test re-test reliability of 0.960 with 50 participants, and 0.961 with 76 participants. Ferguson's δ was 0.964 with 50 participants, and 0.990 with 76 participants, showing good discriminative power. Strong correlations were found between BRCM other scales measuring certain similar aspects, thus establishing the strong concurrent validity of the scale. Exploratory factor analysis showed the scale to be unidimensional.

2.2. Study two

The second empirical study focused on exploring factors that predicted relationship discontinuity (RD) post-BI (Chapter Four). A battery of six informant-based questionnaires measuring various impairments post-BI and the BRCM was administered to a group of 53 carers, who were husbands/wives of someone with a BI from various BI rehabilitation centres and carer groups across the UK. Correlational analysis revealed that absence of emotional warmth, communication difficulties and aggressive behaviours had a significant relationship with RD, and regression analysis showed that aggressive behaviours and communication difficulties significantly predicted RD (although emotional warmth could not be entered into the analysis for statistical reasons). Other BI impairments like activities of daily living and cognitive, emotional, and somatic difficulties were found to share some relationship with RD but did not contribute as a significant predictor of RD. However, physical difficulties were found to share no relationship with RC post-injury.

2.3. Systematic review

BI can cause a significant change in family relationships and the well-being of those involved. Engaging the family in intervention can also help maximise the recovery of the patient. Therefore, a systematic review was conducted to explore the types of interventions that involved family members (Chapter Five). The aim was to summarise the types of interventions used and their methodological quality and effectiveness. Using six databases, articles written in English between the years 1984- February 2018 were searched. The articles were heterogeneous in relation to their study designs, patient and family characteristics, sample size, intervention setting, duration, content, mode of delivery, outcome measures, and data analysis. Only a few studies were found to have obtained statistically significant changes in all the outcome measures, and a handful of studies obtained good quality ratings. There was also a lack of studies that focused on improving family or couple relationships.

2.4. Case study

Following the findings of the systematic review and the need to develop more couple interventions post-BI, a case study was carried out. It aimed to explore whether it was possible to support a partner to experience greater continuity within the relationship following a BI, and what benefits such a change might have (Chapter Six). Integrated Behavioural Couple Therapy techniques were used to address relationship issues for one couple, where the partner had a stroke. Pre- and post-therapy quantitative assessments were conducted to assess if there were significant, reliable changes in the partner's perception of relationship continuity, caregiver strain, relationship satisfaction, and the couples’ level of stress.

Both qualitative and quantitative evidence shows positive changes in the wife’s perception of RC, in the couple’s relationship, and the stress experienced by the wife. However, the case study design prevents any firm conclusions about the impact of the therapy. It was a pilot study to establish whether it may be worth putting more effort into researching interventions that focus on the experience of continuity, both regarding whether this can be enhanced and what impact this might have on other outcomes. The study has provided rich, valuable information and a rationale for conducting further research. The results were consistent with the idea that interventions can enhance the experience of continuity, and that such enhancement may lead to more general benefits for the caregiver and the care recipient.

3. Research and clinical implications

3.1. Study one

Marital dissatisfaction and breakdown post-BI are common and, therefore, it is vital to assess spousal relationships post-BI to understand which aspects of the relationship changes, how the change happens, and the impact it has on both the BI survivor/ care recipient and the partner/caregiver. To be able to quantify RC using the BRCM will, therefore, help in quantitative assessments of concepts and ideas derived in this area from qualitative studies. It will help to understand how partners perceive their caring role and the general quality of the care they are providing to their partners with acquired brain injury (ABI). It will also help in understanding the impact of relationship continuity/discontinuity on partners and in the development of intervention strategies.

The BRCM can be used for research purposes. However, based on the limitations of the study (Chapter Three), there is a need to evaluate the scale further using a larger sample size, across different cultures, ethnicity, and religion. Further research is also required to be able to effectively use it in a clinical/rehabilitation setting, so that couples who are in need of interventions will be identified at an early stage and, therefore, will be helpful to prevent relationship breakdown.

3.2. Study two

An understanding of the factors that predict RD has practical implications for services to support spousal caregivers individually and as a couple to maintain a sense of continuity by forming specific intervention strategies that focus on providing support in dealing with the specific factors that contribute towards perception of RD.

The study had its limitations, and so to have an in-depth understanding of this area, more studies need to be conducted. Specific impairments need to be measured distinctly to evaluate its impact on RD, and impairments that were not covered in the present study need to be explored. Other potential predictors of relationship continuity/discontinuity need to be explored, for example, as the quality of the pre-injury relationship and demographic variables such as culture and ethnicity.

3.3. Systematic review

The review helped in understanding the areas that have been focused on so far and gave an overview of what needs to be done next. The findings provide an understanding of the kind of research that is needed to provide more precise answers about what can be done to support families.

Based on the review findings, some significant points on developing future research have already been discussed in Chapter Five. In summary, more research on improving family functioning and relationships, with a focus on couple relationships, is required. Future research also needs to evaluate interventions that have been developed on strong theoretical foundations, both regarding how family’s function generally and how functioning can be improved, and regarding the specific impact that ABI may have on family functioning. Studies should also be designed using randomised control trials to establish the validity and generalisability of the findings.

3.4. Case study

The study suggested the value of further research on enhancing perceptions of continuity in the relationship after BI, and provided some ideas about what kind of intervention strategies are required to be developed. Further work is needed to develop a better understanding of how perceptions of continuity can be changed, and therefore how these strategies might be improved and what other strategies could be used. A series of further case studies would be an appropriate way forward.

Following this, a feasibility study could be undertaken to gather information about various parameters prior to carrying out a randomized controlled trial to evaluate the effectiveness of the developed intervention. Information that would need to be gathered in a feasibility study includes feedback from both the BI survivors and their family members about how acceptable and useful they found the intervention, and how willing they might be to take part in an evaluation. This would provide information about likely recruitment and drop-out rates in an RCT, which has a bearing on likely recruitment rate and the sample size required to account for possible drop-outs.

The series of case studies and additional pilot studies could also be used to gather other important information prior to planning a RCT. One important issue is the number of sessions that is required to bring a meaningful change in the outcome measures. Information is also needed about other factors that may impact on the effectiveness of the intervention. For example, the timing of delivery may be important; offering the intervention too soon or too late after the injury may not be beneficial. It could also be assessed if it is possible to conduct such intervention in a group setting to cut down costs and make it more accessible in every clinical/rehabilitation setting.

APPENDICES

Appendix 3a

Focus Group Script and Questions

INTRODUCTION

Who am I?

I am a Clinical Psychologist in Training at the University of Birmingham and with the Birmingham and Solihull Mental Health Foundation NHS trust. As part of my doctorate research, I am looking at the experiences of carers of those with a brain injury, and this focus group is part of an introductory piece of work I am completing before I begin interviewing people about their experiences. After the new year, I will start telling people about that bit of work if they want to take part or find out more.

What is the purpose of the study?

We want to investigate whether a questionnaire called the Birmingham Relationship Continuity Measure, which was developed for use in dementia, can be used in traumatic brain injury as well. In this stage of the study, we want to ask some spouses/partners of people with a traumatic brain injury what they think of the questionnaire. We will then revise the questionnaire in response to the feedback we get. In a later stage of the study, we will ask people to complete the questionnaire, along with some other questionnaires, to see how useful it is as a measure of what happens to relationships after a brain injury. Once we have revised the questionnaire and evaluated its effectiveness, we hope we will have a questionnaire that can be used to investigate more effectively what happens to relationships after a traumatic brain injury.

What will I have to do?

You will be shown the Birmingham Relationship Continuity Measure and asked for your opinion about it. This should take no more than 60 minutes of your time. You will not be asked to fill in the questionnaire. If you think something is not clear or isn't relevant to carers of those with a brain injury, I may ask you to say a bit more about why it does not seem relevant or isn't clear.

Do I have to take part?

No, there is no obligation on you to take part. You can leave this group or not answer the questions at any time.

Are there any risks to taking part?

The information you give will be anonymous.

The questionnaires do ask personal and sensitive questions about relationships after brain injury. You will not have to answer these questions, but if you think that you may find reading them too upsetting, please do not take part.

What will happen to the information I provide?

The information will be used to decide whether the questionnaire needs revising or rewording before it is assessed in a later stage of the study.

There are two versions of the Birmingham Relationship Continuity Measure, one for use when the person with the brain injury is male, and one for use when the person with the brain injury is female. Only the male version is shown here. The female version is identical but uses 'she' instead of 'he'.

Instructions

Show the group the instructions

This questionnaire is about your husband (partner) and your relationship with him since the brain injury. Please do not answer the questions with reference to how husband (partner) or your relationship was before the injury.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example).

If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

Ask

Do you feel these instructions are clear? Yes / No

If you answered ‘No’, please explain your answer

Items

Next, you will see all the items from the questionnaire. These are grouped according to what they are supposed to be measuring. An explanation will be given of what each set of questions is supposed to be measuring. Please give your opinion about each item. If you say ‘no’ to any of the questions, I will ask you a bit more about that.

