AN EXPLORATION INTO HOW PARTNERS OF THOSE WITH A BRAIN INJURY EXPERIENCE LACK OF EMOTIONAL WARMTH, AND ITS IMPACT ON THE PARTNER RELATIONSHIP

By

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Thesis Overview

This thesis consists of three chapters. The first chapter is a systematic review synthesising findings on rates of partner relationship satisfaction after brain injury, and variables associated with differences in those rates, both from the perspective of the person with the injury and their partner. The second chapter is an empirical qualitative study exploring how partners of those with an acquired brain injury experience lack of emotional warmth, and its impact on the partner relationship. The third chapter consists of two press releases providing an accessible overview of chapters one and two.

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CHAPTER I: A SYSTEMATIC REVIEW OF RELATIONSHIP SATISFACTION FOLLOWING A BRAIN INJURY

Abstract

Introduction

Previous reviews have attempted to understand the couple relationship after brain injury, however their conclusions are weakened due to their interchangeable use of relational concepts. The aim of this review was to synthesise findings on rates of partner relationship satisfaction after brain injury, and variables associated with differences in those rates, both from the perspective of the person with the injury and their partner.

Method

A systematic search of three databases was conducted. Eleven papers were deemed to meet inclusion criteria. Additional hand searching was carried out which yielded one further paper for inclusion. Papers were rated on their overall quality based on a quality appraisal tool (CLEAR, 2021).

Findings

Papers were generally of low quality. There was significant variation regarding how satisfaction was measured across the papers. Studies identified partners report poorer satisfaction than the injured persons themselves. Few variables were consistently associated with relationship satisfaction, with the most promising results showing stronger associations between satisfaction and aspects of the couple relationship, and cognitive symptoms of the brain injury.

Discussion

This review provides conceptual clarity over relationship satisfaction following brain injury and its associated variables. More research is required to gain a better idea of which variables are more consistently associated with different relational outcomes. Couple interventions should focus on improving areas such as emotional recognition within the relationship and helping the injured person gain insight into their impairments. Future research should recruit larger samples of varying demographics, including both partners in the couple.

Introduction

Partner Relationship after Brain Injury

A brain injury can cause significant physical, cognitive and personality changes to the person, placing strain on their romantic relationships (Wood & Yurdakul, 1997; Wood et al., 2005; Hammond et al., 2011; O'Keeffe et al., 2020), and leading to poorer emotional well-being for both partners (Turner et al., 2010; Payne et al, 2018). Studies have reported increased rates of relationship breakdown of between 15-78% (Godwin et al., 2011) and higher dissatisfaction with the relationship from both partners post-injury (Kreutzer et al., 2016). The caregiver's perception of their partner following injury (Hammond et al., 2011) and higher depression levels in the person with the injury (Blonder et al., 2007) have been suggested to impact on both relationship satisfaction and stability.

Despite this evidence, relationships can be a protective factor, particularly after illness (Anderson & Keating, 2018), with a stronger partner relationship post-injury associated with better emotional well-being for both members of the couple (Kendall & Terry, 2009). This in turn improves the quality of care and support from the caregiver (Riley et al., 2020), leading to better rehabilitation outcomes for the person with the brain injury (Sander et al., 2002; Palmer & Glass, 2003). Therefore, having an understanding as to the variables that might be associated with these differences in relationship outcomes may help improve support for couples after brain injury.

Existing Reviews of Relationships after Brain Injury

Previous reviews have attempted to understand the couple relationship after brain injury. These reviews highlighted discrepancies in the research and offered recommendations for improvements.

Godwin et al.'s (2011) review centred on factors that impact on marital stability and quality, expressing these as two distinct concepts. They termed stability as "the likelihood that couples will stay together following injury" (Godwin et al., 2011, p 44) and concluded that the wide range of reported relationship breakdown rates, were largely due to differences in how this was measured across studies, which meant participant samples were often of varying injury severity. Factors that appeared to increase breakdown

included both demographic variables (age and gender), as well as injury characteristics, such as injury severity (which may have been influenced by study recruitment methods). They noted that participant samples varied extensively in terms of the time post-injury, making comparisons between studies more difficult. They called for larger studies to recruit participants representative of the demographics of brain-injured persons, as well as including both partners' perspectives.

Regarding quality, the authors reported a lack of agreement in terms of how this was defined, however they noted that research reporting to measure this aspect seemed to focus on concepts that may influence the couple relationship, such as dyadic adjustment. Within their review, Godwin et al. refer to relationship satisfaction as an overlapping construct with both relationship quality and adjustment. They reported previous literature concentrated on the individual perspectives of either the person with the brain injury or their partner, rather than on the relationship between the two persons. This led to inconsistent findings, with the authors reporting that these results represented partner perceptions of their relationship quality rather than actual changes within the relationship. Therefore, they included studies in their review that looked at relational constructs i.e., a variable concerned with experiences occurring between the couple, such as satisfaction, rather than individual variables. Similar to the studies reporting stability, participant samples varied in terms of injury severity and time post-injury. They identified that features of the couple relationship, such as communication skills, were more strongly linked to relationship quality than individual characteristics, and that further understanding these links is critical for successful rehabilitation. They also called for a more consistent and unified method of describing and assessing the concepts of a couple relationship that are being measured.

van den Broeck et al. (2022, in press) recently updated Godwin et al.'s (2011) findings, as well as adding outcomes from qualitative research. Regarding participant samples, they reported quantitative research tended to focus more on the perspective of the person with the injury, while the qualitative studies were more likely to recruit the partner. They used Godwin et al.'s description of relationship quality, including papers that measured both adjustment and satisfaction as aspects of this. Results were presented in the context of the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) model, reporting on the impact of: injury

characteristics; physical functioning and personality changes; engagement of activities and the relationship as a couple (for example, change in roles); support from others (family and professionals); demographic variables; and personal factors, such as coping skills. The ICF model, based on the biopsychosocial approach, aims to provide a "standard language and framework for the description of health and health-related states" (WHO, 2002, p.2). This revision of an earlier WHO model offers a more holistic view of an individual's functioning (and with it a reduced focus on disability). The framework demonstrates the bidirectional link between an individual's health and the context they are situated within (such as their environmental factors and personal characteristics), and how these factors may impact on the level of a person's functioning (Jette, 2006). In the context of this model, Van den Broeck et al found further support for associations between relationship quality and age, injury severity, and coping skills, as well as a new finding, regarding an association with depression. Qualitative studies suggested links between relationship quality, and changes associated with both personality and role.

In support of Godwin et al.'s conclusions, they suggested that inconsistencies in study quality, particularly regarding study samples (such as including participants with varying injury severity, and large age ranges) and study design limitations, have continued to lead to mixed findings. They highlighted that some conclusions regarding factors associated with relationship quality were based on a low number of studies which were often not of high quality. They also supported the recommendations to include both members of the couple into research, although commented that this does seem to have been incorporated more readily within qualitative research. The importance of gaining a dyad perspective is consistent with findings from the general population that have observed differences between when couples participate together versus when only one partner does (Bühler, et al., 2021). In terms of areas for further research, van den Broeck et al. (2022, in press) suggest quantitative research is now required to support and further explore the associations that have been found in more recent qualitative findings.

Blais and Boisvert (2005) meanwhile conducted a review into psychological and marital adjustment within the couple relationship. Although their primary focus was on adjustment, which is one aspect of marital quality; when reporting outcomes related to the couple relationship, the authors described studies reporting satisfaction to be an element of adjustment and, at times, used the terms interchangeably to describe the same relationship

aspects. They reported differences regarding the couple perspective in relation to psychological symptoms, and that these were related to injury severity and time post-injury. They noted the couple relationship as being more affected than other types of caregiving relationships (although reported issues with studies combining caregiver samples and reporting all caregiver data together meaning conclusions were unable to be made on the specific effects on partners). The authors commented that with a wide variety of satisfaction definitions and measures used, it is difficult to compare findings, some of which appear contradictory to each other. They suggest our knowledge is limited regarding the variables associated with relationship satisfaction after injury, due to most research being qualitative with small sample sizes and little use of control groups. They suggested that research should specifically look at factors associated with relationship satisfaction, which may help support the development of couples' specific interventions. Similar to the other reviews, they concluded the need to use both validated and consistent measures across studies (although made no specific recommendations regarding this), to include the dyad perspective, and to follow couples longitudinally.

These three reviews focused on the changes in stability, quality and overall adjustment within couples relationships after brain injury. All three offer useful recommendations for future research, such as highlighting the importance of the inclusion of both partners perspectives. One of Godwin et al.'s strengths is that they only included papers that looked at relational constructs over individual variables, which helps to offer a more holistic, rather than individualistic, view of the actual changes that may occur in the relationship after brain injury. Within Godwin et al., the distinct focus in concepts in relation to stability and quality is helpful in demonstrating that different factors may affect these related (but still separate areas) of a relationship. They also make clear that measuring stability on its own is too limited in being able to provide a full evaluation of the relationship after brain injury. Van den Broeck et al.'s use of the ICF model as a structure for demonstrating which factors may play a role in relationship quality is helpful, and their structure influenced this review's own structure in displaying results by grouping similar factors together. Their inclusion of qualitative research also helps to broaden our understanding in the topic, helping to provide richer accounts of couples' experiences, and thus supporting and offering further explanation to quantitative findings. Unlike the other two reviews, van den Broeck et al. also provide a much clearer study inclusion criteria and

methodology, and comment more thoroughly on study quality leading them to be more tentative with their conclusions. Meanwhile, a strength of Blais and Boisvert's review is that they acknowledge some of the possible confounding factors that may affect differences in relationship outcomes, for example, injury severity and time since injury. Despite some of these strengths, the reviews' overall conclusions are weakened due to their many limitations, which it is hoped this review will begin to address.

Research Limitations

These reviews (along with ongoing research relating to the couple relationship following brain injury) would benefit from more conceptual clarity, clearer definitions of the terms and constructs used to define aspects of the relationship, as well as a more unified way of measuring these different aspects. This would allow clearer comparisons of findings and stronger conclusions to be made. The conclusions from the reviews are weakened due to the interchangeable use of concepts related to adjustment, quality and satisfaction. In addition, the distinction between stability and quality drawn by Godwin et al., although useful, may be oversimplistic.

The need to clearly define what relationship satisfaction is is apparent, with Ward et al. (2009) noting the definition of this has changed over time, often with researchers using their own interpretations of the concept, rather than using a theory-based definition. For example, Fincham and Bradbury (1987) suggest relationship satisfaction overlaps with relationship quality and thus argue satisfaction is an element of this broader concept, while Crane et al. (1990) suggest satisfaction fits under the umbrella term of adjustment. Adjustment refers to both the process of the relationship and the overall evaluation of the outcome of this process and this is not theory driven, nor objectively observable (Heyman et al.,1994). This confusion has led to measures being used in the existing research to evaluate several aspects of relationships rather than one construct, which Bradbury et al. (2000) suggest overinflate findings**.** For example**,** the Dyadic Adjustment Scale (DAS) (Spanier, 1976) included satisfaction as one element of adjustment, and thus has been used as a measure of satisfaction which was not its intended purpose (Ward et al., 2009). Graham et al.'s (2011) review regarding the reliability of satisfaction measures identifies the five most widely used measures; these include the terms adjustment, quality and satisfaction interchangeably. Bradbury et al. (2000) suggest although the use of various

measures helped research within the context of relationships to expand, they identify the need to use global measures in order to obtain more coherent and reliable findings.

Relationship Satisfaction

Satisfaction, although related to both quality and adjustment, is a distinct concept. Bradbury et al. (2000) describe relationship satisfaction as an interpersonal process, serving as a person's attitude towards their partner and relationship, with satisfaction varying in both degree and strength. Ward et al. (2009) suggest satisfaction involves the "emotional state of being content with the interactions, experiences, and expectations" of the relationship (Ward et al., 2009, p.415). Both these papers suggest a satisfied relationship is not simply the absence of dissatisfaction. Bradbury et al. point out previous research has conceptually defined satisfaction to be a global evaluation of one's relationship, a single dimension where more positive features are present and negative features absent. Ward et al. suggested researchers classified satisfaction to mean a relationship with no distress, and that definitions should not be based on the relationship being absent of certain aspects. Over time researchers have argued satisfaction is two dimensional, being a "trajectory that reflects fluctuations in marital evaluations over time" (Bradbury et al., 2000, p. 974). This supports the previous reviews that have highlighted the importance of studies assessing changes in satisfaction over time.

Aims

The aim of the review was to synthesise findings on rates of relationship satisfaction within couples following brain injury, and variables associated with differences in those rates, both from the perspective of the person with the injury and their partner. Satisfaction was chosen as the focus of this review as within the general research on relationships, satisfaction is suggested to be the "most widely studied and influential variable" (Graham et al., 2011, p.39), with links to well-being (Bradbury et al., 2000), and in the context of brain injury, can improve rehabilitation outcomes (Palmer & Glass, 2003). It is therefore imperative to have an understanding as to how this may be affected following a brain injury, as well as what variables can mediate the effect of satisfaction in the relationship. It is hoped that by providing a more focused overview for relationship satisfaction and with it, a well-defined inclusion criterion, professionals can use this information to better support couples following a brain injury.

Method

Identifying Primary Studies

Search of Electronic Databases

A systematic search of the literature was carried out in April 2022 using PsycInfo, Medline and Web of Science databases. These databases were selected due to their inclusion of psychological, allied health and medical based literature. Three published reviews investigating relationships after brain injury (Blais & Boisvert, 2005; Godwin et al., 2011; van den Broek et al., 2022, in press) were also hand searched for any additional relevant papers not picked up in the database search, as were each of the papers selected in final inclusion. The search terms that were used to identify these studies are outlined in Table 1.

Table 1

Search Criteria

Construct	Search Terms
Population: partner	couples or partners or marit* or dyad* or husband* or wife or wives or spouse* or cohabitation or marriage
Population: brain injury	traumatic brain injury or TBI or acquired brain injury or ABI or brain damage or stroke
Outcome: Relationship satisfaction (this could be either measured from the perspective of the person with brain injury, their partner, or the dyadic couple)	Relationship Satisfaction/ or exp Satisfaction/ or exp Marital Satisfaction/

The search terms of the three constructs were combined with "AND". Terms were mapped to subject headings, when possible, but otherwise the term was used as a key

word. The search was conducted without any limits on date of publication in the hope that this would provide a full overview of all the available research in this area.

Inclusion Criteria

Cochrane guidance for systematic reviews (McKenzie et al., 2022) was used as an initial guide in helping to consider the PICO elements of the review and define the areas important for inclusion criteria for the review. These areas were then adapted as appropriate to the research questions. The inclusion and exclusion criteria for studies in the review are displayed in Table 2.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Sample are persons with a brain injury and/or their romantic partners.	Other types of caregivers e.g., parents, and not partners.
Adult sample i.e. The person who has experienced the brain injury is over 18.	Studies where a child or adolescent experienced the brain injury.
	Participants with dual diagnoses, war veterans.
If persons with brain injury make up a subset of the sample, the brain injury data is reported separately.	Studies where the data for the brain injury sample is not reported separately to other health conditions.
If partners make up a subset of the caregiver sample, outcome data is reported separately for each type of caregiver.	Study samples where the data for the partners is not reported separately to other caregivers.
Reports original quantitative data, either in a fully quantitative or mixed methods design.	Systematic reviews and qualitative research.
Researchers used a questionnaire assessing relationship satisfaction for either the person and/or their partner. Papers using a questionnaire with a satisfaction subscale	Questionnaires related to satisfaction in other areas e.g., life satisfaction, or to other aspects of the relationship (e.g., marital adjustment).

score (specifically, the Dyadic Adjustment Scale) were only included if the satisfaction score was provided.	
	Intervention studies where a relationship satisfaction questionnaire is used as an outcome measure.
Peer reviewed studies.	Dissertations, book chapters, conference or poster abstracts.
Studies published in English.	Papers that are published in other languages.
Full text available.	Full text unavailable

For the purposes of this review, papers were included if they used questionnaires that included the word satisfaction in its title; reported a subscale score labelled satisfaction, for example in the DAS; or that were otherwise clearly intended by the questionnaire developers to be a measure of satisfaction. This criterion was established by reading the paper that originally developed the questionnaire and scrutinising the items on the measure. This was particularly apparent for the two papers that used the Quality of Marriage Index (QMI) as these papers specified the use of the five items purposely related to satisfaction. Some papers measured satisfaction with a questionnaire that was clearly not measuring satisfaction and not intended by its authors to be; for example, the Marital Adjustment Test, and Golombok and Rust Inventory of Marital State; papers that used these measures were excluded. For papers that used the DAS, they were only included if they reported the satisfaction subscale score separately and only the results relating to this subscale score were included in the review.

As this review was interested in persons with brain injury and their partners, studies where the data for the brain injury sample or partner were not reported separately were excluded. It is suggested that satisfaction can vary across sample populations (Graham et al., 2011) and so to reduce possible confounders of dual diagnosis, papers which recruited veterans were also excluded to improve consistency when drawing

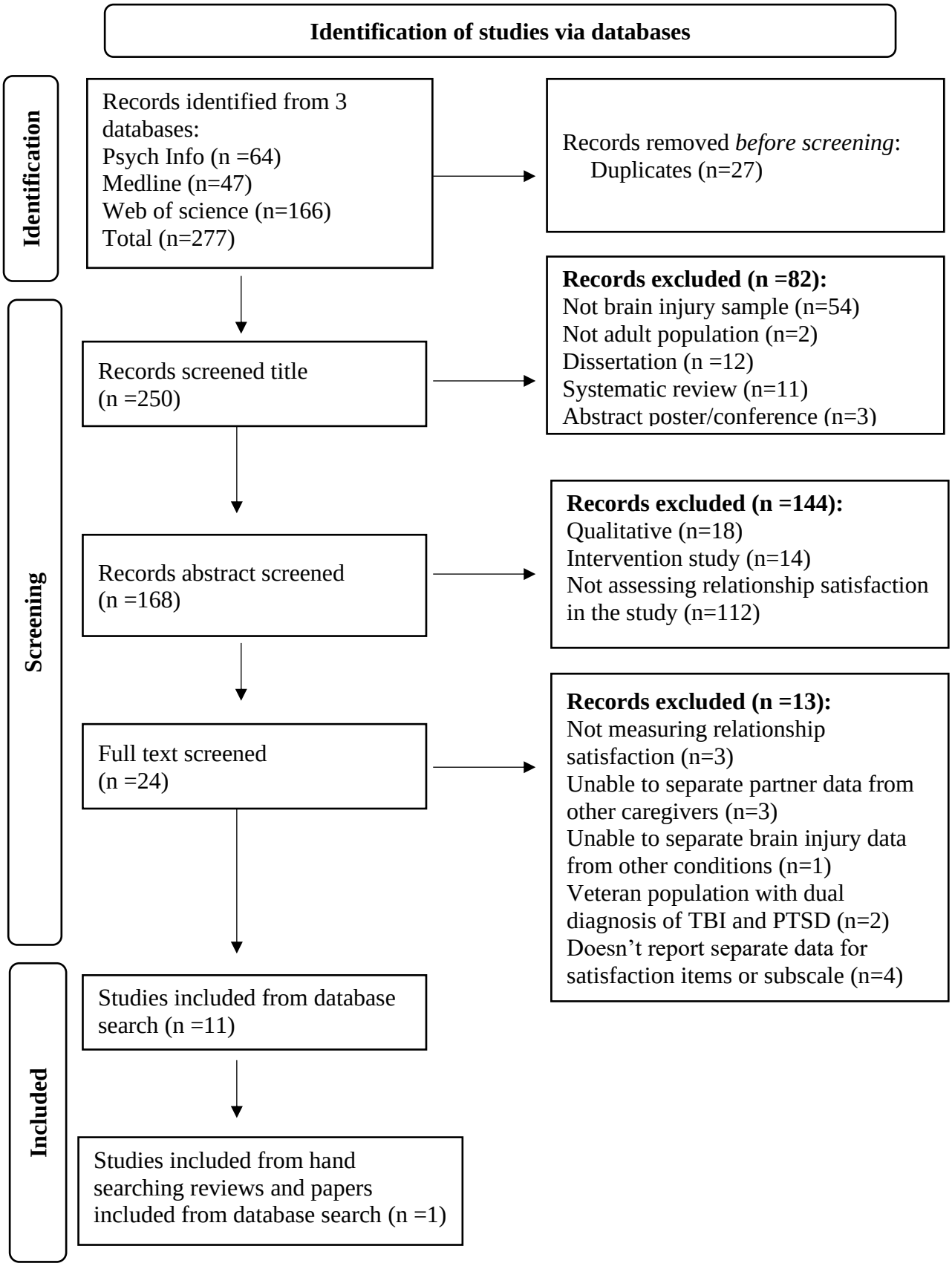
conclusions (as the role of pre-injury factors, including psychiatric history, has shown to be related to marital status after brain injury (Vanderploeg et al., 2003)).

Search Results

The search terms generated 250 studies after duplicates were removed. Screening of these remaining 250 papers involved three stages to ensure papers met inclusion criteria. Firstly, the title of the paper was screened; 82 records were excluded at this stage, mostly due to the papers not having recruited a brain injury sample. For the remaining papers, the abstracts were screened, of which 144 papers were excluded. The reasons for exclusion at this stage were the paper being qualitative research, an intervention-based study, or using a satisfaction measure not specifically related to the partner relationship, for example life satisfaction. The remaining 24 full text papers were read and of these, eleven were included in the final selection. Papers were excluded at this stage following careful review of the measures used and how data was reported. Four papers were excluded based on the specific satisfaction items or subscale used not being reported separately from the overall data. Another three papers were considered not to be using a measure of relationship satisfaction (as outlined in the inclusion criteria). There were also issues in data not being reported separately for the type of caregiver or health condition. An additional hand searching was also carried out which yielded one further paper for inclusion. Figure 1 illustrates how the final twelve papers were selected.