Feels like the same/different kind of relationship

The first set of items is meant to measure whether, since the injury, the relationship no longer feels like a husband/wife/partner relationship, but feels like a different sort of relationship (discontinuity) or still feels basically like the same kind of relationship (continuity),

9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

6	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

16	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the relationship feels different/ basically the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

Spouse/partner feels like a different/the same person

This set of items is meant to measure whether the person feels that, since the injury, the spouse/partner feels like they have changed in some fundamental way (discontinuity) or is essentially the same person despite the changes (continuity).

7	He’s a shadow of his former self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered ‘No’ to any of these questions, please explain your answer

10	Despite all the changes, he's still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No
- If you answered 'No' to any of these questions, please explain your answer

13	Sometimes I feel it's like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

17	Compared to how he used to be, he's a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No

- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

20	I don’t feel I really know him anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

22	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the spouse/partner feels like a different/ the same person? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

<u>Feelings for the person are the same/very different</u>

This set of items is meant to measure whether, since the injury, the feelings that the person has for their spouse/partner have changed in some fundamental way (discontinuity) or are essentially the same (continuity).

19	It's like there's a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

4	I care for him, but I don't love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

8	I don't feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

11	The bond between us isn't what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No

- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

14	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether the feelings the person has for their spouse/partner have changed in some fundamental way, or are essentially the same? Yes/No

- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

Whether it feels like a partnership or not

This set of items is meant to measure whether, since the injury, the relationship no longer feels like a partnership (discontinuity) or still feels like a partnership (continuity).

15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No

- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

23	It doesn't feel like a partnership any more	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

1	He's in a world of his own most of the time.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether, since the injury, the relationship no longer feels like a partnership or still feels like a partnership?? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered 'No' to any of these questions, please explain your answer

<u>Whether the person feels a sense of loss for what has changed</u>

This set of items is meant to measure whether or not the person feels a sense of loss for how things used to be in the relationship.

3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No
- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

18	I feel like I’ve lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

- Is this statement clearly worded? Yes/No

- Do you think this is a good way of asking about whether or not the person feels a sense of loss for how things used to be in the relationship? Yes/No
- From your experience, can you imagine some partners of people with a brain injury may strongly agree with the statement, but others will strongly disagree? Yes/No

If you answered ‘No’ to any of these questions, please explain your answer

Thank you for your participation. Your assistance will be invaluable in developing this questionnaire. We hope that having the questionnaire will enable researchers to study more effectively what happens to relationships after traumatic brain injury.

Appendix 3b

Invitation to participate

Are you a partner/spouse of someone who has had a brain injury (e.g. traumatic brain injury, stroke, brain tumour) in the last ten years?

Are you currently living together?

Would you be interested in taking part in some research being carried out at the University of Birmingham?

We are developing a questionnaire about the spouse's/partner's experience of what happens to their relationship after an acquired brain injury. The questionnaire was originally developed for use in dementia, and we want to adapt it for use in acquired brain injury.

Participation in the research should take no more than 15 minutes of your time. You will be asked to complete three questionnaires. **Please note that the questionnaires do ask sensitive and personal questions about your experience of your relationship with your partner/spouse. If you think you will find this too upsetting, please do not take part.**

This research is being conducted by Natasha Yasmin and Dr Gerard Riley at the University of Birmingham. If you have further questions about the research or are interested in taking part you can either contact Natasha at: [redacted] or call at [redacted], or contact Dr Gerard at [redacted]

Appendix 3c

Participant Information Leaflet

Evaluating the Birmingham Relationship Continuity Measure for use in acquired brain injury.

Before you decide whether you want to take part, please read the following information about the study.

What is the purpose of the study?

We want to investigate whether a questionnaire called the Birmingham Relationship Continuity Measure, which was developed for use in dementia, can be used in acquired brain injury as well. In a previous stage of the study, we adapted the questionnaire in response to feedback from other partners of people with a brain injury. In this stage, we want to investigate how well this revised version acts as a questionnaire in acquired brain injury. We will do this by asking some people like yourself to complete the questionnaire, along with two other questionnaires that overlap with some parts of the Birmingham Relationship Continuity Measure. We will then use statistical analysis to see whether the different items in the questionnaire are indeed assessing what they are meant to assess. We hope that the questionnaire can then be used to study more effectively what happens to relationships after a brain injury.

Am I eligible to take part?

To take part, you need to be able to answer ‘yes’ to the following questions:

- Are you a husband, wife or partner of someone who suffered a brain injury (e.g. traumatic brain injury, stroke, brain tumour) in the last ten years?
- Did the brain injury happen at least nine months ago?
- Did your husband, wife or partner have to stay in the hospital for at least a week because of the brain injury?
- Did you live with your husband, wife or partner for at least one year before their injury?
- Is your husband, wife or partner currently living with you?
- Are you at least 18 years of age?

If you answered ‘no’ to any of these questions, then please do not take part in the study. Also, if you provided care to your husband, wife or partner even before their injury because they were disabled or in need of care and support for other reasons, then please do not take part in the study.

What will I have to do?

You will be asked to complete three questionnaires. This should take no more than 15 minutes of your time.

Do I have to take part?

No, there is no obligation on you to take part. If you do not want to take part, simply do not respond to the invitation letter. The researchers will make no attempt to contact you if you do not respond to the invitation letter. Deciding not to take part will not affect the services you receive from Headway.

You should be aware that, once you have sent us a completed questionnaire, you cannot request that your data are removed from the study. This is because we will have no way of knowing which questionnaire you sent us.

Are there any risks to taking part?

The questionnaires do ask personal and sensitive questions about your relationship with your partner/spouse. If you think you may find this too upsetting, please do not take part.

What will happen to the information I provide?

The information you give will be anonymous. You will not be asked to give your name or any other personal information that might allow you to be identified. If you decide to supply the researchers with your contact details so that an information pack can be sent to you (see below), please be assured that any record of these details will be destroyed as soon as the pack has been sent to you. No record of your name or contact details will be kept.

Completed questionnaires will be treated confidentially and kept securely. They will be stored on password-protected University computers or in a locked office at the University. Only the two researchers and research auditors appointed by the University will have access to the data.

What if I want to complain?

If you are unhappy about the way this research is being conducted, then please contact Professor Kimron Shapiro, Head of Psychology at the University of Birmingham. He can be contacted on: [redacted], or at [redacted]

I want to know more before I decide to take part. What should I do?

Please e-mail one of the two researchers with your question: Either Natasha Yasmin at [redacted] or Gerry Riley at [redacted]

I would like to take part. What should I do next?

There are two ways you can take part:

- You can let a member of Headway staff know, and they will give you a paper copy of the questionnaire pack. The pack contains further instructions about what you should do.
- You can request a pack directly from the researchers by emailing them (addresses given above) or by phoning Gerry Riley on [redacted]. If you request a pack directly from the researchers, you will need to give us a postal or email address that we can send it to. Please be assured that, once we have send out the pack to you, we will immediately destroy any record we have of your address and any correspondence you have with us.

Support

The Headway service you attend can offer support if completion of the questionnaire is unsettling for you, or if you are generally struggling to cope with what has happened. Please speak to a member of staff about this. Alternatively, you may wish to contact one of the following organisations:

1. Headway: website: www.headway.org.uk email: helpline@headway.org.uk telephone: 08088002244.
2. Carers UK: website: www.carersuk.org email: advice@careruk.org telephone: 08088087777.
3. Carers trust: website: www.carers.org email: info@carers.org telephone: 08448004361.
4. Your own GP.

Appendix 3d

Consent Form

Spousal relationships after brain injury

Participant identification number:

Researcher: Natasha Yasmin, PhD Student, University of Birmingham.

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of researcher	Date	Signature

If you would like to receive a summary of the findings from the research, then please provide your postal or e-mail address below.

You **DO NOT** have to give these details if you do not wish to.

Please note it may take up to 18 months before feedback is available and any feedback provided will be about the overall results and not specific to your individual questionnaires.

Address (for receiving summary of findings):

____

Appendix 3e

<u>Questionnaire pack</u>

<u>Please answer the following questions before proceeding. You will not be able to proceed until you answer these questions.</u>

	Yes	**No**
Have you read and understood the information provided on the previous page about this study?		
Do you give permission for the information you provide to be used for this study described on the previous page?		
Are you a husband, wife or partner of someone who suffered a traumatic brain injury in the last ten years?		
Did your husband, wife or partner have to stay in the hospital for at least a week because of the brain injury?		
Did you live with your husband, wife or partner for at least one year before their injury?		
Are you still living with your husband, wife or partner?		
Are you at least 18 years of age?		
Are you able to fill in questionnaires written in English?		
Before the injury, was your husband, wife or partner free from any disability or other condition that required you to provide care and support?		

If you answered **'no'** to any of these questions, please do not proceed any further. You are not eligible to take part. Thank you for your time

If you answered **'yes'** to all these questions and want to participate, please proceed to the next part.

The following questions are about both you and your partner. If you would prefer not to answer these questions, please go straight to the next page.

<u>The person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Employment status before the brain injury:

Current employment status:

Diagnosis (the type of injury):

How long since the brain injury?

<u>Partner of the person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Current employment status:

<u>Your relationship</u>

What relation are you to the person with a traumatic brain injury?

How long have you been together?

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your wife (partner) and in your relationship with her, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

1	She' is more interested in herself now than she is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for her, but I don't love her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like her carer now, not her husband (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, her personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	I don't feel about her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, she’s still her old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn’t what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it’s like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from her.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how she used to be, she’s a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I’ve lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It’s like there’s a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don’t feel I really know her anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	She still has many of the same qualities that first attracted me to her	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn’t feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your husband (partner) and in your relationship with him, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

1	He is more interested in himself now than he is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for him, but I don’t love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, his personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

8	I don’t feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, he’s still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn’t what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it’s like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how he used to be, he’s a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I’ve lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It’s like there’s a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don’t feel I really know him anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn’t feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Note: Schofield Closeness and Conflict Scale and Marwit-Meuser Caregiver Grief Inventory were not included in the Appendices due to copyright issues.

Support Sheet

Thank you for completing the questionnaires. Your assistance will be invaluable in developing this questionnaire. We hope that having the questionnaire will enable researchers to study more effectively what happens to relationships after an acquired brain injury.

Support

If you have been upset by completing these questionnaires, or if you are generally struggling to cope with what has happened, the Headway service you attend can offer support. Please speak to a member of staff about this. Alternatively, you may wish to contact one of the following organisations:

1. Headway: website: **www.headway.org.uk** email: **helpline@headway.org.uk** telephone: 0808 800 2244.
2. Carers UK: website: **www.carersuk.org** email: **advice@careruk.org** telephone: 0808 808 7777.
3. Carers trust: website: **www.carers.org** email: **info@carers.org** telephone: 0844 800 4361.
4. Your own GP.

Appendix 3f

Ethical approval

Appendix 4a

Invitation to participate

Are you a partner/spouse of someone who has had a brain injury (e.g. traumatic brain injury, stroke, brain tumour) in the last ten years?

Are you currently living together?

Would you be interested in taking part in a research project about spousal relationships following brain injury carried out at the University of Birmingham?

What is it about?

We are researching how caring for a partner with brain injury affects the spousal relationship. Brain injury can cause various physical, behavioural, cognitive, and social difficulties, and our research aims to find out which factors help in maintaining a strong marital relationship even after severe brain injury to help in increasing the quality of life of the carers and the quality of marital relationship post-injury.

What will you have to do?

Participation in the research involves completing a package of questionnaires that should take around **60 minutes of your time**. You will be asked to complete a set of questionnaires send through the post. You will also be provided with **£10 Amazon voucher** as a token of gratitude.

I am interested, what should I do next?

Natasha Yasmin is conducting this research **at the University of Birmingham**. If you have further questions about the research or are interested in taking part, you can either contact **Natasha at** [redacted] **or call at** [redacted]

Appendix 4b

Participant Information Leaflet

Spousal relationships after brain injury

Before you decide whether you want to take part, please read the following information about the study.

What is the purpose of the study?

We are researching how caring for a partner with brain injury affects the spousal relationship. Brain injury can cause various physical, behavioural, cognitive, and social difficulties, and our research aims to find out which factors help in maintaining a strong marital relationship even after severe brain injury to help in increasing the quality of life of the carers and the quality of marital relationship post-injury. We will do this by asking some people like you to complete a set of questionnaires.

Am I eligible to take part?

To take part, you need to be able to answer ‘yes’ to the following questions:

- Are you a husband, wife or partner of someone who suffered a brain injury (e.g. traumatic brain injury, stroke, brain tumour) in the last ten years?
- Did the brain injury happen at least nine months ago?
- Did your husband, wife or partner have to stay in the hospital for at least a week because of the brain injury?
- Did you live with your husband, wife or partner for at least one year before their injury?
- Are you currently living with the person who had the brain injury?
- Are you at least 18 years of age?

If you answered ‘**no**’ to any of these questions, then please do not take part in the study. Also, if you provided care to your husband, wife or partner even before their injury because they were disabled or in need of care and support for other reasons, then please do not take part in the study.

What will I have to do?

You will be asked to complete a set of few questionnaires. This should take no more than 90 minutes of your time.

Do I have to take part?

No, there is no obligation on you to take part. If you decide to take part, you will be asked to complete a consent form and a set of few questionnaires taking about 90 minutes. If you need any help completing the questionnaires, the researcher (Natasha Yasmin) will be available to assist you to complete the questionnaires in a private area, or contact her at [redacted]

However, if you do not want to take part, simply do not respond to the invitation letter. The researchers will make no attempt to contact you if you do not respond to the invitation letter. However, if you decide to withdraw after completing the questionnaires, you can still inform us, and your data will be destroyed. Deciding not to take part will not affect the services you receive from Headway.

Are there risks to taking part?

The questionnaires do ask personal and sensitive questions about your relationship with your partner/spouse. If you think you may find this too upsetting, please do not take part.

What will happen to the information I provide?

You will be asked to sign a consent form and, if you want to receive a summary of the findings of the research, you will be asked to provide contact details on the consent form. However, no other record of your name or contact details will be kept. Your name and contact details will not be written on the questionnaires. A code will be written on your consent form and on the questionnaires to enable me to destroy your records if you wish to withdraw from the study. Moreover, the consent form and the questionnaires will be kept in separate locked cabinets at the University of Birmingham. Following the University's protocol, they will be retained for 10 years and then securely shredded.

Scores from the questionnaires will be kept on a computer file on a password-protected computer system. This file will not contain your name or any other information that would allow you to be identified. The only people allowed to access the data will be myself, my research supervisor and anyone authorised by the University to conduct an audit of research.

What if I want to complain?

If you are unhappy about the way this research is being conducted, then please contact Professor Kim Shapiro, Head of Psychology at the University of Birmingham. He can be contacted on: [redacted] or at [redacted]

I want to know more before I decide to take part. What should I do?

Please e-mail one of the two researchers with your question: Either Natasha Yasmin at [redacted] or Gerry Riley at [redacted]

I would like to take part. What should I do next?

There are two ways you can take part:

- You can let a member of Headway staff know. Depending on what you prefer, they will give you a paper copy of the questionnaire pack, or they will email it to you. The pack contains further instructions about what you should do.
- You can request a pack directly from the researchers by emailing them (addresses given above) or by phoning Gerry Riley on [redacted]. Again, you have the choice of receiving a paper or an emailed pack. If you request a pack directly from the researchers, you will need to give us a postal or email address that we can send it to. Please be assured that, once we have sent out the pack to you, we will immediately destroy any record we have of your address and any correspondence you have with us.

Support

The Headway service you attend can offer support if completion of the questionnaire is unsettling for you, or if you are generally struggling to cope with what has happened. Please speak to a member of staff about this. Alternatively, you may wish to contact one of the following organisations:

1. Headway: website: www.headway.org.uk email: helpline@headway.org.uk telephone: 08088002244.
2. Carers UK: website: www.carersuk.org email: advice@careruk.org telephone: 08088087777.
3. Carers trust: website: www.carers.org email: info@carers.org telephone: 08448004361.
4. Your own GP.

Appendix 4c

Consent Form

Spousal relationships after brain injury

Participant Identification No.

Researcher: Natasha Yasmin, PhD Student, University of Birmingham.

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of researcher	Date	Signature

If you would like to receive a summary of the findings from the research, then please provide your postal or e-mail address below.

You **do not** have to give these details if you don’t wish to.

Please note it may take up to 18 months before feedback is available and any feedback provided will be about the overall results and not specific to your individual questionnaires.

Address (for receiving summary of findings):

____

Appendix 4d

Questionnaire pack

Please answer the following questions before proceeding. You will not be able to proceed until you answer these questions.

	Yes	No
Have you read and understood the information provided on the previous page about this study?		
Do you give permission for the information you provide to be used for this study described on the previous page?		
Are you a husband, wife or partner of someone who suffered a traumatic brain injury in the last ten years?		
Did your husband, wife or partner have to stay in the hospital for at least a week because of the brain injury?		
Did you live with your husband, wife or partner for at least one year before their injury?		
Are you still living with your husband, wife or partner?		
Are you at least 18 years of age?		
Are you able to fill in questionnaires written in English?		
Before the injury, was your husband, wife or partner free from any disability or other condition that required you to provide care and support?		

If you answered **‘no’** to any of these questions, please do not proceed any further. You are not eligible to take part. Thank you for your time

If you answered **‘yes’** to all these questions and want to participate, please proceed to the next part.