Figure 1

Prisma Tool



Quality Evaluation

A quality appraisal tool (CLEAR, 2021) was used to examine the overall quality of the twelve studies included for review. The CLEAR tool (Appendix A) was chosen for its suitability because it was designed for quantitative descriptive studies (i.e., non-experimental observational studies). Other quality appraisal tools used in psychological research were considered, however none were felt to be better suited to the design of the studies in this review. The researcher felt it important to be consistent in using the same quality tool across all papers. The CLEAR tool was therefore deemed to be the best fit and it provided well-defined questions to guide the researcher in rating each area of quality. The tool was used to identify any studies of particularly low quality. Due to the small number of papers available, the lower quality papers were not excluded, but the quality analysis was used to avoid drawing conclusions based on evidence that was less robust, and helped to identify common areas of methodological weakness in this topic area. The CLEAR tool covers six key issues: study design; data quality; data collection; study sample; analysis methods; and findings and conclusions. Under each of the key issues, there are several more specific criteria to consider. The tool does not offer a rating system. Papers were read thoroughly and data was extracted on each of the key issues and criteria using the screening questions provided in the CLEAR tool. Appendix B provides a detailed account of the extracted data. In order to provide a summary of quality, papers were then rated on each of the areas in the criterion and how well they met this criterion overall based on three categories: whether the study clearly met the criterion, the study clearly did not meet it, or sufficient clear information was not provided. As each of the six issues in the CLEAR tool had several items to consider, papers were rated on how much of the criteria they met (see Table 3 for ratings). This information was then used to create a summary table of overall quality (Table 4).

Table 3

Summary Table of Quality Analysis Ratings

Rating	**Criteria**
Green	If meets >75% (majority) of criteria items
Amber	If meets 50-75% of criteria items (sufficient clear information was not provided or at least one criterion missing)

Red	If meets <50% (very limited) of criteria items

Table 4

Quality Appraisal Summary Table

Author, Year	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
Bannon et al., 2022						
Blonder et al., 2007						
Blonder et al., 2012						
Clark & Stephens, 1996						
Hess & Perrone-McGovern 2016						
Kieffer-Kristensen & Teasdale, 2011						
McPherson et al., 2011						
Peters et al., 1990						
Peters et al., 1992						
Williams, 1993						
Williams & Freer, 1986						
Williams & Wood 2013						

Results

Quality Appraisal

It must be noted that all papers included in the review were of poor quality in terms of an evidence hierarchy (Murad et al., 2016) due to their uncontrolled observational design, which is at high risk of confounding bias (Hartung & Touchette, 2009). Only three papers received green ratings (deemed to meet at least 75% of criteria items) on all six domains, however this does not mean that they were free from bias. Generally, newer studies were of better quality than older papers. One paper (Peters et al., 1992) was judged to be of much lower quality, either not meeting or lacking significant detail in at least two areas of the quality appraisal.

The most frequent areas in the quality appraisal that studies either clearly did not meet criteria for, or sufficient clear information was not provided, were in relation to the study designs (n=7), sample (n=7), and data quality (n=6). Regarding study design and data collection, the most common issue was inadequate or unclear detail about study procedure for replication. For data quality, five studies lacked detail or did not include any information regarding psychometric properties of the measures used. Papers lacked clarity as to how participants were recruited, and did not often describe the limitations of recruiting a small participant sample, such as difficulties in being able to generalise study findings to a wider population, and lacking power, increasing the chances of a type II error. Common analysis issues included not providing clear rationales of why particular analyses were chosen and the possible limitations from them. Lastly, of the four papers rated as lower quality in regards to the reporting of their findings and conclusions, this was in relation to insufficient acknowledgement of limitations and overgeneralisations of the findings when taking these limitations into account.

Study Characteristics

Table 5 displays the key characteristics from each of the included studies.

Table 5

Key Study Characteristics

Authors, Year, Location	**Sample**	**Relationship Satisfaction Measures used**	**Summary of Results (Changes in satisfaction; Variables affecting satisfaction)**
Bannon et al., 2022, USA	23 participants with mild Traumatic Brain Injury (TBI). Time since injury = < 72 hours. Recruited via emergency department.	Couple Satisfaction Index (CSI)[1]	No significant changes in satisfaction on CSI scores from baseline to 1-month post-injury. Variables: a) significant: injury symptoms and couple characteristics associated with reduction in satisfaction. b) non-significant: age; relationship length.
Blonder et al., 2007, USA	20 participants with stroke and their partners. Mean time since injury = 38.7 days (range 14-121 days). Injury severity measured via NIH Stroke Scale. Participants' mean score= 6 (moderate injury) (range 0-13).	Marital Satisfaction Scale (MSS)[2] -24 items	No significant differences between the satisfaction ratings of the person with stroke and their partner. Variables: a) significant: negative correlation between partner satisfaction and persons with stroke depression scores; negative correlation between partner satisfaction and their own stress levels

[1] Funk & Rogge, 2007
[2] Roach et al., 1981

Authors, Year, Location	Sample	Relationship Satisfaction Measures used	Summary of Results (Changes in satisfaction; Variables affecting satisfaction)
	Recruited via medical centre/hospital rehabilitation.		b) non-significant: injury characteristics not associated with partners' satisfaction.
Blonder et al., 2012, USA	12 participants with stroke compared to 9 healthy control participants. Mean time since injury=32 days (range 12-63 days). No information regarding injury severity. Recruited via medical centre/hospital rehabilitation.	Marital Satisfaction Scale-24 items	Persons with stroke satisfaction was lower than in control group (not statistically significant difference). Variables: a) significant: positive correlations for cognitive symptoms resulting from injury. b) non-significant: depression.
Clark & Stephens, 1996, USA	55 participants with stroke. Injury severity: all participants had to score 6/9 on Cognition Index of the Multilevel Assessment Instrument. Mean time since injury=12.9 months (range 3-26 months). Participants	Quality of Marriage Index (QMI)[3] -5 items)	Persons' average score on QMI (23/25) was suggestive of high levels of satisfaction (25 being maximum score). Variables: a) significant: perceptions of helpful/unhelpful action predicted higher satisfaction.

[3] Norton, 1983

Authors, Year, Location	Sample	Relationship Satisfaction Measures used	Summary of Results (Changes in satisfaction; Variables affecting satisfaction)
	identified through hospital medical records.		
Hess & Perrone-McGovern, 2016, USA	122 participants with TBI. No information regarding injury severity or time since injury. Recruited via Facebook survey & TBI support websites & a university.	Kansas Marital Satisfaction scale (KMSS)[4]	Variables: a) significant: negative correlation between person with TBI's age and their satisfaction; positive correlation with quality of life, and perceived partner support. b) non-significant: gender; time post-injury; relationship length.
Kieffer-Kristensen & Teasdale, 2011, Denmark	35 participants with TBI and their partners compared to 20 couples in matched control group (diabetes). Mean time since injury= 3.7 years. No information regarding injury severity. Recruited via rehabilitation units. Control group recruited via national register.	Dyadic Adjustment Scale (DAS)[5]	Partners of TBI had significantly lower satisfaction scores than the partners in the control group. Partners had significantly lower satisfaction scores than the person with TBI. No differences in satisfaction between the persons with TBI and diabetes.

[4] Schumm et al., 1986
[5] Spanier, 1976

Authors, Year, Location	**Sample**	**Relationship Satisfaction Measures used**	**Summary of Results (Changes in satisfaction; Variables affecting satisfaction)**
McPherson et al., 2011, Canada	56 partners of persons with stroke. Mean time since injury= 31.7 months. Injury severity: participants had to score ≥5 on Functional Independence Measure. Recruited via medical records- former inpatients of rehabilitation units.	Quality of Marriage Index	89.2% of partners rated their current satisfaction as between 6 (happy) and 10 (perfectly happy). Variables: a) significant: correlation with mental component of quality of life, and previous balance in relationship (unable to determine direction of this association). b) non-significant: gender; age; injury characteristics; physical component of quality of life.
Peters et al., 1990, Canada	55 partners of persons with head injury: 10 mild, 25 moderate, 20 with severe injury. Range of time since injury= a few months-8 years. Recruited via hospital medical records.	Dyadic Adjustment Scale	Variables: a) significant: none. b) non-significant: injury severity.
Peters et al., 1992, Canada	31 partners of persons with moderate head injury and 17 partners of persons with severe head injury compared to 24 partners of persons with spinal cord injury.	Dyadic Adjustment Scale	Partners of persons with both moderate and severe head injury had significantly lower satisfaction scores than control group. Variables: a) significant: none. b) non-significant: injury severity.

Authors, Year, Location	Sample	Relationship Satisfaction Measures used	Summary of Results (Changes in satisfaction; Variables affecting satisfaction)
	Range of time since injury= 1-10 years. Recruited via hospital medical records.		
Williams, 1993, USA	40 partners of persons with stroke- split into 3 groups based on severity of aphasia (10 mild; 13 moderate; 17 severe impairment). Range of time since injury= 1 month- 30 years. No information regarding recruitment procedure.	Marital Satisfaction Scale- 48 items	Partner satisfaction was significantly poorer following partner injury (based on pre and post-stroke scores of MSS), regardless of aphasia severity (significant differences across all 3 severity groups). Variables: a) significant: better aphasia knowledge of partner associated with higher satisfaction b) non-significant: time post-injury; relationship length.
Williams & Freer, 1986, USA	16 partners of persons with stroke- split into 3 groups based on severity of aphasia (5 mild; 5 moderate; 6 severe impairment). Mean time since injury= 13 months. Referred via medical professionals.	Marital Satisfaction Scale- 48 items	Partner satisfaction was significantly poorer post-injury (based on pre and post-stroke scores of MSS), regardless of aphasia severity (significant differences across all 3 severity groups). Variables: a) significant: weak negative association with relationship length. b) non-significant: time post-injury; partner aphasia knowledge.

Authors, Year, Location	Sample	Relationship Satisfaction Measures used	Summary of Results (Changes in satisfaction; Variables affecting satisfaction)
Williams & Wood 2013, UK	47 participants with moderate-severe TBI and their partners. Mean time since injury= 2.71 years (range 0.41-8.80 years). Recruited via head injury clinic.	Dyadic Adjustment Scale & Index of Marital satisfaction (IMS)[6]	Partners reported significantly worse satisfaction than the person with TBI on both measures. Variables: a) significant: positive correlation with time post-injury and partner satisfaction but only on IMS; positive correlation with alexithymia and emotional recognition difficulties and partner satisfaction but only on IMS (and not significant in overall regression). b) non-significant: no correlations on DAS satisfaction subscale; injury severity and partner satisfaction; relationship length and partner satisfaction; presence of children and partner satisfaction.

6 Hudson & Glisson, 1976

Location

Studies were conducted in USA (n=7), Canada (n=3), UK (n=1) and Denmark (n=1).

Samples

Participants had experienced either traumatic brain injury (n=4) or a stroke (n=6). The two papers by Peters et al. (1990, 1992) did not specify what type of brain injury participants had sustained. Participant samples ranged in the severity of brain injury sustained, from mild to severe impairment. Five papers included participants with a range of injury severity. Three papers (Blonder et al., 2012; Hess & Perrone-McGovern, 2016; Kieffer-Kristensen & Teasdale, 2011) did not state participants' injury severity. For studies that included the satisfaction ratings of the person with brain injury, the participants generally had milder impairments to ensure consent to participate. In terms of time since injury, this ranged significantly between the papers, with Bannon et al. (2022) recruiting participants within 72 hours of injury, while some papers recruited persons whose injury had occurred many years before their participation in the study. Hess and Perrone-McGovern (2016) was the only paper that did not include information regarding this variable for their sample.

In terms of the types of participants recruited, three studies included both the person with the brain injury and their partners as participants. Four studies just included outcomes from the person with the brain injury and five studies focused solely on partner outcomes.

Sample sizes ranged considerably, the lowest being 12 participants with brain injury in Blonder et al. (2012) and the highest being 122 participants in Hess and Perrone-McGovern (2016). The majority of participants were recruited via hospital records or rehabilitation centres. Only one paper (Williams, 1993) did not detail their recruitment procedure.

Satisfaction Measures

There was significant variation regarding how satisfaction was measured across the papers with nine different measures used. The most common of these were the DAS (n=4) and MSS (n=4). As reported in the data quality section, five studies lacked detail or did not

include any information regarding psychometric properties of the measures used. Of those that did, psychometric properties were reported based on the original paper describing the development of the measure, and therefore were not specifically related to its use within brain injury.

Synthesis of Key Findings

Studies addressed two broad questions, whether brain injury has an impact on relationship satisfaction, and what variables are associated with relationship satisfaction in brain injury.

Does brain injury impact on relationship satisfaction?

Studies have tried to understand whether the occurrence of a brain injury impacts on satisfaction. Some studies have compared couples' satisfaction ratings after brain injury to control groups (with couples either from the general population, or where one of the partners is living with another health condition); other studies have observed whether couples' relationship satisfaction ratings differ pre and post-injury. Studies have also compared satisfaction ratings between people with brain injury and their partners.

Impact of Brain Injury on Satisfaction compared to Other Groups

One study (Blonder et al., 2012) compared the relationship satisfaction of persons with brain injury to the satisfaction of healthy controls. They found persons with brain injury had lower scores on the MSS than the healthy controls, however this was not a statistically significant difference. The data was not normally distributed and so the researchers had to use non-parametric tests which lack power. Additionally, the small sample size means the probability of detecting any real difference between the groups was very low (high probability of Type-II error) and likely contributed to the findings being non-significant.

Two studies (Peters et al., 1992; Kieffer-Kristensen & Teasdale, 2011) compared the satisfaction of couples in a brain injury group to groups of individuals with other health conditions and their partners. Kieffer-Kristensen and Teasdale (2011) compared the satisfaction of couples after brain injury to people with diabetes and their partner. While they did find partners of the persons with brain injury reported statistically significantly lower satisfaction on the DAS satisfaction subscale than partners of persons with diabetes,

there were no significant differences in satisfaction between the individuals with the health conditions. Peters et al. (1992) also found statistically significant differences using the DAS satisfaction scale with partners of persons with brain injury (moderate and severe impairment) reporting lower satisfaction than a group of partners of persons with spinal cord injury.

Differences in Partner Satisfaction Pre and Post Brain Injury

Two studies (Williams & Freer, 1986; Williams, 1993) reported on partners' perceived changes in satisfaction following brain injury. Partners were asked to complete two versions of the MSS, one regarding their perceptions of their relationship satisfaction prior to the injury (completed retrospectively), and the other based on their current relationship post-injury. Scores were then compared between the two. Both studies reported statistically significant differences in satisfaction pre and post-injury, with participants rating their satisfaction post-injury as significantly poorer than pre-injury. In addition, these studies focused on the impact of aphasia symptoms following brain injury, with participants grouped into three severity levels (mild, moderate and severe) according to their performance on the Boston Diagnostic Aphasia Examination. Both studies reported that partners rated their satisfaction post-injury as lower, regardless of the severity of their partner's aphasia. Both papers used the MSS to measure satisfaction and identified common areas that the participants rated their relationship more poorly in. These included aspects such as emotional support and lifestyle changes, and feeling like the relationship was having a negative effect on their overall health.

In addition to these studies, McPherson et al. (2011) also used a partner participant sample, however they only asked partners to rate their current (post-injury) satisfaction. 89.2% of partners rated their satisfaction on the QMI as between 6 (happy) and 10 (perfectly happy), suggesting good rates of satisfaction. It is difficult to compare these ratings with other studies however due to the variance in measures. The high satisfaction ratings may have been skewed due to the study's limitations, for example, no data was collected on non-responders (with only a 49.2% response rate) and only partners of persons with mild injury were recruited.

Differences in Satisfaction Pre and Post Brain Injury for Person with Brain Injury

Only Bannon et al. (2022) looked at pre and post-injury differences in satisfaction for the person with the brain injury. In contrast to the partner studies, they did not find a significant change in satisfaction, however methodological decisions may have impacted on the findings. For example, participants had only been 1-month into their recovery post-injury when they completed their pre and post measures, which might not have allowed time for any relationship changes to become apparent. Participants also had mild impairments, which may not have been significant enough to impact on the relationship so early on. The researchers also reported their sample differed to the usual in brain injury research with the inclusion of more middle-aged and female participants. Despite the changes in satisfaction not being significant, 52% of the participants did report clinically significant relationship dissatisfaction post-injury; Bannon et al. (2022) reports this level of dissatisfaction is higher compared to the general population. Those who reported poorer satisfaction post-injury were found to have significantly lower satisfaction scores at baseline than those who reported an improvement over time.

Similar to the McPherson et al. (2011) study, Clark and Stephens (1996) only assessed individuals' current (post-injury) satisfaction. In their sample, the average score was 23/25 (with 25 being suggestive of high satisfaction). Similarly, to the McPherson et al. (2011) study, the response rate was poor which may have contributed to the higher satisfaction ratings according to the types of participants that were recruited.

Differences in Satisfaction between Partner and Person with Brain Injury

Three studies (Blonder et al., 2007; Kieffer-Kristensen & Teasdale, 2011; Williams & Wood, 2013) reported differences in satisfaction between the person with the brain injury and their partner. Two of these (Kieffer-Kristensen & Teasdale, 2011; Williams & Wood, 2013) found that partners reported statistically significantly worse satisfaction than their injured partner. Williams and Wood (2013) reported the partner's mean score on the IMS in their study was above the cut-off of 30, suggestive of clinically significant relationship problems. In contrast, Blonder et al. (2007) did not find significant differences in satisfaction between the couple's relationship satisfaction ratings.

Summary of Findings

Table 6 summarises the overall findings in relation to whether the occurrence of a brain injury impacts on satisfaction, both from the person with the brain injury and their partner's perspective.

Table 6

Summary of Findings

	Partner	**Person with brain injury**
Comparisons with other groups		
Significant Difference	Kieffer-Kristensen & Teasdale (2011); Peters et al. (1992)	N/A
No Significant Difference	N/A	Blonder et al. (2012); Kieffer-Kristensen & Teasdale (2011)
Comparisons between partner and person with brain injury		
Significant Difference	Kieffer-Kristensen & Teasdale (2011); Williams & Wood (2013)	
No Significant Difference	Blonder et al. (2007)	
Before-after comparisons		
Significant Difference	Williams & Freer (1986); Williams (1993)	N/A
No Significant Difference	N/A	Bannon et al. (2022)

What are the Variables associated with Satisfaction?

Studies have also attempted to understand whether there are key variables that are associated with relationship satisfaction after brain injury. The papers included in this

review looked at a range of variables which have been arranged into four areas: demographic characteristics; characteristics and symptoms of the person's brain injury; characteristics of the couple relationship; and psychological variables.

Demographics

Three studies (McPherson et al., 2011; Hess & Perrone-McGovern, 2016; Bannon et al., 2022) analysed associations between the couple's demographics and their satisfaction ratings. None of the studies found gender to be related to satisfaction. In terms of age however, while neither McPherson et al. (2011) nor Bannon et al. (2022) found this to be related to either partner's satisfaction in their studies; Hess and Perrone-McGovern (2016) did find a significant negative correlation between the person with brain injury's age and their own relationship satisfaction. There may have been some confounding variables leading to this significant association, for example, over fifty percent of this study's sample were under 25 years old.

Characteristics and Symptoms of Brain Injury

Six papers (Williams & Freer, 1986; Williams, 1993; Blonder et al., 2007; McPherson et al., 2011; Williams & Wood, 2013; Hess & Perrone-McGovern, 2016) analysed whether satisfaction was related to the time since the brain injury occurred. Only Williams and Wood (2013) found this variable to be significantly correlated with partner satisfaction when using the IMS measure, which suggested the number of relationship problems perceived by partners worsened over time. They did not find the same association on the DAS satisfaction subscale however, which suggests differences in what these measures are assessing. The authors felt these findings supported research that suggests the risk of relationship breakdown continues to persist for couples over time.

Five studies (Peters et al., 1990; Peters et al., 1992; Blonder et al., 2007; McPherson et al., 2011; Williams & Wood, 2013) were interested in whether injury severity, for example, level of impairment (Blonder et al., 2007) or initial GCS scores (Williams & Wood, 2013), impacted on the partner's relationship satisfaction. None of these found significant associations. This could have been due to methodological issues, for example, the severity groups in Peters et al. (1990) were unevenly distributed with persons with mild injury underrepresented, and Blonder et al.'s (2007) sample consisted of

couples within the first few months of injury when severity may not be as an important factor in satisfaction. Also, participants in the McPherson et al. (2011) study were excluded if they had significantly impaired cognitive ability.

Two papers (Blonder et al., 2012; Bannon et al., 2022) looked at whether a person's brain injury symptoms impacted on their own relationship satisfaction. Both studies found higher satisfaction to be linked to fewer impairments. For Bannon et al. (2022), this was based on the Rivermead Post-Concussion Symptoms Questionnaire (assessing emotional, physical and cognitive symptoms), and they found that a greater number of these symptoms were linked to a decline in satisfaction over time. Blonder et al. (2012) found that difficulties in being able to recognise and understand their partner's facial and emotional expressions, were linked to lower satisfaction in the person with the brain injury.