The following questions are about both you and your partner. If you would prefer not to answer these questions, please go straight to the next page.

<u>The person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Employment status before the brain injury:

Current employment status:

Diagnosis (the type of injury):

How long since the brain injury?

<u>Partner of the person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Current employment status:

<u>Your relationship</u>

What relation are you to the person with a traumatic brain injury?

How long have you been together?

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your wife (partner) and in your relationship with her since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

1	She’ is more interested in herself now than she is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for her, but I don’t love her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like her carer now, not her husband (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, her personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	I don’t feel about her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, she's still her old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn't what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it's like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from her.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how she used to be, she's a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I've lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It's like there's a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don't feel I really know her anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	She still has many of the same qualities that first attracted me to her	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn't feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your husband (partner) and in your relationship with him, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

1	He is more interested in himself now than he is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for him, but I don’t love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, his personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

8	I don’t feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, he’s still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn’t what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it’s like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how he used to be, he’s a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I’ve lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It’s like there’s a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don’t feel I really know him anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn’t feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Relationship Assessment Scale (Pre-Injury)

Please think about your relationship with your husband, wife or partner **before the brain injury.** Please mark on the answer sheet the letter for each item which best answers that item for you.

	Poor **1**	**2**	**Average** **3**	**4**	**Excellent** **5**
1. How well did your partner meet your needs?	**1**	**2**	**3**	**4**	**5**
2. In general, how satisfied were you with your relationship?	1	2	3	4	5
3. How good was your relationship compared to most?	**1**	**2**	**3**	**4**	**5**
4. How often did you wish you hadn't gotten into the relationship?	1	2	3	4	5
5. To what extent did your relationship meet your original expectations?	**1**	**2**	**3**	**4**	**5**
6. How much did you love your partner?	1	2	3	4	5
7. How many problems were there in your relationship?	**1**	**2**	**3**	**4**	**5**

Relationship Assessment Scale (Post-Injury)

Please think about your **current relationship** with your husband, wife or partner. Please mark on the answer sheet the letter for each item which best answers that item for you.

	Poor **1**	**2**	**Average** **3**	**4**	**Excellent** **5**
1. How well did your partner meet your needs?	**1**	**2**	**3**	**4**	**5**
2. In general, how satisfied were you with your relationship?	1	2	3	4	5
3. How good was your relationship compared to most?	**1**	**2**	**3**	**4**	**5**
4. How often did you wish you hadn't gotten into the relationship?	1	2	3	4	5
5. To what extent did your relationship meet your original expectations?	**1**	**2**	**3**	**4**	**5**
6. How much did you love your partner?	1	2	3	4	5
7. How many problems were there in your relationship?	**1**	**2**	**3**	**4**	**5**

Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate by putting a tick below in the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always agree	**Almost always agree**	**Occasionally disagree**	**Frequently disagree**	**Almost always disagreed**	**Always disagree**
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstrations of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behavior)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals, and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure time interests and activities						
15. Career decisions						

	All the time	**Most of the time**	**More often than not**	**Occasionally**	**Rarely**	**Never**
16. How often do you discuss, or have you considered divorce, separation, or terminating your relationship?						
17. How often do you or your mate leave the house after a fight?						
18. In general how often do you think that things between you and your partner are going well?						
19. Do you confide in your mate?						
20. Do you ever regret that you got married (or lived together)?						
21. How often do you and your partner quarrel?						
22. How often do you and your mate "get on each others nerves"?						

	Everyday	**Almost everyday**	**Occasionally**	**Rarely**	**Never**
23. Do you kiss your mate?					

	All of the them	**Most of them**	**Some of them**	**Very few of them**	**None of them**
24. Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**
25. Have a stimulating exchange of ideas						
26. Laugh together						
27. Calmly discuss something						
28. Work together on a project						

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Tick or no)

	Yes	**No**
29. Being too tired for sex		
30. Not showing love		

31. The circles on the following line represent different degrees of happiness in your relationship. The middle point, “happy,” represents the degree of happiness of most relationships. Please fill in the circle which best describes the degree of happiness, all things considered, of your relationship.

O	**O**	**O**	**O**	**O**	**O**	**O**____
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Which of the following statements best describes how you feel about the future of your relationship?

O I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.

O I want very much for my relationship to succeed, and *will do all I can* to see that it does.

O I want very much for my relationship to succeed, and *will do my fair share* to see that it does.

O It would be nice if my relationship succeeded, but *I can't do much more than I am doing now* to help it succeed.

O It would be nice if it succeeded, but I *refuse to do any more than I am doing now* to keep the relationship going.

O My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

Intimate Bond Measure

This questionnaire lists some attitudes and behaviors which people reveal in their close relationships. Please judge your partner's attitudes and behavior towards you in recent times and tick the most appropriate bracket for each item.

		Very true	**Moderately true**	**Somewhat true**	**Not at all**
1.	**Is very considerate of me**				
2.	Is a good companion				
3.	**Is affectionate to me**				
4.	Confides closely to me				
5.	**Understands my problems and worries**				
6.	Is physically gentle and considerate				
7.	**Makes me feel needed**				
8.	Is very loving to me				
9.	**Is fun to be with**				
10	Show his/her appreciation of me				
11.	**Is gentle and kind to me**				
12.	Speaks to me in a warm and friendly voice				

Activities of Daily Living Questionnaire

Instructions: Circle one number for each item.

1. **Self-care**
   - **A. Eating**

     0 = No problem

     1 = Independent, but slow or some spills

     2 = Needs help to cut or pour; spills often

     3 = Must be fed most foods

     9 = Don’t know

   - **B. Dressing**

     0 = No problem

     1 = Independent, but slow or clumsy

     2 = Wrong sequence, forgets items

     3 = Needs help with dressing

     9 = Don’t know

   - **C. Bathing**

     0 = No problem

     1 = Bathes self, but needs to be reminded

     2 = Bathes self with assistance

     3 = Must be bathed by others

     9 = Don’t know

   - **D. Elimination**

     0 = Goes to the bathroom independently

     1 = Goes to the bathroom when reminded; some accidents

     2 = Needs assistance for elimination

     3 = Has no control over either bowel or bladder

     9 = Don’t know

   - **E. Taking pills or medicine**

     0 = Remembers without help

     1 = Remembers if dose is kept in a special place

2 = Needs spoken or written reminders

3 = Must be given medicine by others

9 = Does not take regular pills or medicine OR Don’t know

F. Interest in personal appearance

0 = Same as always

1 = Interested if going out, but not at home

2 = Allows self to be groomed, or does so on request only

3 = Resists efforts of caretaker to clean and groom

9 = Don’t know

2. Household care

A. Preparing meals, cooking

0 = Plans and prepares meals without difficulty

1 = Some cooking, but less than usual, or less variety

2 = Gets food only if it has already been prepared

3 = Does nothing to prepare meals

9 = Never did this activity OR Don’t know

B. Setting the table

0 = No problem

1 = Independent, but slow or clumsy

2 = Forgets items or puts them in the wrong place

3 = No longer does this activity

9 = Never did this activity OR Don’t know

C. Housekeeping

0 = Keeps house as usual

1 = Does at least half of his/her job

2 = Occasional dusting or small jobs

3 = No longer keeps house

9 = Never did this activity OR Don’t know

D. Home maintenance

0 = Does all tasks usual for him/her

1 = Does at least half of usual tasks

2 = Occasionally rakes or some other minor job

3 = No longer does any maintenance

9 = Never did this activity OR Don’t know

E. Home repairs

0 = Does all the usual repairs

1 = Does at least half of usual repairs

2 = Occasionally does minor repairs

3 = No longer does any repairs

9 = Never did this activity OR Don’t know

F. Laundry

0 = Does laundry as usual (same schedule, routine)

1 = Does laundry less frequently

2 = Does laundry only if reminded; leaves out detergent, steps

3 = No longer does laundry

9 = Never did this activity OR Don’t know

3. Employment and recreation

A. Employment

0 = Continues to work as usual

1 = Some mild problems with routine responsibilities

2 = Works at an easier job or part-time; threatened with loss of job

3 = No longer works

9 = Never worked OR retired before illness OR Don’t know

B. Recreation

0 = Same as usual

1 = Engages in recreational activities less frequently

2 = Has lost some skills necessary for recreational activities (e.g., bridge, golfing); needs coaxing to participate

3 = No longer pursues recreational activities

9 = Never engaged in recreational activities OR Don’t know

C. Organisations

0 = Attends meetings, takes responsibilities as usual

1 = Attends less frequently

2 = Attends occasionally; has no major responsibilities

3 = No longer attends

9 = Never participated in organizations OR Don’t know

D. Travel

0 = Same as usual

1 = Gets out if someone else drives

2 = Gets out in wheelchair

3 = Home- or hospital-bound

9 = Don’t know

4. **Shopping and money**

A. Food shopping

0 = No problem

1 = Forgets items or buys unnecessary items

2 = Needs to be accompanied while shopping

3 = No longer does the shopping

9 = Never had responsibility in this activity OR Don’t know

B. Handling cash

0 = No problem

1 = Has difficulty paying proper amount, counting

2 = Loses or misplaces money

3 = No longer handles money

9 = Never had responsibility for this activity OR Don’t know

C. Managing finances

0 = No problem paying bills, banking

1 = Pays bills late; some trouble writing checks

2 = Forgets to pay bills; has trouble balancing check book; needs help from others

3 = No longer manages finances

9 = Never had responsibility in this activity OR Don’t know

5. Travel

A. Public transportation

0 = Uses public transportation as usual

1 = Uses public transportation less frequently

2 = Has gotten lost using public transportation

3 = No longer uses public transportation

9 = Never used public transportation regularly OR Don’t know

B. Driving

0 = Drives as usual

1 = Drives more cautiously

2 = Drives less carefully; has gotten lost while driving

3 = No longer drives

9 = Never drove OR Don’t know

C. Mobility around the neighbourhood

0 = Same as usual

1 = Goes out less frequently

2 = Has gotten lost in the immediate neighbourhood

3 = No longer goes out unaccompanied

9 = This activity has been restricted in the past OR Don’t know

D. Travel outside familiar environment

0 = Same as usual

1 = Occasionally gets disoriented in strange surroundings

2 = Gets very disoriented but is able to manage if accompanied

3 = No longer able to travel

9 = Never did this activity OR Don’t know

6. Communication

A. Using the telephone

0 = Same as usual

1 = Calls a few familiar numbers

2 = Will only answer telephone (won’t make calls)

3 = Does not use the telephone at all

9 = Never had a telephone OR Don’t know

B. Talking

0 = Same as usual

1 = Less talkative; has trouble thinking of words or names

2 = Makes occasional errors in speech

3 = Speech is almost unintelligible

9 = Don’t know

C. Understanding

0 = Understands everything that is said as usual

1 = Asks for repetition

2 = Has trouble understanding conversations or specific words occasionally

3 = Does not understand what people are saying most of the time

9 = Don’t know

D. Reading

0 = Same as usual

1 = Reads less frequently

2 = Has trouble understanding or remembering what he/she has read

3 = Has given up reading

9 = Never read much OR Don’t know

E. Writing

0 = Same as usual

1 = Writes less often; makes occasional spelling errors

2 = Signs name but no other writing

3 = Never writes

9 = Never wrote much OR Don’t know

Note: LaTrobe Communication Questionnaire and Neurobehavioral Functioning Inventory were not included in the Appendices due to copyright issues.

Support Sheet

Thank you for completing the questionnaires. Your assistance will be invaluable in developing this questionnaire. We hope that having the questionnaire will enable researchers to study more effectively what happens to relationships after an acquired brain injury.

Support

If you have been upset by completing these questionnaires, or if you are generally struggling to cope with what has happened, the Headway service you attend can offer support. Please speak to a member of staff about this. Alternatively, you may wish to contact one of the following organisations:

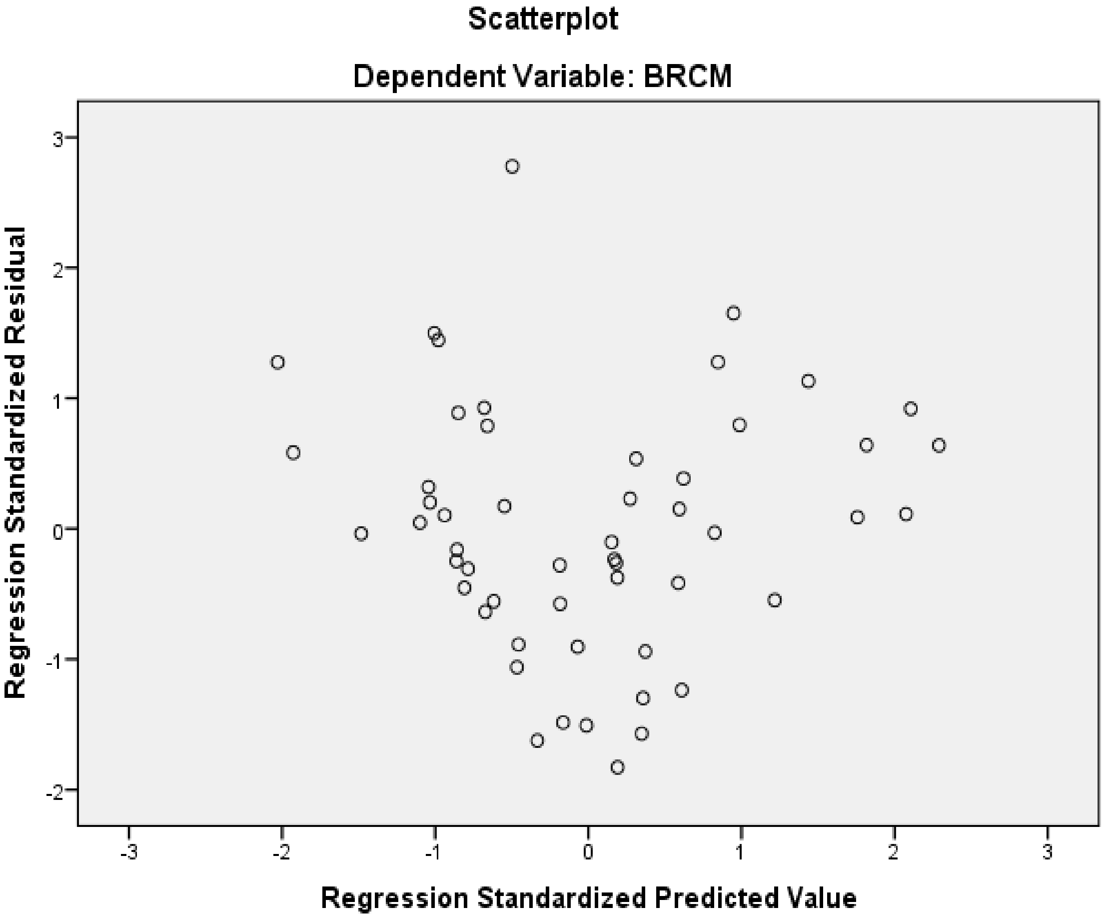
5. Headway: website: **www.headway.org.uk** email: **helpline@headway.org.uk** telephone: 0808 800 2244.
6. Carers UK: website: **www.carersuk.org** email: **advice@careruk.org** telephone: 0808 808 7777.
7. Carers trust: website: **www.carers.org** email: **info@carers.org** telephone: 0844 800 4361.
8. Your own GP.

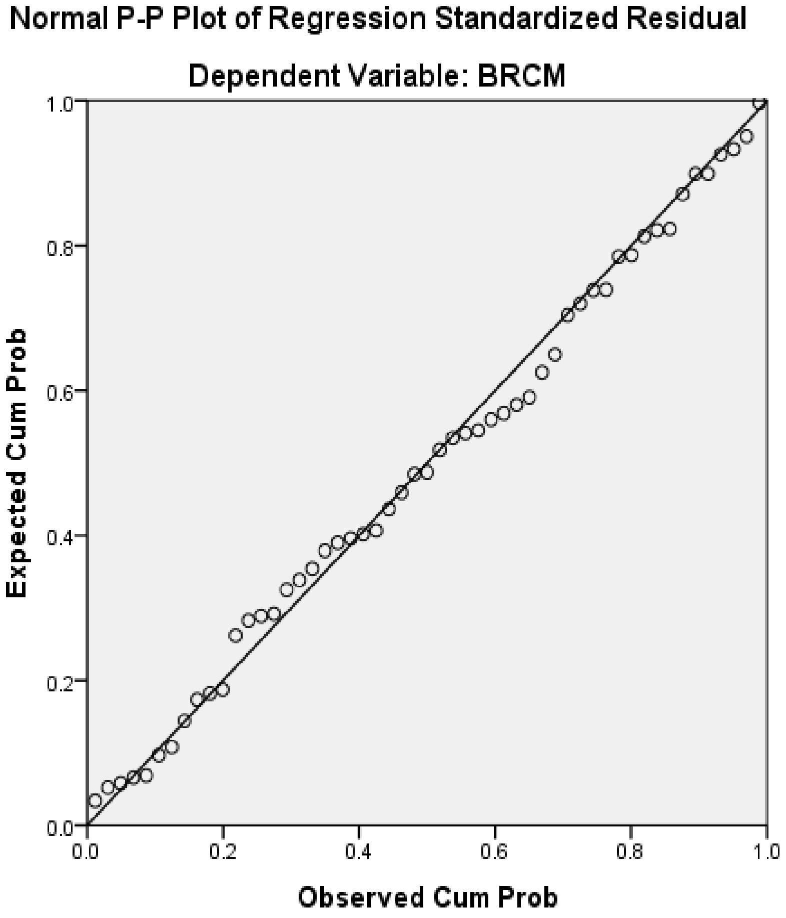
Appendix 4e

Ethical approval

Appendix 4f

Residuals scatterplot and the normal probability plot for regression standardised residual




Normal P-P Plot of Regression Standardized Residual
Dependent Variable: BRCM
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0
0.0
0.2
0.4
0.6
0.8
1.0

Appendix 6a

Invitation letter

Are you a partner/spouse of someone who has had a traumatic brain injury or stroke in the last 6-12 months?