Williams & Wood (2013) looked at whether the partner's relationship satisfaction was affected by particular symptoms of the person's brain injury. They focused on a person's emotional recognition skills post-injury, finding more impairments in this area to be related to poorer satisfaction. After adjusting for covariates of time since injury, relationship length, and the presence of children, they also found partners of persons with alexithymia difficulties (that is a difficulty identifying and describing one's own and other's emotions, which may lead to a concrete thinking style, making it more difficult for individuals to think about the feelings of others) had lower satisfaction scores than persons with no alexithymia. This association however was only present for the IMS and not the DAS satisfaction subscale. Although this finding of lower satisfaction was significant on its own in predicting more alexithymia difficulties, it was not significant in the overall regression model (step one variables being the covariates, and step two being the introduction of the alexithymia measure scores). It is possible that the correlation with alexithymia may have been due to the spurious correlation of both variables with another variable included in the regression, rather than to any direct impact alexithymia had on satisfaction.

Meanwhile, both Williams and Freer (1986) and Williams (1993) looked at how knowledgeable partners were regarding the symptom of aphasia and whether this influenced their relationship satisfaction. While Williams and Freer (1986) did not find a

correlation between these, Williams (1993) (which built upon the findings of Williams and Freer with a larger sample) did find a positive correlation i.e., that less knowledge of aphasia was linked to lower satisfaction scores. This may have been due to the latter recruiting a larger sample size.

Characteristics of Couple Relationship

Five studies (Williams & Freer, 1986; Williams,1993; Williams & Wood, 2013; Hess & Perrone-McGovern, 2016; Bannon et al.,2022) carried out analysis on whether the length of the couple's whole relationship (including time before the injury occurred) influenced satisfaction. There were no associations between relationship length and the person with brain injury's satisfaction (Hess & Perrone-McGovern, 2016; Bannon et al., 2022). In regards to their partner's satisfaction, neither Williams (1993) nor Williams and Wood (2013) found a correlation. Williams and Freer (1986) reported a weak association ($r = .31$), with a longer relationship being linked to poorer satisfaction post-injury. This association is likely to have been affected by relationship length being confounded by the overlap with time since injury rather than a causal association. In terms of other characteristics of the couple relationship, Williams and Wood (2013) did not find the presence of children in the relationship to be related to partner satisfaction.

Four studies (Clark & Stephens, 1996; McPherson et al., 2011; Hess & Perrone-McGovern, 2016; Bannon et al., 2022) looked at more specific aspects of the couple relationship, with couples more likely to rate their satisfaction as higher if elements of a strong relationship were present.

Three studies looked at satisfaction outcomes of the person with the brain injury. Bannon et al. (2022) reported the more satisfied the person with the brain injury was with their relationship before their injury, the more likely they were to rate their satisfaction as higher post-injury. Higher current satisfaction in persons with the brain injury was also related to attachment security and partner support, both in terms of emotional and physical assistance (Hess & Perrone-McGovern, 2016). This was similar to the Clark and Stephens (1996) findings who found persons who perceived their partners' actions of support as more helpful, rated their relationship as more positive and therefore reported higher satisfaction post-injury.

McPherson et al. (2011) looked at partner satisfaction outcomes and found higher satisfaction was related to their perception of having had an equitable relationship pre-injury. Satisfaction was not correlated with current equity, with the researchers suggesting this may be less important once one partner is more in need of support than the other.

Psychological Variables

Both papers by Blonder et al. (2007; 2012) were interested in whether relationship satisfaction was linked to mood in either partner. Blonder et al. (2012) did not find any association between the person with brain injury's satisfaction and their reported levels of depression. Blonder et al. (2007) meanwhile did find a significant negative correlation between the person with brain injury's depression scores and their partner's satisfaction (the more depressed the person with the brain injury was, the less satisfied in the relationship their partner was). This was a significant result even after multiple comparisons were conducted (due to the three outcome variables, of which satisfaction was one, being highly correlated), and the alpha level was amended (using the Bonferroni correction to reduce a type I error of obtaining false-positive results).

Blonder et al. (2007) also reported a significant negative correlation between partner satisfaction and their own stress levels (based on a measure that looked at aspects such as personal distress and negative feelings). This correlation was not significant however after controlling for multiple comparisons and adjusted alpha (using the Bonferroni method).

Two papers also found significant associations between satisfaction and quality of life. Hess and Perrone-McGovern (2016) found a significant positive correlation between the person with brain injury's health- related quality of life (HRQOL) and satisfaction. Following a multiple regression analysis, the three predictor variables of attachment security, partner support, and relationship satisfaction were found to collectively account for a significant level of variance (25%) towards HRQOL. However, satisfaction (nor partner support) personally accounted for a significant amount of variance in HRQOL (with attachment security making up 21% of the collective variance). Meanwhile McPherson et al. (2011) looked at partner outcomes and although they did not find links between satisfaction and physical components of quality of life, such as the partner's physical functioning and general health, they did find a significant correlation with

psychological aspects, such as mental health and social functioning. However, due to the study design, they were unable to report the direction of this association.

Summary of Findings

Table 7 summarises the overall findings in relation to the key variables that were associated with relationship satisfaction after brain injury.

Table 7

Summary of Findings

	Partner	**Person with brain injury**
Significant Association with satisfaction	**Demographics** N/A **Characteristics and Symptoms of Brain Injury** Time post-injury: Williams & Wood (2013) Partner aphasia knowledge: Williams (1993) Alexithymia and emotional recognition skills difficulties resulting from partner's injury: Williams & Wood (2013) **Characteristics of Couple Relationship** Relationship length: Williams & Freer (1986) Previous balance in relationship: McPherson et al. (2011) **Psychological Variables** Depression scores of the person with brain injury: Blonder et al. (2007)	**Demographics** Age: Hess & Perrone-McGovern (2016). **Characteristics and Symptoms of Brain Injury** Injury symptoms (emotional, physical and cognitive): Bannon et al. (2022) Cognitive injury related symptoms: Blonder et al. (2012) **Characteristics of Couple Relationship** High satisfaction of relationship before injury: Bannon et al. (2022). Attachment security and partner support: Hess & Perrone-McGovern (2016). Perceptions of partner's helpful/unhelpful action: Clark & Stephens (1996) **Psychological Variables**

	Partner	Person with brain injury
	Stress: Blonder et al. (2007) Quality of life- Mental component: McPherson et al. (2011)	Quality of life- Health related: Hess & Perrone-McGovern (2016).
No Significant Association with satisfaction	**Demographics** Gender: McPherson et al. (2011) Age: McPherson et al. (2011) **Characteristics and Symptoms of Brain Injury** Time post-injury: Williams (1993); Williams & Freer (1986); Blonder et al. (2007); McPherson et al. (2011) Injury severity: Peters et al. (1990); Peters et al. (1992); Williams & Wood (2013). Blonder et al. (2007); McPherson et al. (2011). Partner aphasia knowledge: Williams & Freer (1986) **Characteristics of Couple Relationship** Relationship length: Williams (1993); Williams & Wood (2013) Presence of children: Williams & Wood (2013) **Psychological Variables** Quality of life- Physical component: McPherson et al. (2011)	**Demographics** Gender: Hess & Perrone-McGovern (2016) Age: Bannon et al. (2022) **Characteristics and Symptoms of Brain Injury** Time post-injury: Hess & Perrone-McGovern (2016) **Characteristics of Couple Relationship** Relationship length: Bannon et al. (2022); Hess & Perrone-McGovern (2016). **Psychological Variables** Depression: Blonder et al. (2012).

Discussion

This review of twelve studies aimed to synthesise findings on partner relationship satisfaction in the context of brain injury, including variables that may affect relationship satisfaction, both from the perspective of the person with the injury and their partner.

Summary of Evidence

Persons with brain injury did not differ significantly from healthy controls (Blonder et al., 2012) or from people with other health conditions (Peters et al., 1992; Kieffer-Kristensen & Teasdale, 2011) in their ratings of relationship satisfaction. In contrast, their partners rated their satisfaction as significantly lower than partners of people with other health conditions (Kieffer-Kristensen & Teasdale, 2011; Peters et al., 1992).

Partners' post-injury ratings of satisfaction were significantly lower than pre-injury ratings (Williams and Freer, 1986; Williams, 1993). For persons with brain injury, the one study that examined this (Bannon et al., 2022) found no significant differences in satisfaction ratings pre and post-injury.

In studies which examined differences in satisfaction between the person with the brain injury and their partner, two of the three studies reported significantly poorer satisfaction in partners compared to the person with the brain injury (Kieffer-Kristensen & Teasdale, 2011; Williams & Wood, 2013).

Studies also examined which variables were associated with relationship satisfaction after brain injury. Of the three studies examining demographic variables (Hess & Perrone-McGovern, 2016; McPherson et al., 2011; Bannon et al., 2022), only Hess and Perrone-McGovern (2016) reported a significant association; being a negative correlation between the person with brain injury's age and their relationship satisfaction.

Of the six studies which examined the association between time since injury and satisfaction (Williams & Wood, 2013; Williams, 1993; Williams & Freer, 1986; Blonder et al., 2007; McPherson et al., 2011; Hess & Perrone-McGovern, 2016), only Williams and Wood (2013) found a significant association with partner satisfaction, but they only found this on the IMS and not the DAS. None of the five studies examining associations between injury severity and satisfaction (Peters et al.,1990; Peters et al., 1992; Williams & Wood, 2013; Blonder et al., 2007; McPherson et al., 2011) reported significant results. In terms of

injury symptoms, Bannon et al. (2022) reported a range of symptoms were related to the person with brain injury's satisfaction. More specifically, a reduction in the person with brain injury's emotional recognition skills was associated with poorer satisfaction for both the person with brain injury (Blonder et al., 2012) and their partner (Williams and Wood, 2013). Williams and Freer (1986) also found the more knowledge a partner had in relation to aphasia, the more satisfied they were in their relationship.

The overall length of the couple's relationship was not found to be associated with the person with brain injury's satisfaction (Bannon et al., 2022; Hess & Perrone-McGovern, 2016). Of the three studies measuring this variable in relation to the partner's satisfaction (Williams & Freer, 1986; Williams, 1993; Williams & Wood, 2013), only Williams and Freer (1986) reported an association (although this was a weak correlation), with a longer relationship being linked to poorer partner satisfaction post-injury.

Four studies reported on other characteristics of the couple relationship. Only one of these papers (McPherson et al., 2011) looked at partner outcomes; finding higher satisfaction was related to the partner's perception of having experienced an equitable pre-injury relationship. Of the three studies that looked at satisfaction of the person with the brain injury, higher satisfaction post-injury was linked to high satisfaction pre-injury (Bannon et al., 2022), attachment security (Hess & Perrone-McGovern, 2016), and partner support (Hess & Perrone-McGovern, 2016; Clark and Stephens, 1996).

Satisfaction was also linked to psychological health, with Blonder et al. (2007) reporting a significant negative correlation between the non-injured partner's satisfaction scores and the person with brain injury's depression, and a significant negative correlation between partner satisfaction and their own stress levels. Two papers (McPherson et al., 2011; Hess & Perrone-McGovern, 2016) found associations between satisfaction and quality of life. While Hess and Perrone-McGovern (2016) reported higher satisfaction in the person with the brain injury and better quality of life, McPherson et al. (2011) were unable to determine the direction of this association.

Limitations of Studies

As reported in the quality analysis, studies were of generally poor quality which likely contributed to the mixed findings. All studies used an observational design; although

significant associations were found, causal conclusions cannot be drawn. For some studies, such as McPherson et al. (2011), the design meant they were unable to predict the direction of the associations detected. Some studies did not report strict control or measurement over potential confounding variables that might have affected satisfaction. This means less confidence can be placed in the reported associations that they were not influenced by another variable. In addition, due to study designs being cross-sectional, couples had to retrospectively judge what their pre-injury satisfaction was like, which could have increased response bias.

Strict inclusion and exclusion criteria were applied to ensure all studies utilised a measure of relationship satisfaction as intended by the developers of the questionnaire. However, there was variability and inconsistency in the measures being used to assess satisfaction, making it difficult to compare findings. There was also inconsistency with when satisfaction was measured, with some studies conducting pre and post measures at the same time point. Satisfaction ratings were also based on self-report which has its own methodological limitations.

The quality appraisal showed issues with sample sizes which were relatively small in most studies. This means many studies were underpowered, and so were likely unable to detect a significant difference where there may have been one. In terms of generalisability, the majority of studies recruited older persons (only Hess and Perrone-McGovern, 2016 recruited a younger sample; all the other papers reported their participant sample's mean age to be over 40). Samples were also over representative of female partners. Additionally, the participant samples across studies ranged in both injury severity (with four studies recruiting participants with milder impairments) and time since injury (from a few days to many years post-injury). This makes it difficult to compare findings, and are likely to have contributed to the contradictory results. Graham et al. (2011) also suggest uncertainty as to the generalisability of findings to couples with other demographics, such as younger or same sex couples.

Interpretation of Findings

Does brain injury impact on relationship satisfaction?

For the person with the brain injury, neither of the two studies comparing satisfaction ratings between them and persons with other health conditions found a significant difference. Following a brain injury, individuals often underreport symptoms (Godfrey et al., 1993) due to reduced insight and awareness into their deficits (anosognosia) (Gasquoine, 2016). This may explain these non-significant findings. Indeed, Burridge et al. (2007) found persons with brain injury had less insight into their social-emotional difficulties than persons with chronic pain and healthy controls. There were no significant differences in the study looking at pre and post-injury satisfaction ratings in the injured persons either (Bannon et al., 2022). Anosognosia is related to time post-injury (Gasquoine, 2016) and so the fact that participants were recruited within a few days of diagnosis may have led to this non-significant difference. Some of the study's other methodological issues may also have contributed, for example the short timeframe between the measures being completed and the recruitment of participants with only mild impairments.

In terms of the non-injured partner's satisfaction, they rated their satisfaction as both significantly poorer following their partner's injury, and when compared to their injured partner's satisfaction. Additionally, two studies reported significant differences in partner satisfaction when compared to partners of persons with other health conditions. These findings are likely due to the non-injured partner directly experiencing the effects of socio-emotional changes in their partner (which other conditions are not directly associated with). These changes have been found to impact on the partner and their experience in the relationship more than for the person themselves (Gosling & Oddy, 1999), with the partner more likely to feel like their relationship is different to their pre-injury relationship (Riley et al., 2020). Gosling and Oddy (1999) suggest the impact of these changes are also heightened by the lack of insight the injured person has into their difficulties (which is amplified after a brain injury compared to other health conditions).

Variables associated with Satisfaction

The only demographic variable that was found to have an association with satisfaction was the person with brain injury's age (Hess & Perrone-McGovern, 2016). This appears in contrast to van den Broeck et al.'s (2022, in press) review which found five studies that reported those who were older rated their relationship quality as poorer.

These contrasting findings highlight the potential issues of using a variety of measures and interchangeable concepts related to relationships; perhaps age has a greater influence on other elements that make up relationship quality (rather than satisfaction).

A potentially unexpected finding was that injury severity was not found to be significantly associated with satisfaction. In the three previous reviews of Godwin et al. (2011), Blais and Boisvert (2005) and van den Broek (2022, in press), injury severity was found to be related to both relationship stability and quality. This review's non-significant findings may be due to methodological issues with the participant samples, for example, a third of the studies recruited persons with only mild impairments, and only two studies (Peters et al. 1990; 1992) compared participants of mild to severe injury. However, it could be that severity overall is less important than the specific type of impairments that couples have to cope with. Indeed, injury severity has not been found to significantly correlate with overall distress in caregivers, but rather it is the specific impairments related to the injury that relate to higher distress (Prigatano et al., 2005). This is supported by the findings in this review in relation to injury symptoms. For example, Bannon et al. (2022) reported a range of symptoms were related to the person with brain injury's satisfaction. Poorer satisfaction was also associated with a reduction in socio-emotional emotional skills for both the injured person (Blonder et al., 2012) and their partner (Williams and Wood, 2013). Studies have reported socio-emotional changes in particular are reported by partners to be more difficult to manage than cognitive and physical changes (Yasmin & Riley, 2021) as they are more specifically related to relationship difficulties. For example, these changes have been found to be associated with reduced intimacy and feelings of isolation (O'Keeffe et al., 2020), loss of companionship (Gosling & Oddy, 1999) and loss of empathy (Burridge et al., 2007), all of which are required for healthy relationship maintenance.

In addition, the more knowledge partners had regarding aphasia, the better they rated their satisfaction (Williams, 1993). Aphasia has been shown to cause partners' distress due to the changes to the injured person's personality (Yeates et al., 2013). Qualitative research has suggested that the more understanding partners have about changes following brain injury, the better their ability to cope (Bodley-Scott & Riley, 2015; Villa & Riley. 2017), which may improve relationship satisfaction.

Variables related to the couple relationship appeared to be more consistently associated with relationship satisfaction. Three of the papers looking at these variables (McPherson et al., 2011; Hess & Perrone-McGovern, 2016; Bannon et al., 2022) were the only three out of the twelve reviewed papers that were judged to have met all six areas of the quality appraisal. A stronger relationship is related to better outcomes post-injury, such as healthier emotional well-being (Kendall & Terry, 2009) and improved quality of caregiver support (Riley et al., 2020). This would help to explain why elements such as partner support were found to be related to satisfaction.

A brain injury can cause significant burden on the partner (Baker et al., 2017) which is shown as likely to increase levels of depression, anxiety and stress (Kreutzer et al., 1994; Turner et al., 2010), supporting the studies that found these psychological variables to be related to satisfaction.

Implications

This review adds to the existing findings of the previous reviews of Blais and Boisvert (2005), Godwin et al. (2011), and van den Broeck et al. (2022, in press). These reviews focused on marital quality which van den Broeck et al. acknowledge includes a number of different variables (only one of which is relationship satisfaction) which are likely to be differently affected. By focusing exclusively on relationship satisfaction, and being stringent in the inclusion and exclusion of relationship satisfaction measures, this review provides conceptual clarity over this aspect of a relationship and its associated variables.

The evidence in relation to variables that may influence satisfaction are promising for couple interventions. In terms of demographics, relationship length, and injury severity (elements which the couple cannot change), there was no to limited evidence for their associations with satisfaction. On the other hand, a reduction in emotional recognition skills, and the presence of partner support received, seemed to have stronger associations with satisfaction. These could be promising aspects for interventions to focus on in supporting couples to improve these areas in their relationship. For example, the Couples Caring and Relating with Empathy Intervention (Backhaus et al., 2016) which has been developed to help increase positive communication, emotional regulation and coping skills. It seems also helpful for interventions to support the person with the brain injury in

enhancing their insight and awareness into their symptoms (such as Ownsworth, McFarland, & Young's, 2000 group program). Improved awareness into impairments has been shown to improve rehabilitation outcomes (Ownsworth & Clare, 2006) and therefore may also help to reduce the impact of symptoms on the partner.

Recommendations for Future Research

Previous reviews suggested research should include both partners, and this remained an issue of this review with only a quarter of the papers achieving this. This recommendation is further strengthened by the findings of this review which suggest that relationship satisfaction differs between the person with the brain injury and their partner, and that the variables associated with it may differ between the two, which further research may help to understand. To enhance understanding of how persons with a brain injury perceive their relationship, more research needs to focus on gathering their perspective. Studies need to include larger samples of varying demographics, which in four studies limited their ability to use multivariate analyses, while also being considerably underpowered to detect significant relationships where they might exist. In addition, if researchers are comparing other couples with brain injury to other health conditions or other types of caregivers, it would be helpful to report these groups as separate data so these findings can be added to the existing literature (four studies were excluded from the review due to this issue). Studies also report the importance of longitudinal research (Peters et al., 1990; McPherson et al., 2011). This would reduce the bias of retrospective ratings, as well as help to understand the direction of the association between variables.

Future research into relational outcomes would benefit from clearer definition of concepts and a smaller variability of measures used. This would enhance the ability of being able to compare findings more appropriately, building a better idea of which variables are more consistently associated with different relational outcomes. Some papers that proclaimed they were measuring satisfaction were excluded from this review due to the measures being used lacking face validity. The Couples Satisfaction Index (Funk & Rogge, 2007) has showed more precision in assessing satisfaction and greater responsiveness to change than the DAS, and has been recommended for future research into relationship satisfaction in the general population (Fincham & Beach, 2010). By using

the same measures for brain injury research, more reliable comparisons between these two groups can be made.

Additionally, given that variables related to the couple relationship seem to be more consistently associated with relationship satisfaction, it would appear appropriate for studies to focus more on these, potentially drawing on qualitative research that has started to identify aspects of the relationship that appear relevant for both persons with brain injury and their partner. Furthermore, the papers were deficit oriented, which is highlighted in van den Broeck et al.'s conclusions, with them recommending the need for studies to also explore any possible positive effects on a relationship after brain injury. The studies in the present review do not take into account or control for what couples' relationships were like before the brain injury occurred. This problem is exacerbated by the use of retrospective ratings, which are likely to have a degree of bias. Further qualitative analysis would be helpful in understanding and exploring the nature of the connections between variables related to the couple relationship and the brain injury, and relationship outcomes.

Conclusions

Research is suggestive of relationship satisfaction being impacted on following brain injury for the non-injured partners, however there is no evidence that this is the case for the persons with the brain injury themselves. Few variables were reliably associated with relationship satisfaction for either the person with the brain injury or their partner. The design limitations and overall quality of the studies available has led to mixed findings, making it difficult to draw solid conclusions and causal associations. However, those that were more consistently associated with satisfaction were in relation to aspects of the couple relationship, such as a reduction in the injured person's emotional recognition skills and the presence of partner support, and symptoms of the brain injury, particularly cognitive related impairments. It is suggested that these aspects should inform the focus of couple interventions. Echoing the recommendations from previous reviews, research should focus on recruiting larger samples of varying demographics, including both partners in the couple, and improving on the study designs, for example by conducting more longitudinal research.