Are you currently living together and having relationship difficulties?

Would you be interested in taking part in research being carried out by the University of Birmingham (UK)

After a traumatic brain injury or stroke couple often face relationship difficulties. We are conducting research exploring ways of helping couples with relationship difficulties, to improve the quality of their relationship.

Participating in this research will involve:

- Completing a set of questionnaires
- 8-10 sessions of couple therapy in which you and your partner will be given the opportunity to talk about your relationship and how you can improve it. Each session will last about an hour.

Your participation and personal information will be treated with the utmost confidentiality. The questionnaires and sessions will involve sensitive and personal questions about your experience of your relationship with your partner/spouse. **If you think you will find this too upsetting, please do not take part**.

If you are interested, kindly complete the consent-to-contact form provided to you along with this letter and return it to any staff member at the AMRI Hospital.

Consent to Contact Form

Supporting couples to help maintain their marital relationship after brain injury.

Researcher/Clinical Psychologist: Natasha Yasmin, University of Birmingham, UK.

I confirm that my partner and I have read the invitation letter to participate in the research. We are happy to be contacted by the researcher/clinical psychologist to arrange a meeting to discuss this further.

Contact details

Name:

Email address:

Phone number:

___________________	___________________	___________________
Name of the husband	Date	Signature
___________________	___________________	___________________
Name of the wife	Date	Signature

Appendix 6b

Participant Information Leaflet

Supporting couples to help maintain their marital relationship after brain injury

This research is being carried out by the University of Birmingham, UK

Before you decide whether you want to take part, **PLEASE READ** the following information about the study.

What is the purpose of the study?

Brain injury puts a strain on marriages. Previous research has suggested that the strain is worse when it feels that the person with the brain injury has become a different person, and the relationship has become a different relationship. This research is a PhD student project about exploring ways of helping couples reconnect with their life before the injury so that the changes do not seem so radical. It is hoped that this will improve the quality of the relationship.

Am I eligible to take part?

To take part, you need to be able to answer '**YES**' to the following questions:

- Did the traumatic brain injury or stroke happen 6-12 months ago?
- Did the person with the injury have to stay in the hospital for at least a week because of the brain injury?
- Were they discharged at least three months ago?
- Did you live together for at least one year before the injury?
- Are you currently living together?
- Are you both at least 18 years of age?
- Has the brain injury put a strain on your relationship?

If you answered '**NO**' to any of these questions, then please do not take part in the study. Also, if do not speak or read English, if either of you has a major health problem other than the brain injury, or if you have been through a couple/marital therapy before, then please do not take part in the study.

Moreover, specific questionnaires will be administered once you agree to participate in the initial stage. If the questionnaire responses state that you are not eligible for the intervention, we will, unfortunately, be unable to proceed further in the study.

What will I have to do?

If you are interested in the study, kindly sign in the consent-to-participate form and return it to AMRI Hospitals. You will then be contacted by the principal researcher to arrange a meeting where specific questionnaire will be administered to assess further eligibility. As mentioned above, if you do not qualify the assessment, unfortunately, you will not be able to participate further in the study.

If you are eligible to participate, you will be asked to participate in approximately ten therapy sessions along with your partner. Each session will last for 1-2 hours and will be conducted by the main researcher who is registered to practice in India as a clinical psychologist. The sessions will be confidential and will focus on exploring ways of improving your relationship. In the first session and at the last session you will also be asked to fill in a few questionnaires about your relationship and about how you found the sessions. This is so that the researchers can assess whether the therapy was effective.

Do I have to take part?

No, there is no obligation on you to take part. The staff from the Department of Neurosciences has assessed your situation and felt that this therapeutic intervention might be beneficial for you both. However, if you do not want to take part, just tell the researcher when she contacts you again. She will not ask you for your reasons, and she will make no further attempts to contact you if you are not interested. Deciding not to take part will not affect the services you receive from AMRI Hospitals.

You should be aware that, once you have started participating in the study if at any point you are not happy to proceed further, you can always opt to discontinue without any explanation. Moreover, once the sessions are over, the principal researcher will contact you a week later to ensure if you will still be ok for her to use your data and if you don’t agree she will not use the information provided by you throughout the sessions, for research purposes. You will not be asked to give a reason for your withdrawal. All your completed questionnaires and any recordings or notes made about the therapy sessions will then be destroyed.

Are there any risks to taking part?

The therapy sessions and questionnaires will involve personal and sensitive discussions about your relationship with your partner/spouse. If you think you may find this too upsetting, or you are not ready to share, then please do not take part. The researcher is a registered clinical psychologist, and so she has the expertise and experience to deal with and manage stressful clinical situations. She will also receive supervision from the clinical psychologist at the Institute of Neurosciences, and from the lead researcher who is registered to practice as a clinical psychologist in the UK.

To compensate you for any costs you incur through taking part, at the end of each session you will be reimbursed for your travel expenses and will receive the cost of a standard meal for two.

What will happen to the information I provide?

The information you provide will be the following:

- Signed consent-to-contact and consent-to-participate paper forms
- Completed paper questionnaires
- The researcher will keep a summary of what was said in the sessions

The consent forms and questionnaires will be kept in separate locked cabinets at the hospital until the research is complete, at which point they will be transferred to separate locked cabinets at the University of Birmingham, UK. They will be kept there for ten years, in accordance with University regulations, and then securely destroyed.

You will be asked for your consent to audio-record the therapy sessions. You do not have to consent to this if you prefer that they are not recorded. If you prefer they are not recorded, the researcher will make handwritten notes during the session. The researcher will use the audio-recording (or handwritten notes) to produce a summary of the session in electronic form. This will be done as soon as practically possible at the end of each session. Once the electronic document is complete, the audio-recording (or handwritten notes) will be deleted. The electronic documents will be stored on the University of Birmingham's password-protected computer system in password-protected files. Again, these will be stored for ten years and then deleted.

Paper and electronic files will only be accessible to the researchers and to anyone authorised by the University of Birmingham to conduct a research audit. However, if the researcher is concerned about the health and wellbeing of anyone involved, she may show the electronic summaries to the clinical psychologist at AMRI Hospitals who is providing supervision.

Only the consent forms will contain your name. It will not be possible to identify you from any of the other documents.

Findings from the research will be written up in the researcher's PhD thesis at the University of Birmingham. They may also be presented at scientific conferences or written up in a scientific paper. However, no information will be used in reporting the findings that would allow you ever to be identified.

What if I want to complain?

If you are unhappy about the way this study is being conducted, or if you feel in need of further support, then please contact Dr Soumitra Chatterjee, Senior GM Medical Service, AMRI Hospitals, Salt Lake, Kolkata. Email: [redacted]. Phone: [redacted]

I want to know more before I decide to take part. What should I do?

Please e-mail the clinical psychologist with your question: **Natasha Yasmin** at [redacted]**;** or the academic supervisor of the project**: Dr Gerard Riley** at [redacted]

I would like to take part. What should I do next?

Natasha Yasmin will contact you on the day following the meeting with her when she gave you this leaflet. If you want to take part, tell her when she contacts you. If you do not want to take part, tell her when she contacts you. She will not ask you for reasons why you do not want to take part, and will not attempt to contact you again.

Appendix 6c

Consent Form

Supporting couples to help maintain their marital relationship after brain injury.

Researcher/Clinical Psychologist: Natasha Yasmin, University of Birmingham, UK.

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions, and have had them answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I consent to the researcher keeping notes about our meetings. ☐
4. I consent to the researcher making an audio recording of our meetings so that she can make a written summary of what was said. [Optional – Do not tick this box if you would rather the meetings were not recorded.] ☐
5. I understand that the researcher will receive supervision from a clinical psychologist in the Department of Clinical Psychology at AMRI Hospitals, and from the clinical psychologist in the UK who is supervising the research; and that this will involve discussing what happens in our meetings. ☐
6. I understand that the researcher is obliged to inform the clinical psychologist at AMRI Hospitals if she is concerned about the safety and well-being of yourself, your partner, or herself; and that this may involve the psychologist being shown notes made by the researcher about what happened in our meetings. ☐
7. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of researcher	Date	Signature

Appendix 6d

Questionnaire pack

Please answer the following questions before proceeding. You will not be able to proceed until you answer these questions.

	Yes	**No**
Have you read and understood the information provided on the previous page about this study?		
Do you give permission for the information you provide to be used for the purposes of this study described on the previous page?		
Are you a husband, wife or partner of someone who suffered a traumatic brain injury in the last 10 years?		
Did your husband, wife or partner have to stay in hospital for at least a week because of the brain injury?		
Did you live with your husband, wife or partner for at least 1 year before their injury?		
Are you still living with your husband, wife or partner?		
Are you at least 18 years of age?		
Are you able to fill in questionnaires written in English?		
Before the injury, was your husband, wife or partner free from any disability or other condition that required you to provide care and support?		

If you answered **‘no’** to any of these questions, please do not proceed any further. You are not eligible to take part. Thank you for your time

If you answered **‘yes’** to all these questions and want to participate, please proceed to the next part.

The following questions are about both you and your partner. If you would prefer not to answer these questions, please go straight to the next page.

<u>The person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Employment status before the brain injury:

Current employment status:

Diagnosis (the type of injury):

How long since the brain injury?

<u>Partner of the person with the brain injury</u>

Gender:

Age:

Ethnicity:

Religious belief:

Current employment status:

<u>Your relationship</u>

What relation are you to the person with a traumatic brain injury?

How long have you been together?

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your wife (partner) and in your relationship with her, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	**[✓ Agree a little]**	**Neither**	**Disagree a little**	**Disagree a lot**

1	She' is more interested in herself now than she is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for her, but I don't love her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like her carer now, not her husband (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, her personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	I don't feel about her the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, she’s still her old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn’t what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it’s like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from her.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how she used to be, she’s a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I’ve lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It’s like there’s a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don’t feel I really know her anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	She still has many of the same qualities that first attracted me to her	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn’t feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Birmingham Relationship Continuity Measure

This questionnaire is about changes in your husband (partner) and in your relationship with him, since the brain injury happened. In deciding on your answer, please think about how things were before the brain injury and how things are now.

Please read each question carefully.

Circle the response that best expresses your view (as shown in the example). If you change your mind, cross it out and circle another response.

Please answer ALL the questions.

Example

	Caring for my partner can be difficult	**Agree a lot**	[✓ **Agree a little**]	**Neither**	**Disagree a little**	**Disagree a lot**

1	He is more interested in himself now than he is in me or our relationship.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	The brain injury has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	I miss having someone to turn to when I need some comfort or support.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	I care for him, but I don’t love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	Since the brain injury, his personality is very different.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

8	I don't feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	Our relationship has changed beyond recognition since the brain injury.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	Despite all the changes, he's still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
11	The bond between us isn't what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	Sometimes I feel it's like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	Despite all the changes, our relationship has remained much the same as it was	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Compared to how he used to be, he's a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	I feel like I've lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	It's like there's a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I don't feel I really know him anymore.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	It doesn't feel like a partnership anymore	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

Relationship Assessment Scale (Pre-Injury)

Please think about your relationship with your husband, wife or partner **before the brain injury.** Please mark on the answer sheet the letter for each item which best answers that item for you.

	Poor **1**	**2**	**Average** **3**	**4**	**Excellent** **5**
1. How well did your partner meet your needs?	**1**	**2**	**3**	**4**	**5**
2. In general, how satisfied were you with your relationship?	1	2	3	4	5
3. How good was your relationship compared to most?	**1**	**2**	**3**	**4**	**5**
4. How often did you wish you hadn't gotten into the relationship?	1	2	3	4	5
5. To what extent did your relationship meet your original expectations?	**1**	**2**	**3**	**4**	**5**
6. How much did you love your partner?	1	2	3	4	5
7. How many problems were there in your relationship?	**1**	**2**	**3**	**4**	**5**

Relationship Assessment Scale (Post-Injury)

Please think about your **current relationship** with your husband, wife or partner. Please mark on the answer sheet the letter for each item which best answers that item for you.

	Poor **1**	**2**	**Average** **3**	**4**	**Excellent** **5**
1. How well did your partner meet your needs?	**1**	**2**	**3**	**4**	**5**
2. In general, how satisfied were you with your relationship?	1	2	3	4	5
3. How good was your relationship compared to most?	**1**	**2**	**3**	**4**	**5**
4. How often did you wish you hadn't gotten into the relationship?	1	2	3	4	5
5. To what extent did your relationship meet your original expectations?	**1**	**2**	**3**	**4**	**5**
6. How much did you love your partner?	1	2	3	4	5
7. How many problems were there in your relationship?	**1**	**2**	**3**	**4**	**5**

Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate by putting a tick below in the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always agree	Almost always agree	Occasionally disagree	Frequently disagree	Almost always disagreed	Always disagree
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstrations of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behavior)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals, and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure time interests and activities						
15. Career decisions						

	All the time	**Most of the time**	**More often than not**	**Occasionally**	**Rarely**	**Never**
16. How often do you discuss, or have you considered divorce, separation, or terminating your relationship?						
17. How often do you or your mate leave the house after a fight?						
18. In general how often do you think that things between you and your partner are going well?						
19. Do you confide in your mate?						
20. Do you ever regret that you got married (or lived together)?						
21. How often do you and your partner quarrel?						
22. How often do you and your mate “get on each others nerves”?						

	Everyday	**Almost everyday**	**Occasionally**	**Rarely**	**Never**
23. Do you kiss your mate?					

	All of the them	**Most of them**	**Some of them**	**Very few of them**	**None of them**
24. Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**
25. Have a stimulating exchange of ideas						
26. Laugh together						
27. Calmly discuss something						
28. Work together on a project						

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Tick or no)

	Yes	**No**
29. Being too tired for sex		
30. Not showing love		

31. The circles on the following line represent different degrees of happiness in your relationship. The middle point, “happy,” represents the degree of happiness of most relationships. Please fill in the circle which best describes the degree of happiness, all things considered, of your relationship.

O	**O**	**O**	**O**	**O**	**O**	**O____**
Extremely	Fairly	A Little	Happy	Very	Extremely	Perfect
Unhappy	Unhappy	Unhappy		Happy	Happy	

32. Which of the following statements best describes how you feel about the future of your relationship?

O I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.

O I want very much for my relationship to succeed, and *will do all I can* to see that it does.

O I want very much for my relationship to succeed, and *will do my fair share* to see that it does.

O It would be nice if my relationship succeeded, but *I can't do much more than I am doing now* to help it succeed.

O It would be nice if it succeeded, but I *refuse to do any more than I am doing now* to keep the relationship going.

O My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

Depression Anxiety Stress Scales

DASS21 *Name:* *Date:*

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

1	**I found it hard to wind down**	**0** **2**	**1** **3**
2	I was aware of dryness of my mouth	0 2	1 3
3	**I couldn't seem to experience any positive feeling at all**	**0** **2**	**1** **3**
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0 2	1 3
5	**I found it difficult to work up the initiative to do things**	**0** **2**	**1** **3**
6	I tended to over-react to situations	0 2	1 3
7	**I experienced trembling (e.g., in the hands)**	**0** **2**	**1** **3**
8	I felt that I was using a lot of nervous energy	0 2	1 3
9	**I was worried about situations in which I might panic and make a fool of myself**	**0** **2**	**1** **3**
10	I felt that I had nothing to look forward to	0 2	1 3
11	**I found myself getting agitated**	**0** **2**	**1** **3**
12	I found it difficult to relax	0 2	1 3

13	**I felt down-hearted and blue**	**0** **2**	**1** **3**
14	I was intolerant of anything that kept me from getting on with what I was doing	0 2	1 3
15	**I felt I was close to panic**	**0** **2**	**1** **3**
16	I was unable to become enthusiastic about anything	0 2	1 3
17	**I felt I wasn't worth much as a person**	**0** **2**	**1** **3**
18	I felt that I was rather touchy	0 2	1 3
19	**I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)**	**0** **2**	**1** **3**
20	I felt scared without any good reason	0 2	1 3
21	**I felt that life was meaningless**	**0** **2**	**1** **3**

Caregiver Strain Index

I am going to read a list of things that other people have found to be difficult. **Would you tell me whether any of these apply to you?**

	Yes	No
Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)		
It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about . . .; concerns about how you will manage)		

Session Evaluation Questionnaire

What was your favourite or the most useful part of the sessions? Why?

What was the worst or least useful part of the sessions? Why?

Please select a number from the scale to answer each question:

How much do you want to come back for future sessions?

_______ _______ _______ _______ _______ _______ _______

(not at all) (very much)

How much did you like the sessions?

_______ _______ _______ _______ _______ _______ _______

(not at all) (very much)

After completing the sessions, how stressed do you feel?

_______ _______ _______ _______ _______ _______ _______

(not at all) (very much)

Please give us any other comments or suggestions that you have about how we can make future sessions better.