This review has brought the literature together in a way that has not been presented before, by focusing on satisfaction as a stand-alone concept, and demonstrating the

importance of a clearer definition of concepts and a smaller variability of measures used. Improving on this would enhance the ability of being able to compare findings more appropriately, building a better idea of which variables are more consistently associated with different relational outcomes.

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CHAPTER II: AN EXPLORATION INTO HOW PARTNERS OF THOSE WITH A BRAIN INJURY EXPERIENCE LACK OF EMOTIONAL WARMTH, AND ITS IMPACT ON THE PARTNER RELATIONSHIP

Abstract

Introduction

Personality changes following a brain injury, such as the lack of expression of emotional warmth, can cause significant difficulty in the partner relationship, The loss of emotional warmth has been found to have high correlation with relationship discontinuity (Yasmin, 2019; Riley et al., 2020), yet limited research has attempted to understand the connection between the two. The aim of the present study was to explore in greater detail how partners experience changes in emotional warmth, and specifically to explore how they impact on the couple relationship.

Method

Seven participants (all partners of persons who had experienced a brain injury) were recruited via the charity Headway. Two semi-structured interviews were conducted with each participant. Interview transcripts were analysed using Interpretative Phenomenological Analysis.

Findings

Participants reported a range of changes in emotional warmth. Not all participants described changes in all behaviours, with some reporting that warmth from their partner was still experienced in some areas. Two superordinate themes were generated with four subordinate themes in each in relation to the impact these changes had on the partner relationship and how participants coped with these changes.

Conclusions

The findings support previous research that emotional changes are detrimental to the partner relationship and offers some understanding into how these changes impact on the relationship and how partners cope with these changes. In terms of clinical implications, more awareness needs to be given to these changes in clinical practice, both in terms of assessing them and offering support for managing them.

Introduction

Partner Relationships after Brain Injury

Although research is still limited into the impact on the couple relationship post brain injury (Blais & Boisvert, 2005; Godwin et al., 2011; O'Keeffe et al., 2020), the importance and value of a strong bond is paramount. Research has shown a strong partner relationship after injury is associated with better emotional well-being for both members of the couple (Kendall & Terry, 2009). This in turn improves the quality of care and support from the caregiver (Riley et al., 2020), leading to better rehabilitation outcomes for the person with the brain injury (Sander et al., 2002; Palmer & Glass, 2003).

The brain injury however, can place strain on the relationship, and poorer quality relationships alongside increased rates of relationship breakdown, are common post-injury. Physical, cognitive and personality changes can all significantly impact on the couple's emotional well-being, and relationship (Blais & Boisvert, 2005; Burridge et al., 2007; Hammond et al., 2011). Studies have reported various relationship breakdown rates of between 15-78% (Godwin et al., 2011), suggesting although there is clearly an impact after injury, limited understanding remains as to the factors involved. The non-injured partner often experiences higher levels of depression, anxiety and stress (Kreutzer et al., 1994; Turner et al., 2010; Kieffer-Kristensen & Teasdale, 2011), as well as high levels of burden, which can impact on family functioning (Baker et al., 2017).

Relationship outcomes are also often worse after injury. Significantly lower relationship quality and satisfaction compared to healthy controls has been reported by both the injury survivor (Ponsford, 2003) and their partner (Burridge et al., 2007; Kieffer-Kristensen & Teasdale, 2011). The caregiver's perception of their partner following injury (Hammond et al., 2011) and higher depression levels in the person with the injury (Blonder et al., 2007) have also been found to impact on relationship satisfaction and stability.

Emotional Warmth

One of the personality changes after a brain injury that can cause significant difficulty in the partner relationship is the lack of expression of emotional warmth, that is a disappearance of positive behaviours, feelings and interactions that bond and connect the

couple. This may be because the person with the brain injury's feelings in this area are reduced, or because as a result of the injury, they find it more challenging to be able to articulate or express their feelings and/or struggle to engage in those behaviours. Some areas (although not an exhaustive list) in which changes in expression of warmth may be displayed by the person with the brain injury are: passivity; coldness; lack of initiative and spontaneity; lack of sense of humour (or it becoming childlike); lack of closeness and connection regarding aspects of intimacy and/or a decrease in shared interests and enjoyment of activities; lack of giving and reciprocating affection; egocentricity and lack of, or insensitivity of, consideration for others; social withdrawal and disinterest; inability to recognize and respond to emotional cues; and difficulties in reciprocal conversations and responding appropriately (Wood & Williams, 2008; Yeates, 2013; Bodley-Scott & Riley, 2015; Fugi-Meyer et al., 2019; Yasmin, 2019; O'Keeffe et al., 2020).

Loss of Emotional Warmth and the Couple Relationship

There is evidence to suggest that socio-emotional and behavioural changes, such as those linked to emotional warmth, have a larger influence on relationships than physical or cognitive changes post-injury (Anderson et al., 2002; Yeates, 2013; Yasmin & Riley, 2021). These changes appear to have a greater impact on well-being and relationship satisfaction (Ponsford, 2003; Yasmin & Riley, 2021) as well as relationship quality, resulting in higher incidence of breakdown (Laratta et al., 2021). Partners in O'Keeffe et al.'s (2020) study reported to find the loss of emotional connection in the relationship as one of the most distressing changes. Participants also reported the changes in interactions with their partners led to reduced intimacy and feelings of isolation. A loss of companionship (Gosling & Oddy, 1999) and loss of empathy (Burridge et al., 2007) have been linked to lower partner relationship satisfaction, with both studies also reporting reductions in affection and emotional responsiveness from the person with the injury impact on partner satisfaction. Gosling and Oddy (1999) suggested this was heightened by the lack of insight the person with the brain injury had into their difficulties. Alexithymia has also been linked to lower relationship quality and dyadic cohesion (Williams & Wood, 2013). Bodley-Scott and Riley (2015) found a lack of positive behaviours and interactions was one of the three most challenging changes to deal with and highlighted interventions should support with the deficit of these behaviours.

How do these changes damage the relationship?

Although research demonstrates that changes in emotional warmth can be detrimental to the partner relationship, there is limited understanding into how these changes cause problems. One framework that can help to understand the impact on the partner relationship and the partner's experiences better is relationship discontinuity (Yasmin et al., 2020). This framework is used here to offer further support to our understanding, rather than being used to guide the research study itself. Studies such as Yasmin and Riley (2021) have started to investigate links between discontinuity and emotional warmth; the present study builds on this research by attempting to understand how partners experience and adjust to these changes. An alternative model to discontinuity is relational coring (Godwin et al., 2014). This model has some overlap with the discontinuity framework, for example, it highlights the different types of loss that may come from living with a partner with a brain injury, as well as the importance of forming a new identity as a couple, and the possibility of the existence of elements of the old relationship still being present. Thus far however, studies have not mapped their findings in relation to changes in emotional warmth onto this theory, whereas there is some existing research that has begun to do this in relation to the discontinuity framework. Therefore, as there is such limited understanding into this area, it was felt that furthering the existing research within the discontinuity framework would be most helpful.

Relationship Discontinuity

It is suggested that there are five areas that impact on relationship discontinuity (Riley et al., 2013). These are: relationship redefined, that is the where the partner perceives the relationship to have changed from the relationship it once was. Different person, that is if the partner perceives their loved one to be fundamentally different to before the injury. Different feelings, where feelings of love have diminished or other feelings have become more prominent. Couplehood, that is how much the partner feels the relationship has become less of a partnership and feelings of togetherness have reduced. The final area is related to feelings of loss in relation to the partner and/or the relationship. Relationship continuity in contrast is whereby the partner and the relationship are considered to be the same, or with similar characteristics and feelings, as before the injury (Riley et al., 2020). The development of a discontinuity measure demonstrated the areas to

be interdependent of each other, that is if a partner identifies with one element of discontinuity, they are more likely to identify with the other areas (Yasmin et al., 2020).

Emotional Warmth and Relationship Discontinuity

Research has begun to explore how impaired emotional warmth can lead to relationship discontinuity, with both Yasmin (2019) and Riley et al. (2020) reporting high correlation between the two. Yasmin and Riley (2021) carried out a further quantitative study investigating whether particular brain injury symptoms were more or less likely to lead to relationship discontinuity. Although in the study many of the brain injury symptoms investigated were associated with a more discontinuous relationship; in a multiple regression, emotional warmth was one of only four symptoms that made a significant contribution to the variance in discontinuity scores. They therefore reported partners who perceived a more discontinuous relationship were significantly more likely to experience less warmth and affection, and that discontinuity was more likely when this element was present compared to other injury symptoms.

Qualitative studies have also explored the possible connections between the lack of emotional warmth and discontinuity. Bodley-Scott and Riley (2015) found that elements such as coldness, lack of affection and empathy were destructive to the partner relationship, and led to feelings of loss and sadness of the partner and the relationship. They also highlighted that a reduction in pro-social behaviours, such as in engagement in conversation and shared humour, appeared to lessen the shared enjoyment of the couples' life together, which altered the partners' feelings of togetherness and led to a redefining of the relationship. Villa and Riley (2017) suggested partners found it difficult to express warmth themselves if this was not reciprocated by their partner with the brain injury, and/or if the partner felt feelings of love from the person with the brain injury had diminished (undermining same feelings). They suggested that loving feelings were integral to the relationship and its identity, and the way they perceived their partner, which worsened their perception of feeling the person, and therefore the relationship, was now different (undermining same person and leading to relationship redefined). Therefore, the presence of emotional warmth appears vital to the ongoing perceived continuous relationship.

Aims of Present Study

Although studies have begun to make connections between the loss of emotional warmth and the impact on relationship discontinuity, these findings have been within the context of broader issues. Further work is needed to understand how loss of emotional warmth from the person with the brain injury contributes to the experience of discontinuity in the partner. More generally, it has been identified that these symptoms have a damaging impact on the relationship (Anderson et al., 2002; Burridge et al., 2007; Bodley-Scott and Riley, 2015; Villa and Riley, 2017; Yasmin & Riley, 2021), but there is little understanding of the nature of that impact. There is limited research that has attempted to understand how partners experience and adjust to the changes in emotional warmth, with a focus on behavioural changes and less on emotional components (Braine, 2011; van den Broek et al., 2022).

The aim of the present study was to explore in greater detail how partners experience changes in emotional warmth, and specifically to explore how they impact on the couple relationship.

Method

Design

Phenomenological research is interested in the lived experience of individuals and the meaning they make to their experiences (Larkin, et al., 2006). Interpretative Phenomenological Analysis (IPA) is idiographic in nature, placing emphasis on the importance of each participant's story (Alase, 2017). This individual focus on each participant was felt to likely offer a better understanding of the complex experience of living with someone with a brain injury, compared to other qualitative methods. As there is limited understanding in this area of research, it was felt that using a less client- led technique with more structure, such as thematic analysis, might have lost valuable and rich information, with more focus on the convergence, and less focus on the divergence of experiences between individuals and therefore, possibly offering a difference in what themes may have been generated. The researcher takes a dual position by listening to the participant's account and gaining an insider perspective into how they make sense of their experiences; then during analysis, tries to develop an interpretation of what meaning the

participant has placed on their experiences (Reid et al., 2005). This process is known as a double hermeneutic. For these reasons, IPA is most suited to this study, which has also been utilised in other research investigating carers experiences and partner relationships (Smith, 2011) due to the subjective and multifaceted nature of a participant's experience (Tuffour, 2017). Ethical approval was granted through the University of Birmingham (Appendix A).

Participants

Inclusion Criteria

Due to IPA's idiographic approach, it was important to obtain a purposively selected homogenous sample to ensure participants had personal significance to the research topic. This also helps to gain a better insight into converge and divergence within the specific sample (Smith et al., 2009). Table 1 displays the study's inclusion criteria.

Table 1

Inclusion Criteria for Participation in the Study

Inclusion criteria	**Rationale**
Partners of persons with a Brain Injury. Both the participant and their partner with the brain injury must be over 18 years old.	To be able to give informed consent.
The participant must have suitable English.	To be able to give informed consent and undertake the interviews.
Participants were required to have been in a relationship with the person with the brain injury for at least 3 years prior to their brain injury diagnosis.	In order for participants to be able to reflect on their experiences pre and post-injury.
The brain injury had to have occurred at least 18 months prior to participation in the study.	It was hoped this meant participants would have begun to come to terms with the possible initial distress of their partner's diagnosis, and would be able to reflect on changes they had experienced and how they coped with these changes.

Inclusion criteria	Rationale
Participants had to have been cohabiting with their partner and had been living with them before they experienced their brain injury.	It was anticipated that those dealing with the issue of a loss of emotional warmth on a daily basis would be more likely to be able to give a rich account of their experiences.
Participants had to have identified a problem with a lack of emotional warmth in their relationship post-injury.	To ensure that participants had experience of the research topic.
Participants were advised to only take part if they thought discussions related to their relationship would not cause them undue distress.	To minimise the risk of any undue distress to the participant.

Recruitment

Participants were recruited through the brain injury charity Headway via one of two ways. The researcher attended a local carer group to present the research and for those unable to attend the group, the invitation to participate study advert (Appendix B) was emailed to them. The advert was also placed on the national Headway website and participants were invited to contact the researcher for more information.

If individuals were interested in participating, they were given the participant information sheet (Appendix C) and asked to complete a consent to contact form (Appendix D). The researcher contacted participants at least 48 hours after they had received the information sheet to confirm they met inclusion criteria. Participants were also given the opportunity to ask questions. If the participant was happy to take part, they were asked to complete the consent to participate form (Appendix E) and interviews were arranged.

Sample

IPA is suited to small sample sizes of up to 10 participants to allow the researcher to obtain detailed accounts of each individual's experience, and then be able to hold in

mind each participant, their transcript and the themes generated in each during the analysis phase (Smith and Osborn, 2015). Therefore, the aim was to interview 6-8 participants in line with these recommendations.

Overall, seven participants took part in the study. Three of these were recruited from Headway carer groups, the others responded to the website advert. Recruitment took place over eight months. A summary of participant demographic information is displayed in Table 2.

Table 2

Summary of Participant Demographic Information

Pseudonym and age of participant	**Pseudonym and age of partner**	**Type of brain injury**	**Length of time since injury (years)**	**Relationship length (years)**	**Children living in family home**
June, 82	Robert, 84	Stroke x2	10, 7	63	No
Rosie, 47	Tom, 49	ABI (Hypoxia)	8	21	Yes
Sally, 57	John, 53	Stroke	4.5	25	No
Helen, 39	Ben, 43	TBI (accident)	1.5	26	Yes
Isabella, 58	Penny, 58	ABI (aneurysm)	2	32	Yes
Emma, 52	Charlie, 63	Stroke	2	25	Yes
Otis, 61	Grace, 59	TBI (accident)	32	40	No

Data Collection

To allow for in-depth interpretative exploration and analysis, it was appropriate to conduct semi-structured interviews with partners of persons with a brain injury. This method is commonly used in IPA research (Smith, 2004) as it fits well with the idiographic, participant-oriented approach. The use of a topic guide (Appendix F) suited

the inductive and phenomenological nature of IPA (Smith, 2004) as it structured the interviews, but did not require specific questioning based on the researcher's explanations of what themes may come up (which may have been required in less client-led techniques), while allowing the participants flexibility to discuss what was important to them. Participants were also invited at the end of their interviews to share anything about their experiences which had not been asked.

Two semi-structured interviews of 60-90 minutes in length, with an average time of 72 minutes, were conducted with each participant. Due to Covid restrictions, all interviews were conducted and audio recorded via Zoom, and then stored securely via the platform before transcription. Mirick & Wladkowski (2019) demonstrated the benefits to conducting qualitative research over the internet, such as being able to reach a wider geographical area of participants. Participants reported to find non-verbal researcher feedback helped them to build rapport and feel validated, and that interpreting non-verbal cues was no more difficult than in face-to-face interviews.

The two interviews were conducted within 1-4 weeks of each other depending on participant availability. The advantages of conducting two interviews included building rapport, and participants having time to reflect on the relationship changes they had experienced, allowing for a richer second interview. The first interview focused on the participant's relationship pre-injury and the changes in emotional warmth experienced. The second interview focused on the partner's understanding of these changes, the impact the changes had on the relationship, and how they had coped with these changes. The use of two interviews in this way mirrors a similar approach by Fernandes (2019) who was also interested in the experience of changes in partner relationships following a health diagnosis.

At the start of each interview, the researcher answered any technological queries and ensured participants could complete the interviews privately. Participants were advised that their involvement was voluntary and they could stop their interviews at any time. At the end of each interview, participants were asked if they wanted any information redacted, and were reminded of their right to withdraw and the limits to this (within seven days after the second interview due to the analysis process having started at this point). Participants

were directed to the sources of support on their information sheet if it appeared that the interview had caused any distress.

Data Analysis

Participants were given pseudonyms during the transcription phase to protect anonymity. Audio recorded interviews were transcribed verbatim by the researcher before the analysis process begun.

Interpretative Phenomenological Analysis

The two interview transcripts for each participant were initially read through by the researcher who noted initial observations and reflections. The researcher then coded the two transcripts, noting participant's key objects of concern and their experiential claims (Larkin et al., 2006). Attention was paid to the language participants used to express their experiences to gain a deeper understanding of their sense making (Tuffour, 2017). Emergent themes for each participant were produced before moving on to the next participant's transcripts. Once themes were generated for each participant, the researcher looked for links between participants' themes in order to form superordinate themes, capturing examples of shared and divergent experiences across participants. Smith and Osborn (2015) suggest that themes should be included based on their frequency across participants, but also on the richness of the quotes, and how the themes help to illuminate opposing experiences. An IPA researcher supervision group was used to obtain feedback on themes and support their validity and plausibility. Direct quotes are used to illustrate participants' experiences of the themes. An example of the development of themes through the analysis process is provided in Appendix G.

Researcher Position

The researcher's own biases can influence their interpretation of the participants' experiences (Noon, 2018). Therefore, as they are integral to the analysis process, it is imperative to understand the researcher's positioning. The researcher has a personal interest in the research topic, having experienced living with a close relative who suffered a stroke, and being involved in the caring aspects of this. As a result of this journey, the researcher has a particular clinical interest in understanding the experiences of other caregivers of persons with a brain injury, the challenges they have faced, and the support

they have received, and is thus empathetic to the partner's stories. The researcher's personal experience of service support was limited and may have been an area that could have influenced the interpretation of the data without the processes put in place to maintain rigour.

To help reduce the researcher's influence on the analysis process and ensure rigour, a reflexive diary was kept. Following each interview, the researcher noted their own reflections and emotional responses, along with participant claims that would be useful to reflect on in the second interview. Smith et al. (2009) note the importance of the researcher bracketing off preconceptions during the interview to allow the participant freedom to talk about their experiences in the way they choose to express them. The researcher's reflections were also noted during the analysis process.

Findings

Participants provided rich data about the changes in emotional warmth that had emerged following their partner's injury, how they had experienced these changes in the context of their relationship, and how they coped with the changes. Alongside this, they talked about their general experiences of living with someone with a brain injury. The focus of the findings is in relation to the changes in emotional warmth and the participants' experiences of these, with a summary of their general experiences provided at the end.

Changes Identified

Participants reported a range of changes in emotional warmth, with many identifying a reduction in areas. Not all participants described changes in all behaviours, with some reporting that warmth from their partner was still experienced in some areas, such as shared humour. In addition, two participants reported that spending more time together improved their connection.

Reduced Empathy and Consideration for Partner's Needs

All participants reported significant reductions in this area. Helen, Emma and Rosie reported their partner's ability to understand their emotions had significantly reduced ("emotions puzzle him, just delude him in a way that they didn't used to", Emma; "the

emotional side of things just seems alien to him", Helen; "I can think I'm being really obvious about how I'm feeling and he really hasn't got a clue", Rosie). Rosie also commented on how incongruent Tom's response to her needs was: "I could have a full-on meltdown cry and he'd probably say what should we have for lunch". In contrast, Otis felt Grace still had the ability to think about his needs, but the way in which she showed this was different ("I think that, you know, there's a sense in which I am thought about, I don't think there's a sense in which it is overly articulated though").

Changes in Conversation

All participants reported difficulties in having reciprocal conversations with their partners, for example Isabella explained: "it's very difficult to have a normal conversation with Penny that goes backwards and forwards, because it takes her quite a while, it takes her a long time to absorb what you're saying". This had meant a reduction in the frequency and type of conversation they had with their partners ("I don't speak to him as much as I did, our conversations are rather sort of essential", June; "it impedes quite a lot of the conversations that we would have had before… you don't have that person to talk to like you used to, instead it's functional", Emma). For Sally, she and John appeared to clash on the topics that they wanted to discuss which reduced their conversations with each other ("I try and talk about the future and things I'd like to do. But he's less interested in that so there's not much to talk about"). Meanwhile, Otis reported Grace's communication was less "expressive", such that "the range of ways in which you might use words to communicate" were lost.

Changes to Affection and Intimacy

Participants also experienced changes to reciprocity in affection. For Rosie and Sally, this was significant ("there is no affection in any way ", Sally; "the affection side of things is very, very limited", Rosie). Otis reported Grace's affection was now more "passive" and shown in more non-verbal ways, "in the sense of just you know, maybe holding hands or giving each other hugs". In contrast to these experiences, June reported Robert was still able to initiate affection towards her ("I think the nice thing about it, you know when he's in bed, and he likes to just you know perhaps hold, hold my leg, or you know just hold a bit of me").