Appendix 6e

Ethical approval

AMRI
HOSPITALS
SALT LAKE

Authorization certificate for research study work

This is to certify that we authorise Ms. Natasha Yasmin PhD, student of Psychology from School of Psychology, University of Birmingham, UK, to do her research study work on the topic : "Spousal relationships after brain injury" in AMRI Salt Lake, Kolkata, West Bengal, India.

She will be working in the department of Neurosurgery under Dr. G.R.Vijay Kumar and Dr. Dibyendu Kumar Roy and in the department of Clinical Psychology with Ms. Uttara Roy.

She will be allowed to do her study in our hospital for a period of three months commencing from 14.03.2018.

[redacted]

Brig. Dr. Soumitra Chatterjee [redacted]

Sr. GM Medical Services

AMRI Hospitals - Salt Lake (A Unit of AMRI Hospitals Ltd.), JC-16 & 17, Salt Lake City, Sector - III, Kolkata- 700 098
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OTHER UNITS : AMRI Hospitals - Dhakuria | AMRI Hospitals - Mukundapur | AMRI Medical Centre - Southern Avenue | AMRI Hospitals - Bhubaneswar

Appendix 6f

Educational handout

Emotional/ Behavioural issues & Relationships following Brain Injury

- Brain injury can cause many difficulties in a person's life. These problems can also affect the loved ones and carers, and the relationship they share with the injured.
- Following a brain injury, some people may experience problems related to emotional and behavioural difficulties, besides physical difficulties.
- Learning to manage these problems is just as important as learning how to cope with physical disabilities, memory difficulties, attention deficits, or other problems that comes with brain injury. Carers understanding, and awareness of these problems can also go a long way towards coping.

Some questions for the family members/partners.

What does it mean to have emotional or behavioural problems? Do you as a carer see a change in behaviour, personality or mood?

Brain injury causes various physical and cognitive impairments. They often restrict an individual’s normal functioning. The brain injured person loses their independence to do stuff they once enjoyed doing, and sometimes they even need to quit their job. All these can affect their confidence, self-esteem and their emotions, and can therefore possibly make them sad, aggressive and so on. Besides, injury in different parts of the brain also affects their emotions and behaviours. A list of all the emotional and behavioural difficulties are provided at the end of the handout.

Is the person you care for is aware of the emotional and behavioural difficulties he/she is experiencing?

Sometimes, the brain injured person may lack insight, and be unaware of his or her problems. This can be misunderstood by others as stubborn behaviour.

Can improvements in these difficulties be made?

Support and **encouragement** from carers and other family members, friends and relatives can bring improvements.

How long will it be before you see an improvement?

Both the brain injured person and their carers must be aware that recovery of psychological issues takes time. Patience and perseverance will help individuals and carers cope better.

Emotional & Behavioural effects

Personality changes

Many people experience changes in aspects of their personality. These can range from subtle changes in some areas to dramatic transformations. This can be particularly difficult for family members and friends to deal with as they find themselves dealing with a different person. For the person with the brain injury, losing a sense of their own identity can also be challenging to cope with.

Loss of confidence

This is very common after brain injury and a person can need a lot of encouragement and reassurance.

Mood swings or 'emotional lability'

The person may tend to laugh or cry very quickly, and to move from one emotional state to another quite suddenly.

Depression

Depression and a **sense of loss** are common. Depression may be caused by injury to the areas of the brain that control emotion, but can also be associated with the person gaining an insight into the other effects of their injury. After brain injury, many things that are precious to the individual may be lost forever, and there may be much sadness, anger, guilt and confusion, surrounding this.

Anxiety

Anxiety can be another consequence of brain injury. Life has been changed forever in a matter of seconds, and the future can look frightening. Anxiety can quickly lead to frustration and anger and needs to be identified and alleviated as early as possible.

Frustration and anger

Frustration can build up quickly, especially when things that were once so easy are now difficult or impossible. The resulting anger may be very difficult for the person to control.

Abusive or obscene language

This may be spontaneous and uncontrollable and may be an outlet for the person's anger and frustration. This behaviour can be embarrassing and upsetting for loved ones.

Disinhibition

There may be a loss of control over social behaviour so that the person may behave in an over-familiar manner or may make sexual advances with the wrong people at the wrong time. They may also be unable to inhibit what they are thinking and may make inappropriate and offensive outbursts.

Impulsiveness

A person with a brain injury may tend to speak or act without thinking things through properly first.

Obsessive behaviour

Obsessive behaviour can occur. For example, a person may be afraid that their possessions will be stolen, and may check their belongings repeatedly.

Couples relationships after brain injury

Relationships are an essential and intimate part of life. They give us a sense of security and wellbeing and contribute towards our sense of self-identity. It is often our closest relationships that provide the vital emotional and practical support needed when hardships are faced, such as when a brain injury occurs.

Relationships between partners are one of the most commonly affected types of relationships after brain injury. Both partners often feel a strong sense of commitment to the other, especially after a life-changing event has occurred, such as one partner sustaining a brain injury. Couples usually spend a significant amount of time together, and so the brain injury survivor's partner is often aware of the effects of the injury, including 'hidden' effects. Further, in supporting brain injury survivors, partners often take on caring roles. This can lead to the boundaries between the roles of 'carer' and partner becoming blurred. If the survivor's personality has changed, the partner may feel that they are no longer the person they initially chose to be in a relationship with, resulting in feelings of confusion, longing, sadness and loss. The survivor themselves may no longer feel the same way about the relationship as they did before the injury. However, enduring challenging experiences like this can also, with support, strengthen some couple relationships.

Below are some of the common ways in which this can happen.

Changes in communication

Your partner might have problems with word finding, comprehension or speech production and they might also struggle with understanding and using non-verbal communication, such as body language and facial expressions. Day-to-day discussions can become difficult, as it might take them more time and effort to make themselves understood. They might also struggle with expressing romantic feelings. Such communication problems can be frustrating and upsetting for both of you, and you might communicate with one another less over time.

Changes in personality

Many brain injury survivors report feeling like a new person after their injury. Indeed, the emotional, cognitive and behavioural effects of brain injury can cause an overall change in their personality, which is often also noticed by their partner. Sometimes, however, a survivor might be unaware of how their personality has changed or how the injury has affected them. This is known as lack of insight and can be a particular challenge for partners to deal with.

Either way, a change in personality can cause difficulties in a relationship. You may feel that you are no longer in a relationship with the person you initially chose to be with. Sadly, some partners even go so far as to describe the brain injury survivor as becoming a stranger. Some survivors might also experience emotional, psychological or cognitive effects that alter their feelings towards their partner.

Changes in intimacy

Intimacy can be described as an emotional, physical and psychological closeness between two people that is often accompanied by romantic feelings. It provides security and satisfaction for many couples. This can either be sexual, although not always. Intimacy can refer to non-sexual acts as well, such as hand-holding, caressing, kissing and holding one another. For example, intimacy between a couple can be affected by anger issues.

Changes in behaviour

Changes in behaviour after brain injury are frequent, especially following an injury to the area of the brain known as the frontal lobe. Behaviour can become uninhibited and socially inappropriate, such as swearing or making inappropriate comments in public. This might cause you to feel embarrassed, frustrated or saddened. Your partner might also make sexually inappropriate remarks or engage in a sexually inappropriate behaviour, which can be particularly upsetting or embarrassing for you. A lack of motivation might affect your partner's ability to engage in activities. As a result, your social life might be affected, and you might, in turn, feel depressed, isolated or frustrated.

Changes in cognitive ability

Cognitive (thinking) skills are commonly affected by brain injury. Memory problems are particularly common and can affect relationships if, for instance, your partner struggles with remembering significant key dates (such as anniversaries or birthdays) or important memories (such as your wedding day or first date). They might also struggle with remembering things on a day-to-day basis, such as appointments and planned outings. You might find yourself having to repeat things several times, and this can get tiring. You might also feel upset if your partner is not able to remember important and sentimental memories. Problems with attention, multi-tasking and decision making are collectively known as executive dysfunction, and can also cause practical and emotional challenges.

Practical changes

Your partner might be unable to work or drive after their injury. As a result, you may need to readjust aspects of your life to accommodate for such changes. There might also be a change in the type of activities, or pace of activities that you can partake in together. For instance, fatigue might make it harder for your partner to socialise and spend late evenings out, or there may be certain places that they are no longer able to visit if they now struggle in noisy environments. If you previously relied on a joint income and your partner is no longer able to work, you might need to consider applying for welfare benefits.

Role changes

Practical changes can cause yours and your partner’s roles to change. For instance, you may need to take on new responsibilities that your partner previously did, such as managing household finances. This can be stressful, as you will likely be having to manage these new responsibilities in other aspects of your life. However, it will also probably be difficult for your partner to adjust to this change, and their self-esteem might be affected if they are no longer able to do tasks that they did before their injury. You might also have taken on a caring role if you are supporting your partner with day-to-day tasks. Adjusting to the roles of both partner and carer can be challenging, especially if you have to support your partner with things such as washing and dressing.