Four participants reported their partners had demonstrated reduced interest in sex and intimacy, which for Emma and to some extent, Helen, was a mutual feeling. Emma reported sex was something neither her or Charlie were concerned with post-injury ("no interest from either party since the stroke") and reported a shared loss of sexual feelings: "certainly when we hug and kiss, there's nothing sexual about it". Helen reported initially "it (sex) was very constant, I would say at least four times a week when he came home" but the longer lasting effects of Ben's injury had changed this over time: "I have not wanted to and he's not wanted to, I think we're both in our own thoughts as well, so erm I would say physically maybe once a month now". June and Isabella meanwhile expressed differences had been present immediately after their partner's injury. Isabella described the "sexual relationship" as "completely missing" which was exacerbated by them not being able to sleep in the same bed due to Penny's physical needs, while June reported her and Robert had an "active sex life" before Robert's injury, which had now been reduced to a "cuddle in bed". Otis on the other hand, reported intimacy was still present between him and Grace ("in terms of intimacy and stuff there's still that sense in which you know, a couple has their way of going about…just demonstrating affection and being close and you know having sex and stuff").

Reduction in Shared Interests and Activities

Many participants also reported changes in shared interests and engaging in activities with their partners. For example, Rosie described a clear difference in her life with Tom ("we would go out a lot more together. And now I guess it's sort of rare that we go out together"). Sally and Otis both mentioned doing more activities by themselves rather than as a couple ("some of them I do on my own, some of them I do with other people, but it's not the same", Otis). In contrast to the majority of participant's experiences, both Helen and June reported the support their partners needed from them meant they did more with their partners. Helen explained this had strengthened the family unit:

> "I would say it's probably changed for a positive now. Because, before the injury we kept thinking about a camper van… we never got round to it, never done it, was just always thinking about it but we've actually done it…we can actually go out and do stuff as a family"

Changes to Humour

Humour was the one element that more participants reported hadn't changed following their partner's injury than had, with June, Emma and Otis feeling that shared humour was still there ("he's still got a sense of humour and he does still laugh quite a lot", June; "the sense of humour is still largely the same", Emma). Meanwhile, Rosie and Sally both reported changes to the type of humour their partners understood. While Rosie reported Tom's humour was more "childlike", Sally commented that John "can't have a laugh the same way we used to" and noted "with the old person, I could crack a joke and he'd get it…now he takes it literally, takes it seriously rather than understanding it's a joke".

Themes Generated Specific to Research Aims

In line with the research aims, two superordinate themes were generated in relation to the impact these changes had on the partner relationship and how participants coped with these changes. Their corresponding subordinate themes are displayed in Table 3.

Table 3

Summary of Themes

Superordinate Themes	Subordinate Themes
Impact of changes on the relationship	Doubting the feelings of the person with the injury
	Being with their partner is less rewarding
	Reduction in their own bonding behaviours and warmth
	Retention/presence of warmth helps sustain the relationship
Coping with changes	Differences in understanding
	Hope for future change
	Finding different ways of maintaining warmth
	Maintaining previous ways of bonding and communicating

Impact of Changes on the Relationship

This superordinate theme seeks to understand the impact that the changes in emotional warmth had on the partner relationship, of which four subordinate themes emerged. Participants doubted their partners' loving feelings towards them, and reported to find their relationship to be less rewarding. In response to these experiences, participants

had reduced their own emotional warmth towards their partners. The final theme acknowledges the retention or presence of warmth can help to sustain the relationship.

Doubting the Feelings of the Person with the Injury

Participants alluded to feelings of uncertainty regarding their partner's feelings toward them and the intent or function behind any actions where they expressed emotional warmth. Otis noted being more concerned now about who showed or initiated affection: "who's being the proactive one, and you know who leads and who follows". Isabella in particular queried if her affection towards Penny was received warmly or whether she was imposing her own feelings of love onto Penny. For example, she described "manipulating" the affection between her and Penny; "I'm making it happen, but on the other hand, if I don't make it happen, she's got no way of making it happen". This had led Isabella to doubt whether affection was equally wanted by Penny:

> "and it feels like (pause) should I do that you know, is it, am I doing it for myself that's what I have to ask myself, am I doing it for myself or am I doing it for Penny and I think I am doing for Penny, but I think it's a fine line".

She appeared to use her knowledge of who Penny was as a person and the memories of their relationship together as a way to reduce the impact this had on her ("you're having to rely on your history to keep you going"; "I don't doubt my relationship so I don't need it validating").

Emma and Sally felt uncertain as to whether their partners' feelings for them were genuine. In Emma's case, she wondered whether a hug from Charlie was an "automatic, muscle memory" response that had been learnt:

> "the logical thing if somebody's embracing you is to respond… he just instinctively will give me a hug. And I think that is a very, that's, that doesn't take any executive function does it, it's a really, it's a, it's a gut thing"

Meanwhile, for Sally, a hug from John felt like "somebody putting an arm around you and nothing else". She perceived that on the rare occasions John did show affection, that he was doing this as a response to her being upset, rather than genuine love, which felt devoid of any emotion behind it: "bit of a going through the motion thing…more of a kind of physical thing than any emotion with it". Over time, Sally had started to perceive John's

affection towards her to be more childlike: “He behaves more like a child who needs their mum kind of thing rather than their partner”. She therefore had questioned whether his affection was coming from a “perspective of a child who's been on his own at home whilst mummy's been at work or… coming from a partner who would just like a hug”.

June and Rosie also felt their partners had become more “childlike”, and so doubted that they had the same capacity to reciprocate loving feelings. June described Robert as being dependent on her: “I think he realizes that he does need me”, but felt this was in the way of him needing her like “a child” rather than a partner. For Rosie, the fact that Tom’s humour had become childlike, meant that she had started “treating him more like a child” and thus made her doubt that he had loving feelings because of how they responded to one another: “I guess like how he is in in some ways, I feel more that I’m like not mothering him but it's that, it's more that sort of relationship than like a husband-and-wife relationship”.

Being with the Person is Less Rewarding

Five participants suggested elements of their lives with their partners were now less satisfying. For example, Sally described her life with John before his injury had been fun and enjoyable, but now it felt dull:

> “Before we enjoyed doing things together; travelled, we did all sorts of things, kept ourselves fit and active…fairly good life, fun, enjoyable, it was exciting…on a day-to-day basis his life is pretty dull now. It's a very different relationship if you're not able to do the things that you used to do.”

June and Emma expressed a lack of enthusiasm in conversing with their partners due to the effort it took, coupled with the lack of response they received. For example, June described becoming frustrated with Robert when he didn’t respond to her: “I do snap and get cross with him but he just doesn’t respond to that you know, it just doesn’t affect him”. She expressed sadness in not being able to rely on Robert to support her with decisions about their life together any longer: “I can't discuss it with him because he would just look blankly at me, he understands quite a lot of things, but he can't really make any helpful suggestions”. Emma equally expressed challenges in being able to have meaningful conversations with Charlie: “making that time to spend long enough with him

so he can have conversations just becomes more time consuming, harder for him. And I, I can't get enthusiastic about, you get frustrated and probably cross".

Emma and Otis explained intellectual stimulation had been an integral part of their relationships ("I suppose the kind of the intellectual side of it where especially when it's been an important part of a relationship and that's gone in a lot of areas", Emma). For Emma, the difficulty in being able to engage in this now contributed to her feeling "lonely", while Otis explained the ease in which he and Grace could do this had changed: "there's something lost in that kind of easy sparring that couples do". He remarked their conversations were now more limited: "we might have the same conversation regularly you know or repeatedly in small chunks, as opposed to just yeah the… kind of fuller outline of what the situation or the circumstances might be".

Reduction in their own Bonding Behaviours and Warmth

In response to the two previous themes of being uncertain or doubting their partner's feelings for them, and the relationship being less rewarding, a third theme relating to participants reducing their own expressions of warmth towards their partners emerged. For example, Isabella had stopped showing affection as she was uncertain if Penny's feelings reciprocated hers:

> "I did use to make a make a point of like kissing her good night, as times gone on, I stopped doing that because I've thought is that making it harder for her because she's not able to voluntarily. I just felt it was a bit invasive on my part that it was just like I, was I just doing it for myself or was she actually getting something from that"

Sally explained John's "neediness and reliance" on her, coupled with her feeling like he wasn't trying to show her love, affected her feelings: "he doesn't seem to be willing to make an effort which makes a difference to the way I feel". For Rosie, the discrepancy between Tom looking the same but experiencing personality changes ("both look like Tom but they don't act like the same man") and thus being uncertain if his loving feelings remained, impacted on her ability to show affection: "I would much prefer us to be much more like lovey dovey and cuddles and things. But if you, I sort of see it like I couldn't go up to a complete stranger, a strange man in the street and start hugging them".

Sally, Emma and Helen all mentioned a reduction in seeking emotional support from their partners. For example, Helen reported to have “sort of distanced myself” from Ben. For Sally, her perception that John’s feelings for her were more childlike, meant she had stopped asking John for emotional support: “I don't ask anymore”.

Retention/Presence of Warmth helps Sustain the Relationship

Despite the impact that the changes in emotional warmth from their partners had had on their relationships, many participants reported some aspects of their partner’s warmth pre-injury was still present, which helped them to maintain loving feelings. June’s feelings for Robert were helped by the fact that Robert was able to show love intermittently, remarking “there is still something there, it surfaces now and again”. Similarly, Isabella described noticing “things that have happened that have, you know consolidated that warmth”. She illustrated this by explaining “sometimes she’ll, you know touch my arm in a very affectionate way which you know, seems like a minor thing, but for me it's quite a big thing, she is acknowledging the relationship”. Emma even reported perceiving some benefits after the injury: “there’s a lot of stuff lost but there's also in a weird way some stuff gained”, describing the injury event as like a “reset button”. She explained that she still felt warmth from Charlie: “certainly when I, when we hug and kiss… it's warm and it's lovely and it's comforting”. The fact that Charlie’s humour was still intact, something that was integral to their connection as a couple possibly helped feelings of love to remain: “one of the things that most attracted me to him is his sense of humour, he makes me laugh and he still does”. This was similar for Otis who described “a level of intimacy” between him and Grace remained, along with “shared humour” and interests. He reported Grace was still able to show love: “as far as she can you know she is still very demonstrative and caring and loving”, and because she had changed in other ways, this was more significant to him: “there's something meaningful in how she offers support with not too many words but a reassurance”.

Coping with Changes

The second superordinate theme attempts to explore how participants coped with the changes in emotional warmth in their relationship. Despite this being a small part of the interviews, this yielded a wealth of data from participants.

Differences in Understanding

How participants understood and made sense of the changes in their partner following their injury, affected their ways of coping. For example, all participants had an understanding that the changes were as a result of injury to particular areas in the brain ("it's been fairly evident that certain parts of the brain have been affected", Sally; "the physical damage as well as the neurological damage, you know that has caused the, where I can see that, where the emotional warmth has been impacted on", Otis). This seemed to help participants have empathy for their partners in that the implication was that they did not have control over their behaviour ("not his fault", Rosie; "I know it's not something he can help", Emma). This in turn appeared to help participants cope with some of the changes experienced ("I sort of get the difficulty he may have with expressing himself with emotions and it can be elements of the brain injury", Helen; "I just think it was because of her brain injury that she wasn't aware of it, not that she was like not thinking oh it's you know, Isabella is doing all this for me", Isabella).

Some participants described the specific areas they believed to be affected: ("some of the frontal lobe was affected and, and then the parietal lobe", Sally; "his frontal brain so his mainly his executive function, so being able to plan, organize, like read body language", Rosie). This acknowledgement that only certain parts of the brain were damaged appeared to help them to make sense as to why their partners were still able to manage certain tasks. For example, Rosie used this understanding to explain why Tom could still work when he could not be affectionate: "I'm sure it's like a different part of his brain or in the same place that got affected but that bit didn't get affected". For Emma and Charlie, a shared understanding was beneficial to them both, and their relationship: "we both had an appetite to understand what was going on in his brain, what was damaged, what was causing this…all the stuff that we'd seen was different, it gave us something to grab onto". For Emma, the understanding that Charlie's inability to read her emotions and be able to support her the way she wanted, was down to a change in a "cognitive process", appeared to help her accept this change and cope better.

Conversely, despite all participants having some understanding of the changes in the context of the brain being damaged, many described a sense of unknown, or lacked detail in relation to this. For example, in describing her understanding as to why John's

affection was limited, Sally remarked: “I’m not quite sure why. I guess it's the brain injury, I don't know”. This uncertainty seemed to make it harder for her to experience this difference in John (“I’ve really been struggling to understand what's going on”) and became tearful talking about what an alternative explanation might be: “maybe he just {cries} can’t connect to any emotion in him”. This may have reinforced the level of doubt Sally had in perceiving John’s feelings as being genuine. Similarly, Helen appeared uncertain of where Ben’s newfound difficulties in communication stemmed from: “maybe that part is you know, maybe an element actually, that's, I don't really know, I don't know that other part”.

Participants also described how this limited understanding had been exacerbated by the lack of support and explanation from external services. In regards to John’s lack of ability in showing emotions, Sally reported “nobody's ever explained it”. For Isabella, she felt service perceptions of Penny’s recovery meant she was not provided with information she wanted regarding how to support Penny: “she wasn't going to have a life so they certainly weren't going to give me any advice”.

Hope for Future Change

For Helen and Isabella who were earlier on in their journeys of recovery with their partners, a sense of hope that the changes to emotional warmth were not permanent seemed to help them accommodate the changes better and possibly reduce their emotional impact. This hope also seemed to effect how much positive change they noticed in their partner over time. For example, Helen reported feeling Ben’s insight into his emotions would improve in the future: “I feel actually there could be more progress on that area, it’s just going to take time”. Similarly, Isabella described noticing “things that have happened that have, you know consolidated that warmth”. She illustrated this by explaining “sometimes she’ll, you know touch my arm in a very affectionate way which you know, seems like a minor thing, but for me it's quite a big thing, she is acknowledging the relationship” and stated these aspects helped her to keep holding on to the relationship as “an act of faith” that the emotional warmth between them would improve with time.

Finding Different Ways of Maintaining Warmth

Participants and their partners had also discovered new ways of bonding and communicating with one another. Otis emphasised this need to ensure the relationship continued: “the sense of finding new ways to kind of maintain closeness is really, really important”. Helen, Otis and Emma described their partners were now using more non-verbal ways to show affection. For Helen, this change had reassured her that Ben’s feelings were still there: “the hug is more important than the words”. Otis explained he and Grace had developed a “secret language”: “a kind of intuitive kind of sense and feeling that we've got in terms of like a range of looks and eyes”. They had worked together to establish “a suitable array of alternatives” of showing warmth, and learnt different ways of communicating this to each other:

> “Since there's less recourse to having to say kind of you know phrases and encouraging kind of comments, her looks and how she holds herself and a kind of sense of being able to just, you know hold your hand and to hold the glance as well, and the glance, the look is really important”.

Emma noted Charlie had the ability to show affection but he relied on her prompting to do this: “he will reciprocate, he just won’t initiate”. She described taking the lead in explaining to Charlie what she needed from him when in emotional distress: “I just say yes I’m feeling a bit grim, give me a hug and he’ll give me a hug”, although this appeared to be something that was not completely satisfying to her: “then he’s done something”. She explained her relationship with Charlie was “more straightforward” now in how they showed warmth: “we’ve gone from like in any adult relationship probably some fairly complex ways of expressing emotions to each other and now it’s stripped back a bit”. They appeared to have a routine in showing affection to each other where both knew what to expect, which possibly helped Charlie to respond successfully:

> “Probably three or four times a day I’ll just give him a hug randomly you know and we always have a hug and a kiss before bedtime. And he, he always responds warmly to that you know physically warmly… there's a real simple simplest simplicity about that, it's very uncomplicated”

Maintaining Previous Ways of Bonding and Communicating

Despite participants experiencing significant differences in emotional warmth from their partners, many spoke about adapting to try to maintain warmth. In order to preserve connection with their partners, both Otis and Isabella had made adjustments to things they enjoyed doing with their partners to suit their abilities post-injury ("what are the things that we can still do but try and get there differently, as opposed to the things that are now impossible", Otis; "I tried to think what would we have normally done. I just think well I can't do that exactly the same, but I can come as near to it as possible", Isabella).

Isabella explained how important time in bed with Penny was to feel close and connected with each other:

> "When we went to bed, we would lie there having a chat you know, having a hug you know, even if we weren't going to have sex, we would still like hold each other. You know, we often like would listen to music and like dance in the bed, we would just get the papers, lie in bed, chat"

She discussed how she had continued to ensure this "special thing" remained despite significant changes to their relationship: "what I do now on a Sunday morning is that I lie in the other bed and we do what we would have done, you know chatting away and listening to the Archers". She explained how this had been positive for their relationship: "I think it feels closer to how things used to be, it feels closer to a kind of a relationship". Despite this, she described feeling guilty for continuing to try and maintain closeness in this way, which was dictated by her carer role:

> "I'm not meant to use that time like that because Penny should be, should be resting you know, so I feel I can do it once a week and it not be too, you know I feel I can take a couple of hours out once a week and it won't (pause) upset her routine too much"

Time in bed with Robert had become more special for June who described it as "one of the few times when I feel life's a bit normal", when she didn't have to worry about Robert and his needs which made her more "relaxed".

Participants also talked about continuing to build connection through engaging and sharing in talking about their old life and interests with their partners. For example, Isabella explained a shared interest in politics helped to maintain her and Penny's bond: "I

think politics, is the thing that connects me and Penny, really links us together, and I think helps us a lot in kind of navigating this world that we're in". Emma also expressed maintaining regular conversation about things her and Charlie enjoyed together preserved their connection: "we do do that quite a lot. Just chatting. You know about where we've been, what we've done before, you've got more of a history together to chat about and enjoy that retrospectively".

Participants' General Experiences of Living with Brain Injury

Participants' accounts of their experiences about living with someone with a brain injury echoed themes in previous qualitative research (for example, Gill et al., 2011; Godwin et al., 2014; Bodley-Scott & Riley, 2015; Villa & Riley, 2017). A summary of these accounts is presented here.

All participants expressed the relationship with their partner post-injury felt very different. Rosie stated her relationship with Tom was "not the relationship that we used to have" and that it felt like they were "more like two individuals". Emma also explained "the whole nature of the relationship's changed", with June describing the relationship balance having "altered". Sally identified the transition from partner to carer "erodes the relationship in a way", while Helen explained feeling like she had lost her "team mate". This transition to a different sort of relationship had affected participant's well-being. For example, June described feeling "on edge", while Isabella expressed it left her feeling "incredibly frustrated and trapped".

Both Rosie and June described their partners as being fundamentally different which was more striking when they looked the same on the outside. For example, June described Robert as being like a shell:

> "It makes me feel really that a lot of the time it's just his shell sitting there because physically he's roughly as he was but erm you know, he looks more or less the same but there's so much gone from inside"

In addition, all participants mentioned feelings of sadness and loss; related to the loss of the person their partner once was and the life they had together, as well as a loss of a sense of identity. Rosie, Helen and Isabella described having mourned for their partners. Rosie talked about having to "grieve for the old Tom"; while Isabella described her

experience being “similar to a bereavement in a lot of ways, but the person is still there”. Isabella and Otis felt their partner’s injury had resulted in them losing a sense of their identity. For example, Isabella described how she had given up her life to care for Penny: “it's not possible to have two lives, I run Penny's life and then, if I’m lucky I get a little bit of life on the side”. Meanwhile, Otis described discontent that the person he was before Grace’s injury was “disappearing”.

> “you end up becoming a person you don't want to become almost… I think how boring am I, how stimulating am I, and am I disappearing, you know, is it, are there, amongst all of that, can I still see some distinct senses in which I’m growing as a person or learning or feeling, you know… in any meaningful sense”

Discussion

The aim of this study was to explore how changes in emotional warmth in the person with the brain injury impact on the couple relationship. Participants also discussed how, as a couple, they tried to cope with these changes in a way that protected the relationship and lessened their emotional impact.

Summary of Findings

Relationship Impact Leading to Discontinuity

Previous qualitative studies have suggested ways in which changes in emotional warmth might result in the partner experiencing relationship discontinuity. The results from this study support and expand on the discontinuity research while offering an understanding of what the connections between the two might be.

Firstly, Bodley-Scott & Riley (2015) and Villa & Riley (2017) suggested partners may find it difficult to express warmth and loving feelings if this is not reciprocated, and/or if the partner felt feelings of love from the person with the brain injury had diminished (undermining same feelings). Furthermore, the disappearance of exhibiting reciprocal love and care can undermine the relationship’s identity (relationship redefined). The findings of the present study offered a more detailed and novel perspective on this suggestion. In the theme ‘doubting the feelings of the person with the injury’, participants

highlighted how they were uncertain about what their partner's feelings were towards them (which was also reported in Gill et al., 2011). The lack of expressions of affection, having to prompt and initiate displays of warmth, and more childlike displays of affection, made the participants question the strength of the feelings their partner had for them. This created difficulties for themselves in expressing their feelings, with some participants reporting holding back due to their worries of imposing unwanted affection. Some participants felt unable to seek emotional support from their partners which to them seemed to redefine the relationship.

Secondly, Villa & Riley (2017) proposed the person with the brain injury showing love and care towards their partner was part of their identity, so the loss of this meant their partner perceived their identity had changed (different person). Rosie and Sally reported a lack of affection from their partners post-injury, which for Sally, was in contrast to the person John was before. For Rosie, Tom's lack of feelings made him feel like a stranger and this made it difficult for her to express any feelings back.

Lastly, Bodley-Scott & Riley (2015) identified the decline or absence of broader pro-social behaviours could corrode the sense of shared enjoyment of life (impacting on togetherness and relationship redefined). Participants in this study also discussed, in the theme 'being with the person is less rewarding', how difficulties within these areas made the company of the person with the brain injury less rewarding. For example, through the loss of integral parts of the person pre-injury, such as intellectual stimulation; how it took more effort to make conversation, reduced the types of conversation had, and led them to withdraw or become frustrated.

Conversely, in the theme 'retention/presence of warmth helps sustain the relationship', participants described the significance of the positive expressions of warmth that did remain post-injury and how important these were in confirming that their partner still cared for them. For some participants, seeing elements of the old person, such as their humour, helped feelings of love to remain. For Otis, because Grace had changed in other ways, the fact that she was still able to maintain some intimacy as well as shared humour and interests, meant these elements were more meaningful to him. Isabella also described how she saw Penny showing her some affection to be her acknowledging their relationship.

Coping with the Changes

Participants' coping was influenced by the understanding and sense making they had developed since the injury. Understanding changes in the context of brain areas being damaged appeared to reduce blame on the person with the injury (consistent with the findings of O'Keeffe et al., 2020), while a lack of understanding caused confusion for participants. For Helen and Isabella whose partners' injuries were more recent, having hope for future change seemed to help them accommodate the changes in their partners better.

Participants and their partners had discovered new ways of maintaining warmth. This appeared consistent with them creating "new ways of relating" (Anderson and Keating, 2018, p.2267) which was also illustrated in Bodley-Scott and Riley's (2015) study where one participant reported to have worked with her partner to develop different ways for him to show he cared about her. One of the ways couples demonstrated this in this study was using more non-verbal ways to show affection. For example, Otis felt he and Grace had developed a non-verbal language which helped them to communicate and offer gestures of warmth in different ways to before the injury.

Many spoke about having made adjustments to things they did with their partners pre-injury. For example, Isabella described how time in bed together with Penny had been a way for them to feel close and connected. Although they were now unable to share a bed, she had replicated this as far as possible, prioritising spending time together in doing things they enjoyed. Fernandes (2019) reported a similar coping technique in partners of persons with dementia who found altering their behaviour to suit their partner's abilities, for example, in terms of the level and type of conversation they made with their partner, maintained a sense of connection, and minimised the loss of the relationship.

Another way of coping was through participants reminiscing about their life with their partner and maintaining shared interests that had brought them together in the first place. For example, Emma expressed how being able to share memories and talk about her past together with Charlie helped preserve their connection. This way of coping was also highlighted in Gill et al. (2011) who suggested holding on to pre-injury foundations of the relationship and spending time together could improve the relationship post-injury.

Limitations

Although the small sample size suited to IPA enables in-depth exploration, it limits the generalisability of the findings. While participants varied in demographic characteristics, the sample size does not warrant conclusions to be made from these variables, and indeed only one male partner participated. There were times when participants struggled to communicate their experiences into words which suggests some participants' sense making is still to be done. The distinct focus of each of the two interviews may have unintentionally guided participants to separate their relationship into pre and post-injury which may have led them to think of the changes in this way. It may have been preferable to impose an upper limit on the time since injury, for example, in the case of Otis and Grace, the injury occurred 32 years ago, which may have made it more difficult to reflect on how warmth and bonding behaviours had changed when comparing before and after the injury. The researcher also specifically asked about particular behaviours which perhaps made the participants more likely to focus on these changes and less on others, although participants were asked if they wanted to discuss any other changes at the end of the interview. In addition, the focus on warmth meant a wealth of information gathered from the participants about their general experiences (which were similar to themes in existing qualitative research) was not reported on.

Clinical Implications

This study supports previous suggestions that changes in emotional warmth are difficult to cope with and have a significant negative impact on the partner relationship. More awareness needs to be given to these changes in clinical practice, both in terms of assessing them and offering support for managing them. Clinical practice tends to mirror the research focus on cognitive losses and challenging behaviours (Braine, 2011; van den Broek et al., 2022), and less on the loss of feelings and behaviours that bind relationships.

This study highlights the need for partners to be given appropriate information regarding changes in emotional warmth in order to help them understand the specific effects of their partner's injury, which may help to increase empathy and reduce blaming. As highlighted in Bodley-Scott & Riley (2015) and Villa & Riley (2017), the more understanding partners have about these changes, the better their ability to cope which may help improve relationship continuity. A case study using Integrated Behavioural Couples Therapy conducted by Yasmin and Riley (2020) and carried out over 12 weekly sessions,

demonstrated ways in which a sense of relationship continuity between the couple could be increased. For example, by the therapist providing education on the effects of the injury, such as communication, as being a symptom rather than a change in the identity of their partner, and using roleplay to help the couple improve or restore old ways of communication (promoting the fact that elements of the same person were still there). In addition, the couple were supported to reminisce on the ways that they used to connect and spend time with each other, and encouraged to consider how to restore these into their relationship (helping to maintain a sense of warmth and togetherness). Throughout the intervention, the therapist also highlighted to the couple the areas in their relationship which it seemed were still continuous to the one experienced before the brain injury.

Two participants in this study held hope for future change, which appeared related to the recency of their partners' injuries. Optimism following brain injury can be beneficial, for example in developing problem-solving coping skills (Scheier & Carver, 1987), which might help improve rehabilitation outcomes. However, often expectations of recovery can be unrealistically optimistic. Therefore, Riley et al. (2015) suggested that services should support partners in managing and maintaining realistic recovery expectations, as the disappointment of these expectations not being met, can impact on emotional well-being.

Maintaining previous ways of bonding and communicating is important for relationship continuity. Services should focus on encouraging couples to identify activities they enjoyed doing together and either restoring these, or adapting them to suit new abilities, which has been shown to stimulate feelings of connection to the old relationship and a stronger sense of couplehood (Yasmin and Riley, 2020).

Additionally, couples should be supported to discover alternative ways of expressing their emotions to each other. Hess and Perrone-McGovern (2016) highlight the person with the brain injury may require support to express their feelings and suggest the use of 'I' statements may help the person to do this. Group couples' interventions have also been developed to target the difficulties in expressing feelings and communicating, as well as learning how to respond to each other's needs (Backhaus et al., 2019; Rasmussen et al., 2021), with Yeates et al. (2013) demonstrating promising improvements between the

couple in attunement and emotional expression after brain injury using emotionally-focused couples therapy.

Conclusions

These findings support previous research that changes in emotional warmth are detrimental to the partner relationship and begins to offer some understanding into how these changes impact on the relationship and how partners cope with these changes.

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CHAPTER III: PRESS RELEASES

Literature Review Press Release

University of Birmingham Press Release

Relationship Satisfaction is Affected after Brain Injury: More Understanding is Required as to *How* this Affects Romantic Relationships in Order to Improve Support for Couples

A systematic review of twelve studies published in scientific literature investigating relationship satisfaction after brain injury found that this differs between the person with the brain injury and their partner. Partners of people with a brain injury report poorer satisfaction than the injured persons themselves, and compared to the partners of persons with other health conditions.

The non-injured partner reporting poorer satisfaction than their partner is likely due to them directly experiencing the effects of personality changes in their partner post-injury. These changes have been found to impact on the partner and their experience in the relationship more than for the person themselves (Gosling & Oddy, 1999). Following a brain injury, individuals often underreport symptoms due to reduced insight and awareness into their deficits (Godfrey et al., 1993). This may explain why people with brain injury did not report a significant difference in satisfaction post-injury.

What are the Variables associated with Satisfaction?

Few variables were consistently associated with differences in relationship satisfaction for either the person with the brain injury or their partner. In terms of demographics, relationship length, and injury severity (elements which the couple cannot change), there was no to limited evidence for their associations with satisfaction. Instead, aspects of the couple relationship, such as a reduction in the injured person's emotional recognition skills, and the presence of partner support, seem to have stronger associations with satisfaction. Cognitive injury-related symptoms also led to poorer satisfaction in both partners.

The fact that injury severity was not found to have a significant association with satisfaction was unexpected and in contrast to previous findings (Blais & Boisvert, 2005; Godwin et al., 2011; van den Broek, 2022, in press). This non-significant finding may be

due to methodological issues with the participant samples included in this review. However, it is argued that severity overall is perhaps less important than the specific impairments that couples have to cope with. Studies have reported socio-emotional changes in particular (which this review found is associated with poorer satisfaction in both partners) are reported by partners to be more difficult to manage and lead to greater relationship difficulties than cognitive and physical changes (Yasmin & Riley, 2021).

Why is this Important?

Higher relationship satisfaction has been found to improve well-being (Bradbury et al., 2000), and rehabilitation outcomes (Palmer & Glass, 2003). This review provides conceptual clarity over relationship satisfaction and its associated variables. Previous reviews have attempted to understand couple relationships after brain injury, however their conclusions have been weakened due to their interchangeable use of concepts within relationships.

What Can We Do About It?

Having an understanding as to how satisfaction might be affected following a brain injury and the variables that may impact on satisfaction can improve support for couples after brain injury. Couple interventions should focus on improving areas such as emotional recognition within the relationship. For example, the Couples Caring and Relating with Empathy Intervention (Backhaus et al., 2016) has been developed to help increase positive communication, emotional regulation and coping skills. Interventions should also help to support the injured person to enhance their insight and awareness into their symptoms. Improved awareness has been shown to improve rehabilitation outcomes (Ownsworth & Clare, 2006) and therefore may also help to reduce the impact of symptoms on the partner.

This review has brought the literature together in a way that has not been presented before by focusing on satisfaction as a stand-alone concept. There were significant limitations to the quality of the papers reviewed which likely contributed to the mixed findings, such as inconsistency in the measures used, and small participant samples who varied in their severity of impairment. It highlights further research is required to gain a better idea of which variables are more consistently associated with different relational outcomes. It is recommended that research focus on recruiting larger samples of varying demographics,

including both partners in the couple. Following couples over time would also help to understand how satisfaction changes post-injury and aspects that affect it.

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ENDS

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Empirical Study Press Release

University of Birmingham News Release

"It's not the relationship that we used to have"

Changes in emotional warmth are detrimental to the partner relationship following brain injury: couples should be offered support to manage these

Emotional warmth (positive behaviours, feelings and interactions that bond and connect a couple) is paramount to maintaining a good relationship. A recent qualitative study of seven partners of persons with a brain injury highlighted how changes in emotional warmth significantly impact the partner relationship. More awareness needs to be given to these changes in clinical practice, both in terms of assessing them and offering support for managing them.

Poorer quality relationships and relationship breakdown are common post-injury. However, a strong partner relationship after injury is associated with better emotional well-being for both partners (Kendall & Terry, 2009) and improved rehabilitation outcomes for the person with the brain injury (Palmer & Glass, 2003). Changes in emotional warmth appear to have a greater impact on well-being and relationship satisfaction than physical and cognitive changes (Yasmin & Riley, 2021), yet much of the support offered to partners are in relation to socially undesirable behaviours, such as aggression (Bodley-Scott and Riley, 2015). Previous qualitative studies have suggested ways in which changes in emotional warmth might result in the partner experiencing relationship discontinuity, whereby their partner and the relationship are considered to be different, with different characteristics and feelings, to before the injury (Riley et al., 2020). The results from this study support and expand on the discontinuity research while offering an understanding of what the connections between the two might be.

Participants reported a range of changes in emotional warmth, with many identifying a reduction in areas. These changes included: reduced empathy and consideration for partner's needs; reduction in shared interests and activities; as well as changes to conversation, affection, intimacy and humour. Not all participants described changes in all behaviours, with some reporting that warmth from their partner was still experienced in some areas, such as shared humour. In addition, two participants reported that spending more time together had improved their connections with their partners.

In terms of the impact the changes had on the relationship, participants felt their relationships were less rewarding, and highlighted how they were uncertain about what their partner's feelings were towards them. Participants reported lack of expressions of affection, having to prompt and initiate displays of warmth, and more childlike displays of affection, made them question the strength of the feelings their partner had for them. This created difficulties for themselves in expressing their feelings, with some participants reporting holding back or reducing the warmth they showed their partners due to their worries of imposing unwanted affection. In contrast, participants described the significance of the positive expressions of warmth that did remain post-injury and how important these were in confirming that their partner still cared for them. For example, seeing elements of the old person, such as their humour, helped feelings of love remain.

Participants' coping was influenced by the understanding they had developed since the injury and how they had made sense of their partner's injury and its impact. Understanding changes in the context of brain areas being damaged appeared to reduce blame on the person with the injury. Participants and their partners had also discovered new ways of bonding and communicating with one another, such as using more non-verbal ways to show affection. In addition, participants spoke about adapting to try to maintain warmth, such as making adjustments to things they enjoyed doing with their partners to suit their partner's abilities post-injury. Participants also talked about continuing to build connection through reminiscing about their old life and interests with their partners.

This study highlights the need for partners to be given appropriate information regarding changes in emotional warmth in order to help them understand the effects of their partner's injury, which may help to increase empathy and reduce blaming. Services should support partners in managing and maintaining realistic expectations of recovery. Interventions should focus on encouraging couples to identify activities they enjoyed doing together and helping them to restore these old ways, or adapting them to suit new abilities, which has been shown to stimulate feelings of connection to the old relationship (Yasmin and Riley, 2020). Additionally, couples should be supported to discover alternative ways of expressing their emotions to each other, for example, through interventions such as emotionally-focused couples therapy.

The author would like to acknowledge the individuals who gave up their valuable time to participate in the research.

ENDS

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Appendices

CHAPTER I

Appendix A: CLEAR Quality Tool

Table 1. Checklist for Assessing Technical Quality of Quantitative Descriptive Studies

1. Study Design
Criterion 1.1: Is the study design clear and appropriate for addressing the research questions?
– Demonstrates how the overall research strategy was designed to meet the aims of study (e.g., what the study will do) – Discusses the rationale for the study design (e.g., why the study does it this way) – Presents a convincing argument for different features of design (e.g., reasons for different components or stages of research; selection of any groups for examination and description of any comparisons [e.g., across groups or over time]; rationale for particular methods or data sources, multiple methods, time frames)
Criterion 1.2: Are the program(s) or conditions applying to the group(s) of interest clearly described in sufficient detail to understand and replicate?
Criterion 1.3: Are key features of the design including time, place, and context (e.g., labor market conditions) clearly described?
Criterion 1.4: Does the study explain limitations of the design and draw appropriate implications for interpreting findings?
2. Data Quality
Criterion 2.1: Are data sources and respondents (including respondents to key items) clearly identified and appropriate for addressing the research questions?
– Documents data sources and variables used to address specific research questions – Discusses any strengths and weaknesses of the data sources
Criterion 2.2: Do key variables have face validity, and does the study discuss their reliability and validity?
Criterion 2.3: Are issues of data completeness, consistency, accuracy, and validity (if relevant), as well as steps researchers took to resolve these issues, addressed clearly, in sufficient detail, and appropriately?
– These issues could include, as relevant: response rates, potential reasons for nonresponse, attrition, movement in and out of the sample, missing data, and inconsistent data
Criterion 2.4: Is the description of any constructed variables clear, and do these constructed variables make sense given the outcome of interest for the research question?

3. Data Collection	
Criterion 3.1: Are the data sources and instruments clearly described and appropriate for the research questions?	
	– If the study uses administrative data or surveys conducted by federal agencies, some or all of the data collection criteria may not apply (e.g., the American Community Survey). Studies using these types of data should discuss or refer to the publicly available materials about the data's reliability and unbiasedness as well as the basic data collection methods. – Discusses creation of the analytic sample, including details on sampling methods if appropriate.
Criterion 3.2: Does data collection reflect sound and systematic methods to produce reliable data?	
	– Discusses who collected the data and procedures used – Describes quality assurance procedures in data collection and verification – Discusses how data collection settings or methods may have influenced the data collected – Discusses instrumentation for surveys, if appropriate
Criterion 3.2: Does data collection reflect methods that produce unbiased results?	
	– Presents evidence of independence and objectiveness of the research team – Documents consent procedures and information and incentives provided to respondents, if applicable
4. Study Sample	
Criterion 4.1: Does the study examine a population relevant to the research questions?	
Criterion 4.2: Is the sampling design clearly defined and defensible?	
	– Indicates whether sample is purposive or representative – Discusses sample identification and recruitment procedures, if relevant – If a sample of respondents cannot be drawn to represent a relevant universe, it is acknowledged and explained – Approach to selection reflects purpose of the study and use/interpretation of the findings – Discusses what can be generalized to a wider population from which sample is drawn/site selection is made and limitations on drawing wider inferences – Discusses methods for drawing samples from extant data sources or identifying and sampling respondents for data collection
Criterion 4.3: Are inclusion and/or exclusion restrictions clear and defensible?	
Criterion 4.4: Is the analytic sample appropriate and described clearly and in adequate detail?	
	– Gives rationale for the sufficiency of the sample size for answering the research question(s) of interest.
Criterion 4.5: Does the study discuss limitations of the sample and/or sampling procedure?	

5. Analysis Methods	
Criterion 5.1: Are the analysis methods clearly described, appropriate for the research questions, sufficiently rigorous, and correctly executed?	
	– Describes and gives rationale for methods of analysis, including use of specific analysis methods, models, and procedures for hypothesis testing – The description of the analysis methods should be sufficiently detailed to understand how the analysis was conducted and how the empirical findings are to be interpreted – The reviewer should have some confidence that the findings could be replicated based on the description of the methods
Criterion 5.2: Does the report clearly explain and justify key analysis decisions?	
Criterion 5.3: Are appropriate statistical procedures used?	
	– These procedures could include: methods to account for stratification, methods to account for clustering, sample weights
Criterion 5.4: Are limitations of the analytic methods discussed, especially those that could lead to bias?	
	– These limitations could include: treatment of missing data, confounding factors, omitted variables, endogeneity, statistical power – Discusses how limitations of the analytic methods could affect interpretation of the findings – Discusses sensitivity tests conducted and their results
6. Findings and Conclusions	
Criterion 6.1: Are findings fully supported by the data and analysis?	
	– Are findings presented accurately and objectively without introducing a point of view? – Findings make sense as a whole and are coherent; seemingly odd or inconsistent findings are acknowledged and addressed appropriately – Findings are placed in appropriate context given limitations in design, data sources, and analytic methods of the study
Criterion 6.2: Are conclusions supported by the findings?	
	– Conclusions are based on a reasonable interpretation of the findings. – Conclusions do not appear to reflect biases on the part of the researchers or authors. – Conclusions are placed in appropriate context with respect to the theory proposed and/or conclusions based on previous literature.

Appendix B: Full Quality Appraisal of Papers

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
Bannon et al., 2022, USA, examining the impact of Mild TBI on the relationship satisfaction of persons with mild TBI. Measures completed at baseline (within 2 weeks of injury) and 1 month after	Correlational 1.1: Appropriate design. Identifies why chose specific sample/setting. Explains why chose specific timepoints for data collection. 1.2: clear procedure and recruitment strategy (with rationale) 1.3: sufficient detail regarding recruitment and where/how data collection took place 1.4: identifies study is preliminary in nature and therefore small sample and	2.1: As per inclusion criteria 2.2: Appropriate and valid measures used. Only internal reliability mentioned in terms of psychometrics. 2.3: response and attrition rates clearly described and at what points in the study. States compensation given to participants. Identifies number of excluded participants	3.1: Appropriate and valid measure used: Couples satisfaction index. Identifies clear procedure as to how analytic sample was generated. 3.2: Description of procedures. Describes various ways of data collection and limits to these. No mention of quality assurances but no missing items from data used for analysis (once excluded participants with missing data). Identifies for	4.1: 23 persons with mild TBI 4.2: Attempts to obtain representative sample. Clearly described sample characteristics. Explains clearly and includes visual diagram how recruited to the sample in the study and limits to this. Identifies lacking homogenous sample and possible limits to generalising results. 4.3: clear inclusion and exclusion criteria- excluded severe TBI for capacity reasons.	5.1/5.2/5.3: Appropriate and rationales given for t tests, correlations, regressions. Detailed account as to how used data and steps for regressions. Post hoc analyses described. Enough detail for replication. Data supported with clear tables. 5.4: Identified small sample size and low power and what adjustments	6.1: Identifies similarities to sample and other studies results- consistent with previous literature. Acknowledges regression findings need replication in larger samples before full interpretation. 6.2: Previous literature used to support findings and conclusions. Recommendations for future research to build on preliminary results.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	conclusions to be cautious based on this. Describes limitations clearly e.g., potential bias to sample/how recruited and difficulties with non-heterogenous sample. Identifies limitations in not including dyad measures; potential bias with self-reports; timing of when participants completed measures and the impact this may have had on results. Highlights support of literature for preliminary findings.	with missing data. 2.4: n/a	some participants, baseline and follow up data was collected at the same time which may have impacted outcomes. No mention of bias from setting data was collected in. 3.2: participants received small incentive compensation. Consent procedure detailed. Variety of ways participants completed questionnaires, doesn't identify if any differences in bias e.g., telephone with	4.4: Identifies small sample and clear limitations to sample obtained and the need for larger sample replication. 4.5: Identifies small sample size and low power. Clear limitations: sample setting, heterogeneity of the sample in comparison to real world, the need for dyad measures, timeframe for data collection	made due to this. Conducted post hoc analyses due to power issues.	

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
			researcher vs independent with tablet. Clear criteria in terms of participant capacity to be able to give consent- these participants were excluded from study. Recruitment procedures carried out with medical team support.			
Blonder, Langer, Pettigrew, Garrity, 2007, USA The effects of neurobehavioral characteristics in persons with unilateral stroke on spousal	Correlational 1.1: Unclear rationale for design, however explains difference in this study compared to others in considering factors regarding the person with	2.1: As per inclusion criteria 2.2: Does not explicitly state psychometric properties (however mentions in discussion that	3.1: Appropriate and valid measures used (Marital Satisfaction Scale). Convenience sample appropriate. 3.2: Lacking detail of who and	4.1: 20 persons with Stroke and their partner. 4.2/4.3: Strict inclusion criteria to eliminate confounding variables. Unclear how participants were approached. As preliminary	5.1/5.2: Spearman's Rank Order correlations rationale offered. Mann Whitney U tests as further exploration.	6.1: Tables for each finding/person variable and whether significant. Findings placed in context of preliminary study. Does not support findings from other studies, however suggests reasons why

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
psychosocial function e.g., marital satisfaction	stroke impacting on partner. 1.2/1.3: No detailed procedure for replication. 1.4: identifies study is preliminary in nature and small sample. Limitations to correlational design in determining causality of findings. Assessments at one time point, use of self-reports.	properties are excellent). 2.3: Identifies limitations with not collecting data on excluded participants (high % due to strict inclusion). 2.4: n/a	how collected data. No mention of quality assurance procedures. 3.3: Paid incentive but doesn't state how much or how objective. Consent procedure through hospital.	study, identifies limits to sample. 4.4: No mention of whether sufficient sample size. 4.5: Limitations of sample in relation to findings but not for procedure.	5.3: Adjusted alpha explained. 5.4: Limitations to correlations regarding causality. Confounding variables already attempted to eliminate via inclusion criteria. Sample size limited statistical significance. Identifies lack of statistical power.	didn't find significant results. 6.2: highlights despite limitations and non-significance, suggests need for future research.
Blonder, Pettigrew & Kryscio, 2012, USA	1.1: correlational to determine associations, differences between groups.	2.1: As per inclusion criteria 2.2: Psychometric	3.1: Appropriate and valid measures used (Marital Satisfaction	4.1: 12 persons with stroke compared to 9 healthy control participants. Does	5.1/5.2/5.3: Mann–Whitney U and the exact test due to small	6.1: Tables for each finding/person variable and whether significant. Effect size stated for

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Associations between facial and prosodic processing, mood, and marital satisfaction	1.2/1.3: unclear how recruited participants other than from hospital e.g., opportunistic that met inclusion? Does not state how many participants declined to take part. 1.4: no specific limitations specified other than preliminary study.	properties detailed. 2.3: Excluded participants before data collection began but doesn't say how many and therefore whether sample is representative of setting. 2.4: N/A	Scale). No mention of how recruited particularly control participants (recruited through general hospitals- no statistical differences between groups but may not be representative of general population). 3.2: Lacking detail of who and how collected data. No mention of quality assurance procedures. 3.3: Paid incentive but doesn't state how much or how	not explicitly state injury severity. 4.2: Unclear how participants were approached. 4.3: inclusion criteria to eliminate confounding variables- unclear how many excluded. 4.4: No mention of whether sufficient sample size. Preliminary study. 4.5: Very limited mention of limitations.	sample and lack of normal distribution. nonparametric correlations- justification for method provided. 5.4: did not correct for multiple comparisons increasing likelihood of type 1 error, provides justification for this. Highlights small effect size.	significant results. Acknowledges limitations of small sample and issues with generalising but support previous findings. 6.2: not placed in context of preliminary study- makes conclusions for future despite small sample.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
			objective. Consent procedure through hospital.			
Clark & Stephens, 1996, USA. Whether persons with stroke's perceptions and motivations of their partner's caregiving actions and how helpful/ unhelpful these are were related to satisfaction.	Cross sectional correlational 1.1: clear aims of study but no description as to how these link to design. Describes previous study that this study is built upon but no mention as to why important specifically for persons with stroke. 1.2/1.3: describes inclusion criteria. Unclear who contacted participants for recruitment. Opportunity sampling.	2.1: as per inclusion criteria 2.2: good description of psychometric properties of satisfaction measure as well as perception measure that satisfaction was assessed against. 2.3: clear description of response rates- initially 39% but 8 participants unable to give consent. No mention of	3.1: Quality of marriage index- 5 items. Does not state what these are- have to refer to original measure. 3.2: unclear procedure as to how participants completed the questionnaires (seems to be with the researcher which could influence bias). Doesn't identify any potential bias with this method of data collection. No quality assurance procedures	4.1: 55 persons with stroke 4.2: opportunity sample- poor response rate. describes selection process. Identifies why gender bias might be present. descriptive characteristics presented. Identifies limits to generalisability. 4.3: offers some rationale to inclusion criteria (e.g., age). No explicit exclusion criteria stated other than ability to consent.	5.1/5.3: regression analyses and correlations. Regressions for both models reported. Describes how regressions were conducted and process of choosing control variables/ procedure for error variance. Tables provided. 5.2: description as to why used	6.1: Tables for each finding/person variables and whether significant with descriptions. Acknowledges only partial support to hypothesis. Describes both regression models and variance for satisfaction in both. No limitations stated. 6.2: Previous literature used to support overall direction of findings and conclusions and suggestions as to what findings show. Little mention of limitations but does identify issues with

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	1.4: weak description of limitations but does identify limits to interpretation of findings due to cross-sectional design but findings supported by previous longitudinal research.	missing data- presumably as this is because measures were completed with researchers but this is unclear. 2.4: n/a	mentioned. Identifies some possible bias as to how the measurement of perceptions (which satisfaction was assessed against) were conducted. 3.3: documents clear consent procedures with use of test and excluded participants on this basis. No mention of incentive provided. Unclear bias in terms of researcher objectivity due to unclear procedure and how researcher was	4.4/4.5: no explicit mention of small sample size but does identify limits to generalisability. Describes poor response rate which contributed to small sample.	these tests in relation to hypotheses. 5.4: no limitations described in relation to analytic procedures.	generalisability, although findings are supported by previous research. Possible overinflation of results considering small sample.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
			involved in data collection.			
Hess & Perrone-McGovern, 2016, USA influence of health-related quality of life (HRQOL), attachment security, partner support, and relationship satisfaction after TBI.	Correlational 1.1: clear aims of research and design fits with aims. 1.2: clear procedure in how participants were recruited with inclusion criteria. Rationale given for excluded participants and response rate stated. 1.3: participants completed measures independently. Convenience sampling- responded to ad. 1.4: clear design limitations discussed and how	2.1: As per inclusion criteria 2.2: Good detail re. psychometric properties. 2.3: Addresses missing data- researchers selected measures that would suit client group. Acknowledges attrition as limitation by clearly reporting participants N=64 were excluded due to missing data (>10%) and mean	3.1: Appropriate and valid- Kansas marital satisfaction scale 3.2: data collection appears to be independent of researcher via internet questionnaires. Identifies limitations to this method e.g., self-report; response styles and combining data from two sources (Facebook & university)- this means not able to tell if differences between groups. 3.2: internet data collection implies	4.1: 122 TBI persons. Although states correlation for time since injury, no mean data supplied regarding this in demographic information. 4.2: clear limitations stated (see below). 4.3: inclusion criteria stated (broad). % of sample for demographics displayed in table. Reasons why used exclusion for relationship <6m. 4.4: N=122. States how many excluded prior to this and why.	5.1/5.3: correlations and regression analysis appropriate. All correlations reported. Adjusted r squared calculated, coefficients table. 5.2: Appropriate and clear tables with clear rationale as to why used analysis type. 5.4: Limitations highlighted in context of the analysis it	6.1: Tables for each finding/person variable and whether significant. Findings consistent with previous literature. Identifies future research need for longitudinal research. Appropriate context given limitations. 6.2: highlights findings add to existing research with mixed conclusions.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	this may affect findings.	substitution used for those <10%. 2.4: n/a	researchers independent of data collection. Clear separate informed consent procedures for internet and university samples.	4.5: Clear demographic limitations including implications for generalisability (study had higher N females than general TBI population)	related to but not how could affect interpretation. States if missing data for variables.	
Kieffer-Kristensen & Teasdale, 2011, Denmark Association between satisfaction and marital stress in ABI compared to matched control.	Differences between groups 1.1: Explains 1st study to compare families with children after ABI and why important. Rationale for why chose control group and why diabetes. 1.2: outline of procedure. 1.3: Recruited via rehab units /database. All	2.1: as per inclusion criteria 2.2: Danish translation- unclear if this has the same psychometric properties as original DAS? No properties for measures outlined (but explains DAS is "widely used"). 2.3: Identifies N=2 attrition	3.1: appropriate and valid. Dyadic Adjustment Scale (DAS) with satisfaction subscale results. 3.2: participants independently completed measures however researcher visited home- potential bias? No quality assurances mentioned	4.1: 35 ABI persons and their spouses compared to 20 couples in matched control group (diabetes). No information regarding injury severity. 4.2: acknowledges significant differences between groups for employment. Range of ABI injury (% given for each). Clearly	5.1/5.3: Mann–Whitney U/Wilcoxon (non-parametric). Alpha significance level consistent throughout although no justification for why .05 chosen. Tables for all variables with p values.	6.1: findings in context of previous literature. No mention of implications on non-parametric data for conclusions. Acknowledges limitations of small sample but supports previous findings. 6.2: acknowledges conclusions only related to this client group (e.g., parents of school aged children).

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	participants meeting criteria were invited to participate (convenience). 1.4: limitations to sample size and generalisability regarding inclusion criteria (parents of children aged 7-14) and possible future research including control group of no children/other ages.	and why. Outlines how many were contacted and how many participated and reasons why. Confirms no attrition/missing data during study. 2.4: n/a	however states no missing data. 3.3: researcher blind to participant information re. injury etc when collecting data. Doesn't appear incentives were used. Informed consent required.	details number of participants contacted and why N didn't participate. Identifies limitations to small sample and age of children. 4.3: rationale for why chose exclusion criteria re. children. No clear criteria related to ABI injury (<5yrs since injury) or relationship length (had been cohabitating prior to injury). 4.4: identifies small sample size as limitation and justification for this. Key	5.2: acknowledges non-normal distribution and use of parametric. 5.4: doesn't specify any limitations related to analysis methods particularly non-parametric data (e.g., less power).	

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
				demographics of sample given. 4.5: 55/105 participated. Unclear why so many didn't participate (didn't respond to invite). Researchers went through participant database details to ascertain family status to check inclusion- doesn't mention if any participants excluded as this information unavailable?		
McPherson, Wilson, Chyurlia & Leclerc, 2011, Canada Examine relationships	Cross sectional correlational 1.1: rationale as to previous gaps in research and what this study aimed to do (clear hypotheses/aims).	2.1: as per inclusion criteria 2.2: psychometric properties stated with reference. Why	3.1: appropriate and valid Quality of Marriage Index (QMI). 3.2: participants completed measures independently	4.1: 56 partners of persons with stroke 4.2: Asked all eligible participants who met criteria. Identified through medical records.	5.1/5.3: clearly described analysis procedure for replication. Pearson correlations for relationship	6.1: findings presented objectively. Appropriate context given limitations. Clear tables provided for each measure and analysis conducted.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
between caregiver quality of life (HRQL), caregiver role, relationship satisfaction, balance and reciprocity in caregivers of partners who had experienced a stroke.	1.2: outline of procedure- completed measures independently. 1.3: clear procedure in how participants were recruited. 1.4: identifies low response rate leading to small sample however details how tried to overcome this in contacting non-respondents. Identifies limitations of recruiting from one setting. Identifies possible bias from non-responders as no information collected on these people. States cross-sectional	used and how/why scores were transformed (reduce positive skew response). 2.3: states response rate (49.2%). States how many provided incomplete data (N=2) and thus how many excluded, leading to 56/120 completed dyads. States limitation that no information collected on those that didn't respond. Outlines procedure of attempts to	and then sent back to researcher. Researcher checked for missing data and excluded if this was present. Offered home visits (after 8 weeks of non-response) to those unable to complete independently- doesn't state how many this was for. Checked data met analysis assumptions. 3.3: attempts to be objective via participants completing independently. Informed consent procedure-	4.3: clear inclusion criteria. No explicit exclusion criteria. 4.4: key demographic table. Acknowledges smaller sample size than hoped. 4.5: acknowledges only female caregivers through one clinic setting- limiting generalisability. States limitation that no information collected on those that didn't respond. Acknowledges limitation of inclusion criteria of partners with mild impairments.	between variables. Regression analysis to identify predictors. 5.2: gives criteria for effect size. States why predictors were chosen (based on literature and outcomes). 5.4: power calculation stated- sample size needed to be 46. States a larger more diverse sample would permit more sophisticated multivariate analyses including an	Stated how many and percentage of participants reported specific findings for each measure. Table for all correlations even if non-significant. 6.2: places conclusions in context with literature with suggestions for future research to explore findings further. Identifies the implications the study limitations have on generalisability.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	correlational design meant could not determine the directionality or determine causality between the variables.	increase sample size. 2.4: transformed QMI scores to reduce positive skew response.	participants had to opt in. no incentive stated. Participants were contacted twice if didn't respond- bias to respond?		analysis of gender and cultural variation.	
Peters et al., 1990, Canada Whether injury severity impacts on relationship satisfaction/ adjustment.	1.1: states rationale for having groups based on injury severity (lack of research). Attempts to identify variables that could predict marital adjustment- rationale as to how selected these variables (pictorial diagram). 1.2: clear rationale and procedure as to how groups participants into	2.1: as per inclusion criteria 2.2: no psychometric properties stated. 2.3: no drop out (as seen in result tables). Doesn't state if eligible participants were invited and declined to participate. 2.4: n/a	3.1: appropriate and valid. Dyadic Adjustment Scale (DAS) with satisfaction subscale. 3.2: unclear if interviewers were the researchers. Data collection via different methods- acknowledges lack of control over social desirability bias. Doesn't state which measures	4.1: 55 persons with head injury based on spouse self-report (grouped into severity- unequal groups). 4.2: identified through health records but doesn't state how many participants were identified, contacted and recruited- possible bias with representing population.	5.1/5.3: ANOVA to compare differences between groups. Regression analysis. 5.2: explains regression analysis procedure and which analysis used for which hypothesis. 5.4: no limitations re	6.1: findings supported and identifies some variables with more power in predicting adjustment than others. Offers suggestions why this may be. 6.2: methodological limitations which states clearly and acknowledges influence on results and limit generalisability. Offers suggestions for improving this

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	severity group (could replicate). 1.3: participants interviewed via range of methods- some measures self-administered and others by interviewer- potential bias? Doesn't state how participants were invited/volunteered to participate or how many were asked vs participated. 1.4: acknowledges improvement on previous study but also has own methodological limitations which states clearly and acknowledges influence on results and limit		were self-reported and which were administered by interviewer and why. 3.3: no consent procedure stated. Appears no incentive given. Potential bias if interviewer as researcher. Robust independent classification of injury severity based on GCS score.	Acknowledges difficulty with generalising findings and issues with sample (under representing mild injury). 4.3: broad inclusion criteria. No exclusion criteria stated. Very broad criteria and large range for relationship length. 4.4: acknowledges small sample and fewer participants in mild severity group. Displays key demographics in table for each of the groups. 4.5: limitations stated and suggests this may influence results and generalisability.	analysis method stated.	e.g., larger sample, longitudinal, inclusion of female persons with head injury. Offers some clinical recommendations from findings.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	generalisability e.g., lack of control over socially desirable responding, under representation of mild injury, retrospective and cross-sectional design, reliance on volunteers.					
Peters et al., 1992, Canada Comparing the impact of injury (head/spinal cord) on marriage	1.1: states study aims with a rationale for why compared between injury type and why selected these groups. 1.2: unclear how participants were contacted for replication. 1.3: unclear how contacted/opted in to study and how many participants were contacted vs	2.1: as per inclusion criteria 2.2: no mention of psychometric properties. 2.3: no mention of attrition/ missing data- may have been overcome by interviews by researcher (i.e., completed measures with participant).	3.1: appropriate and valid. Dyadic Adjustment Scale (DAS). 3.2: researchers interviewed participants (potential desirability bias). 3.2: no mention of incentive. Spouses had to give informed consent for injured partner to take part (unclear	4.1: 31 partners of moderate head injury and 17 partners of severe head injury compared to 24 partners of spinal cord injury 4.2: doesn't state how many participants were identified, contacted and recruited. doesn't state in text how many in SCI	5.1/5.3: ANOVA to identify significant differences between groups. Demographic and group means in table. Uses Tukey's Honestly Significant Difference (used for unequal	6.1: findings presented objectively. 6.2: identifies generally consistent with previous research. However, overgeneralisation without acknowledgement of limitations.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	participated- attrition rates. 1.4: very limited mention of limitations. Identifies due to inclusion criteria, only able to comment on intact relationships and future research needing to look at change over time.	Unclear how many participants contacted vs participated- attrition. 2.4: n/a	how they completed the measure if not able to give consent).	group- only in table (24) (+ 17 moderate + 31 severe HI participants). All female partners. 4.3: wide inclusion criteria with potentially wide variety of injuries (but clear procedure regarding how participants were allocated severity group). No exclusion criteria explicitly stated. 4.4: no acknowledgement of small sample from one site- limit generalisability. 4.5: table shows no significant differences between groups.	groups) to see where the significant difference lies. 5.2: means tables provided. Brief description why used analysis methods. 5.4: Identifies needs more detailed analysis. Confirms no missing data in means table.	

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
				Doesn't state any limitations for sample.		
Williams, 1993, USA Impact of aphasia on marital satisfaction	Correlational 1.1: uses previous research to offer rationale for use of pre/post measures. Expanding upon previous study including larger sample. 1.2: rationale as to why/how participants grouped into aphasia severity (unequal groups) with clear, robust method to assist replication regarding tests used. 1.3: no detail on recruitment procedure (see 4.2) Paper/pen	2.1: as per inclusion criteria. 2.2: brief statement of psychometric properties (MSS) No detail on properties for MCLI and states removal of 4 items on MCLI "deemed inappropriate for population" but unclear rationale. 2.3: no mention of attrition- assumed all participants completed measures fully	3.1: appropriate and valid. Marital Satisfaction Scale (MSS) & Comparison Level Index. 3.2: assumed researchers checked for full responses as participants completed with them in room- query open to biased responses. Considered impact of completing measures (stated didn't counterbalance as felt not needed as pre and post measures	4.1: spouses of persons with stroke and aphasia (grouped via severity). 4.2: N=40 builds on previous study where N=16. No detail regarding who/how/where recruited from e.g., advert/in clinic or period of time recruiting. No mention as to how big sample size was before using exclusion criteria (was 40 an aim or 40 was maximum could recruit based on criteria?)	5.1/5.3: clear rationale for analysis and how/why conducted. Non-parametric as unequal groups. ANOVA for pre/post differences. Spearman p investigating if difference related to variables. Gives correlations even if non-significant. 5.2: doesn't explain why used cut off as	6.1: states corroborates and strengthens previous findings but with larger sample. inconsistent findings acknowledged between MSS/MCLI and why this may be. 6.2: Researchers state felt sample size enough to generalise findings on back of previous study- states felt improves reliability despite differences to previous findings. Acknowledges further research required to back up claims. Acknowledges some

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	completion of measures- participants completed independently with instructions. Detailed procedure of how participants completed measures. 1.4: acknowledges relied on retrospective, self-report ratings of past relationship satisfaction and appropriate implications of this. Possible bias with researchers grouping participants into severity rather than independent clinician (although using validated measure to do	as with researcher. 2.4: n/a	completed 1 week apart). Researchers detailed how they used scale scores for calculating MCLI (to avoid confusion). 3.2: verbal and written instructions provided presumed so participants could complete independently. No incentive detailed. No mention of consent procedures other than persons deemed unable to give consent excluded.	4.3: rationale for inclusion/exclusion criteria. 4.4: key demographics table for each group. 4.5: acknowledges some spouses unable to remember months since injury (however no detail to how many this was for). Provides rationale for including these participants. Researchers state felt sample size enough to generalise findings on back of previous study- states felt improves reliability despite	25 for looking at differences on specific items on MSS/MCLI. 5.4: acknowledges unable to ascertain clinically significant difference between pre/post satisfaction. Discusses differences between MCLI/MSS may be due to different scoring systems.	limitations of study- appears in context.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	this). Considered impact of completing measures (stated didn't counterbalance as felt not needed as pre and post measures completed 1 week apart).			differences to previous findings.		
Williams & Freer, 1986, USA, determine if a relationship exists between marital satisfaction and knowledge of aphasia of the spouse of a person with stroke.	Correlational 1.1: no explicit rationale for design other than why partner participants are important. Also offers explanation as to why persons were grouped into severity of aphasia and measures used for this classification. 1.2: lacking sufficient detail regarding	2.1: as per inclusion criteria 2.2: overview of psychometric properties. 2.3: identifies 5 participants refused to take part and reasons for this. No mention of any missing data from participants that did take part.	3.1: appropriate and valid: marital satisfaction scale. 3.2: limited detail regarding procedure but appears participants completed measures in clinic. Identifies possible influences of completing pre and post measures at same	4.1: 16 partners of persons with stroke (grouped according to aphasia severity) 4.2: opportunistic. Identifies restrictions including possible overrepresentation of couples who felt secure due to the nature of professional referral to the study rather than	5.1/5.3: ANOVA and correlations rationales given and appropriately described. 5.2: describes need for even group sizes and procedure to do this (randomisation of excluded participant).	6.1: findings presented objectively and supported by analysis data. Acknowledges limitations of findings. 6.2: no mention of findings in relation to previous literature however mentions that literature in this area is very limited. Clinical implications stated with reference to limitations in

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	procedure and how participants were recruited for replication. Mentions professionals referred participants but no mention where from/how. 1.3: appears participants completed measures in clinic (see 3.2) 1.4: identifies limitations of pre/post measures completed at same time (i.e., not longitudinal study).	2.4: n/a	time and attempts to reduce this. 3.2: no consent procedure detailed or mention of how participants were recruited. No incentive stated- appears measures collected as part of clinic visit. No mention of how researchers are objective- possible bias with participants completing measures in presence of professional?	participant opt in. Issues with generalisability. 4.3: limited inclusion/exclusion criteria. 4.4: table of descriptive characteristics. Attempts to make equal groups- used measure to do this but was equal groups by chance or did researchers exclude other participants to ensure equal groups? Mentions randomisation of excluded participants to ensure equal groups for analysis. 4.5: identifies limits to sample as	5.4: no mention of limitations to analytic procedures used.	terms of generalisability. Identifies need for replication in larger samples.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
				not random. Identifies bias to sample in terms of who was referred to the study. Identifies small sample and difficulties with generalisability.		
Williams & Wood 2013, UK examine the impact of alexithymia on ratings of relationship quality and satisfaction following TBI	1.1: Clear aims with rationale as to why include TBI persons and partner. 1.2: recruited over 12m period. unclear procedure for replication if participants were contacted to take part. Appears participants were asked to complete measures as part of their treatment in clinic (see 3.2).	2.1: as per inclusion criteria 2.2: good psychometric properties stated for both measures. 2.3: States no attrition. 2.4: Clearly stated-TAS scores not based on conventional cut off- used groupings from previous research to	3.1: appropriate and valid: Dyadic Adjustment Scale (DAS) satisfaction subscale, Index of Marital satisfaction. 3.2: unclear who collected data- appears to be as part of clinic. No quality assurance procedure but no missing data. Appears participants completed	4.1: 47 TBI persons and partner. 4.2:sample representative of all those attending clinic over 12m period, states how many of these met criteria (47/102). Discusses limitations to sample in detail and impact on generalisability. 4.3: exclusion criteria clearly	5.1: clear rationale for analysis and how/why conducted. Paired samples t test to compare ratings between person and partner. Correlations for confounding variables. ANCOVA and regression.	6.1: contrasting finding related to children acknowledged and explained why might be inconsistent with previous findings (not examined as variable). Gives rationale as to why findings might be inconsistent with previous research. Acknowledges other variables not examined. 6.2: conclusions appear to be

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	1.3: appears participants completed measures in clinic- unclear how this was carried out and whether person and partner completed together- potential bias? 1.4: Clear and detailed limitations: noted "important variable" related to children's age wasn't examined leading to researchers not able to determine if linked. Limitations regarding analysis method and measure used. Limits to sample	categorise. Stated used partner ratings to look at satisfaction- rationale given.	measures in clinic- unclear how this was carried out and whether person and partner completed together- potential bias? Participants excluded if researchers felt couldn't give informed consent- bias to sample? 3.3: full ethical approval confirmed, no incentive provided ("routine" treatment). Data collected via means of both persons with TBI and their	stated with rationale. 4.4: description of key demographics of sample e.g., gender, relationship length). Sample drawn from all those attending clinic using inclusion criteria (i.e., not able to make sample size larger without changing criteria). Acknowledges limits to this. 4.5: Limits to sample size on analysis available. Noted bias in participant selection including demographics and generalisability. Participants	Detailed for replication. Clear tables for all analysis. 5.2: justified decision to not use conventional TAS cut off with existing literature. Stated used partner ratings to look at satisfaction- rationale given. 5.3: confounding variables examined thoroughly. 5.4: statistical control by examining confounding variables and	objective based on data evidence and in context with limitations.

Author, Year, Country of origin, Aim	Study Design	Data Quality	Data Collection	Study Sample	Analysis Methods	Findings and Conclusions
	size on analysis available. Noted bias in participant selection and generalisability.		partners' reports and/or practitioner records and hospital case notes.	excluded if researchers felt couldn't give informed consent- bias to sample in terms of impact of severity of TBI?	acknowledges others may be present as limitation. Acknowledges analysis methods related to the data set was limited and gives rationale why didn't explore further (increased risk of type 1 error).	

CHAPTER II

Appendix A: Ethical approval

Re: "An exploration into how partners of those with an acquired brain injury (ABI) experience lack of emotional warmth, and its impact on the partner relationship"

Application for Ethical Review ERN_20-1523

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards

Susan Cottam
Research Ethics Manager
Research Support Group

Appendix B: Study advert

Are you interested in taking part in research?

UNIVERSITY OF BIRMINGHAM

Are you living with a partner who has experienced an acquired brain injury (e.g., stroke, head injury)?

Study title: An exploration into how partners of those with an acquired brain injury experience lack of emotional warmth, and its impact on the partner relationship

What is the purpose of the study?

The research aims to explore what it is like to live with a partner who expresses their feelings to you in a different way than how they used to before their acquired brain injury (ABI). This study is particularly interested in the changes in emotional warmth in your relationship. Some of the changes I am interested in is how your partner expresses:

- Empathy
- Humour
- Affection

What does the study involve?

You will be asked to participate in two interviews via Zoom each lasting around 60 minutes. Ideally, interviews will take place within 1-2 weeks of each other.

Am I eligible to take part?

You **can** take part if:

- You and your partner are **aged 18** or over.
- You are a partner of someone who experienced an ABI **more than 18 months ago**.
- You had been in a **relationship with your partner for at least 3 years** prior to their ABI.

- You are **currently living with your partner** and were living with them before they experienced their ABI.
- Compared to how they used to be, your **partner is showing less warmth and affection** towards you.

You **cannot** take part if:

- You think discussions related to your relationship may be too distressing for you.

What should I do if I am interested in finding out more?

Please contact me using the details below. I will then give you more information and answer any questions you may have about participating.

Adele de Gray, Trainee Clinical Psychologist (contact information omitted)

Appendix C: Participant Information Sheet

UNIVERSITY OF BIRMINGHAM

Version 2: Date July 2021

Title of Study: An exploration into how partners of those with an acquired brain injury experience lack of emotional warmth, and its impact on the partner relationship

I would like to invite you to participate in my research study as part of my Clinical Psychology Doctorate degree at the University of Birmingham. Your participation is entirely voluntary.

This information sheet will help you to understand more about the study and what it involves. Please read this information carefully before you decide to take part. It should take you around 10 minutes. You may wish to discuss your participation with family, friends or Headway staff.

Please feel free to ask any questions you may have. You can contact me: Adele de Gray, or my supervisors at the University of Birmingham. Our contact details are at the end of this information sheet.

What is the purpose of this research?

Individuals with an Acquired Brain Injury (ABI) such as a head injury or stroke, can struggle to express emotional warmth after their injury which can cause significant difficulties in relationships.

Some examples with which a person with ABI may struggle with include:

- Showing empathy.
- Expressing affection.
- Responding to their partner's emotions.
- Sense of humour.
- Closeness and connection with others.
- Lack of consideration for others, insensitivity to or neglect of the needs of others.

This study is interested in how you as a partner experience these changes, including what they are like to live with and how it affects your relationship.

Am I eligible to take part?

You **can** take part if:

- You and your partner are aged 18 or over.
- You are a partner of someone who experienced an ABI more than 18 months ago.
- You had been in a relationship with your partner for at least 3 years prior to their brain injury.

- You are currently living with your partner and were living with them before they experienced their brain injury.
- Compared to how they used to be, your partner is showing less warmth and affection towards you.

You **cannot** take part if:

- You think discussions related to your relationship may be too distressing for you.

Do I have to take part in the study?
No. Your participation is entirely voluntary. Deciding not to take part will not affect you or your partner's ongoing support from Headway.

What will happen to me if I agree to take part?
I will contact you a minimum of 48 hours after you have received this information sheet to enquire if you are happy to participate and to answer any questions you may have. If you would like to take part, I will ask you to complete and return the Consent to Participate form you received with this information sheet via email or post and we will arrange two interview slots. Please note, I will need to have received your consent form before the interviews can take place.

How long will my participation in the study take?
The study involves two interviews each lasting up to 60 minutes. You will need to be able to commit to both interviews to participate.

Where and how will the interviews take place?
Interviews will be conducted via Zoom electronically. You will need to have a good Wi-Fi internet connection. You can use Zoom on a computer, or a mobile or tablet using the Zoom app. You will need to be somewhere private to participate in the interview and consent to the interview audio being securely recorded. Following the interviews, a word-for-word transcript of the interview will be produced for data analysis.

What will happen if I do not want to carry on with the study?
You do not have to participate in the research even after you have signed the Consent to Participate form. If you change your mind, please let me know. You do not have to give a reason. Your decision will not affect yours or your partner's support from Headway.

You do not have to answer all the questions in the interview if you do not want to. If you begin an interview but change your mind, you do not have to continue or give a reason why you want to stop. If you withdraw from the study early, all your data will be securely erased.

It is important that you are aware there will be some limits on withdrawal of your data once the interviews have been conducted:

- After an interview has finished, you will be asked if you wish for anything you said to be removed from the interview. These sections will not be transcribed and will not be included in the analysis.
- You can email the researcher to withdraw your consent or ask for anything to be removed from your interview **up to 7 days after the second interview** has been conducted. You will be reminded of this at the end of your second interview. In the event of withdrawal, all data will be securely destroyed.
- After 7 days following the second interview, it will not be possible to withdraw your data from the study as data analysis will have started.

What will happen to the information I give?
Interviews will be audio recorded and transcribed. I will go through all participants' transcripts to look for similarities in order to extract themes for this research study.

Where will the data be stored?
Your contact details and consent forms will be uploaded and stored electronically on a secure database held by the University of Birmingham. Any paper consent forms will be shredded after being scanned and uploaded to the secure database. Any notes relating to the interview will be stored on the secure database or an encrypted memory stick provided by the University of Birmingham. Notes will not contain any personal identifying information.

Audio recordings of Zoom interviews will be initially stored on Zoom's cloud storage facility. They will be transferred to the University's secure storage database immediately after the interview, and, once transferred, both the temporary file and Cloud recording will be deleted from the Zoom account. Once transcribed, audio recordings will be securely erased from the database, and only the written transcript will be kept. The transcript will be held in a separate file to your contact details and consent forms so they cannot be linked.

Will the information I provide be treated confidentially?
Only the research team (myself and my supervisors) and those authorised by the University of Birmingham to conduct research audits will have access to your data. Only your consent forms and the audio recordings will be personally identifiable to you. The audio recordings will be securely deleted as soon as they have been transcribed. The consent forms will be stored in a separate password protected file to all other information.

I have a duty of care to discuss any serious concerns and/or risks related to your safety, the safety of others, or disclosures of abuse made during the interviews to my research supervisors. I may need to take further action such as liaising with safeguarding teams or making a referral to social services. I will inform you at the interview if I feel I need to discuss any concerns with my supervisors.

After each interview, you will be asked if you wish for anything that you said to be removed from the interview. Direct quotes from your interview transcripts may be used in the write

up. Any identifying information will be removed or altered so that you cannot be identified. You and your partner will be given a pseudonym in the transcript and write up.

What will happen to the results of the research study?
The results of the study will be written up in a doctoral thesis. A copy will be stored at the University of Birmingham. The findings may also be published in academic journals or presented at conferences.

You will be sent a summary of the research findings via email or post. Headway will also receive a copy. This may be up to 2 years after your participation in the study.

What will happen to my data after the study has ended?
Interview notes will be securely erased following write up. Your personal contact information will be securely destroyed by the research team once you have received details of the research findings. In accordance to University regulations, your consent to participate form and anonymised interview transcript data, will be stored on the secure database for 10 years, after which they too will be securely destroyed by the research team.

What are the possible disadvantages and risks of taking part?
Due to the potentially personal and sensitive nature of the interview topic, the interviews may cause some distress. If this happens, the researcher will ask you if you want to take a break from the interview, stop the interview or withdraw from the study. At the end of this information sheet, there are details of organisations that may be able to help you if the interview causes any distress.

What are the possible benefits of taking part?
It is anticipated that you will not directly benefit from participating in the study. However, you may find participating is helpful to you and your relationship with your partner by discussing the impact your partner's brain injury has had on you both.

What if I need to make a complaint?
This study has been approved by the University of Birmingham's Ethics Committee.
If you are unhappy about how the research has been conducted, you can contact Dr Birgit Whitman, Head of Research Governance & Integrity at University of Birmingham on [redacted] or via researchgovernance@contacts.bham.ac.uk.

Sources of support
If you feel you need more support in helping to cope with your partner's brain injury, you should speak to a member of staff at Headway or to your GP.

The following websites and helplines also provide advice:

- Headway: helpline- 0808 800 2244; www.headway.org.uk
- Stroke Association: helpline- 0303 303 3100; www.stroke.org.uk

- Brain Injury Group: helpline- 0800 612 9660; www.braininjury group.co.uk
- Carers UK: helpline- 020 7378 4999; https://www.carersuk.org/
- Carers Trust: helpline- 0300 772 9600; https://carers.org/
- Relate: helpline- 0300 100 1234; www.relate.org.uk

If you would like to discuss any aspect of this research please contact:
Adele de Gray, Trainee Clinical Psychologist (contact information omitted)

Research supervisors: Dr Gerard Riley: Dr Darrelle Villa: (contact information omitted)

Appendix D: Consent to Contact Form

Version 2: Dated July 2021

1.2 CONSENT TO CONTACT

Please provide a phone number and either an email address or a postal address you can be contacted on.

I will contact you via telephone to give you the chance to ask any initial questions.

Then, if you would like to proceed, I will ask you to complete a Consent to Participate form.

Please indicate below the method that suits you best.

I agree to be contacted about the study.

I prefer to be contacted by:

- THE RESEARCHER SPEAKING TO ME AT A VIRTUAL HEADWAY GROUP
- PHONE CALL
- EMAIL
- POST

Please provide your contact details below:

Phone number: ……

Email address: ……..

Postal address:

……

……

....

Name (Please print) Signature

Appendix E: Consent to Participate Form

Title of Study: An exploration into how partners of those with an acquired brain injury experience lack of emotional warmth, and its impact on the partner relationship

Name of Researcher: Adele de Gray, Trainee Clinical Psychologist

Fair processing statement: This information is being collected as part of a research project concerned with partners of those with an acquired brain injury by the School of Psychology at the University of Birmingham. The information which you supply will be stored at the University of Birmingham and will only be accessed by authorised personnel involved in the project. The information will be retained by the University of Birmingham and will only be used for the purpose of research. By supplying this information, you are consenting to the University storing your information for the purposes stated above. The information will be processed by the University of Birmingham in accordance with the provisions of the Data Protection Act 2018. No identifiable personal data will be published.

Please initial each box to confirm you agree:

1. I confirm that I have read the information sheet dated..... (version.....) 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 from the study without giving any reason and without my or my partner's ongoing support from Headway being affected. ☐

3. I understand that the study involves me completing two interviews with the researcher and that these interviews may be of a sensitive nature. I consent to these interviews being audio recorded. ☐

4. I understand that if I want to withdraw any part of my interview following participation, I must let the researcher know within 7 days of the second interview being conducted. If I contact the researcher within these 7 days, my data will be securely destroyed. I understand that it will not be possible to remove my data from the study after this time. ☐

5. I understand that if I disclose any information in the interviews that raises concerns and/or risks about my safety or the safety of others, the researcher may stop the interview and discuss their concerns with me. I understand the researcher may need to discuss any disclosures with their supervisors. I understand that information may need to be passed on to statutory services such as safeguarding services. ☐

6. I consent to the research team and those authorised by University of Birmingham to conduct audits to hold my data securely. I understand what will happen to the information I provide, and the arrangements to ensure its confidentiality and security. ☐

7. I have declared any current or recent involvement in research. Please state here: ☐

   ……
   …

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

_____	_____	_____
Name of Participant	Date	Signature

Circle type of consent: Electronic/ written.

Please now either email or post this consent form to me, Adele de Gray, Trainee Clinical Psychologist.

Appendix F: Interview topic guide

Interview One: Pre-injury relationship and changes in emotional warmth and prosocial behaviours on the part of person with the injury.

- **Background:** Get a timeline, history, demographics, information about the injury – ages of both, when did you meet, when did you move in together, when did the injury happen, how long were you in a relationship before the ABI? what sort of injury was it, how long in acute hospital/rehab, how much care and support does s/he need now.
- **Pre-injury relationship:**
    - What was your relationship like before the injury? What 5 words or phrases would you use to describe it? What was good / not so good about your relationship? What things did you do together?
    - What positive things did s/he bring to the relationship? What 5 words or phrases would you use to describe what they brought? what qualities attracted you?
    - What did you enjoy about spending time with him/her?
    - How did s/he show that s/he loved and cared for you? What were your experiences of emotional warmth in the relationship before your partner's ABI? How was this expressed?

- Showing empathy.
- Expressing affection.
- Responding to their partner's emotions/emotional reciprocity
- Sense of humour.
- Closeness and connection with others.
- Lack of consideration for others, insensitivity to or neglect of the needs of others.

- **Changes:** How do you feel your partner has changed in these areas since their ABI? What changes have you experienced in the relationship?

- Go through the things mentioned in the previous section that are about <u>both</u> expressing love, affection and care within the relationship, <u>and</u> broader prosocial behaviours that

cement relationships and strengthen social bonds with others (humour, conversation, shared interests etc.). For each one, ask whether it has changed since the injury.

Interview Two: Exploring these changes in more detail

Make a list prior to the interview of changes in expression of love and care, and broader prosocial behaviours, that were mentioned in the first interview.

- Any reflections from interview one?
- Reminder of what changes were spoken about in the previous interview
- What's your **understanding** of why s/he is less X?
- Do you think the fact that s/he is less X has affected **your own feelings** towards him/her? What impact has this had on you as a partner?
- Do you think the fact that s/he is less X has affected **your relationship**? Consider emotional well-being, relationship quality/satisfaction. How would you describe your relationship now? Consider elements related to continuity/discontinuity.
- How have you **coped** with the fact that s/he is less X? Is there anything you've done to try to improve it? or to reduce the impact it has?

Appendix G: Example of IPA analysis process

G.1: Example of initial coding process

293	humour that was there when I met him and and well always	Feels partner never lost his humour- stayed throughout difficulties in life
294	has been there and it's very immediate and a little bit surreal.	
295	So it's that sort of sense of humour that just taps into	?possibly humour didn't rely so much on brain processes so still intact "we click"- sense of being couple, connection
296	wherever your brain wants to go and we just we click on that	
297	and the brain injury has not taken that away, in fact, if	Suggests injury is responsible for other traits that are now absent
298	anything, and some sometimes it's it kind of how do I put it	
299	(pause) it's like his brain relaxes in a way that it didn't before	Sees some positive from injury
300	the stroke and sometimes he can say things, and he'll say the	Not trying to be funny but participant sees him as funny- ?feels natural, unforced
301	first thing that comes into his head, and some every now and	
302	then, he'll say something, and I'll think it's hilarious and he	
303	doesn't realize he's been funny. But then, many, many other	
304	times, he'll do what he used to do before and say something	Injury as a point in time- same person
305	odd because he knows it's odd so he can still, the sense of	Has confidence that partner knows what he is doing is funny- ?like his brain is working the same as before
306	humour is still largely the same that there's, there's bits	Humour as important quality that builds connection
307	where (pause) we've always both been sort of interested in,	
308	he's very into history, geography and archaeology and that	Have similar interests and humour is built on that- bringing them together
309	sort of thing, we've both always been into, into history and	
310	politics, you know we'd both make, we may be watching the	
311	news and some of the humour is around, will be around that	
312	sort of around politics or what's going on in the world or kind	Some elements of old humour unable to join in as related to higher level processes- limited understanding feeds into loss ?sense of loss/sadness "can't do that anymore"
313	of dark humour about that bit in time and he doesn't do that,	
314	he can't do that anymore, because he doesn't get the	
315	obviously that understanding the kind of it feels like the	
316	academic side of it, you know the kind of what's going on in	
317	detail and the details of what's going on and so that's an	Sadness of "missing" connection in talking about things both enjoyed at a higher level- basic reciprocity?
318	aspect that I miss is being able to chew over the stuff with	
319	him and talk about I suppose kind of academic stuff that we	
320	both had an interest in, and then there would have been that	
321	so yes, before, sense of humour attracted me, we used to do	Shared enjoyment of being outdoors- spending time together
322	a lot of outdoorsy stuff, we'd go for walks we go camping	
333	that sort of thing, and as we got older, we did, you do less	
334		
335		

G.2: Bringing quotes together into emergent themes

Different sort of love/warmth *Solid foundations/pre injury person as grounding for acceptance with changes*	I feel like I say it's a different sort of love I feel. I feel a sort of a warmth towards him that's more often almost because because he's dependent, it brings out a sort of nurturing, carer, parenting side of things, and it becomes like I say, it's it's it's a different sort of, becomes a sort of becomes a relationship with you looking after a family member(2:163), it's more of a sort of it's a very deep family kind of though being a carer for your partner is different to being the partners that you were 10 years ago(2:77) I don't miss miss it (sex) massively I don't kind of erm (long pause) And I actually don't, I have no idea whether whether it's something he even thinks about and I'm thinking no, I'm thinking it's probably just it's not on the radar anymore(2:747) I think I probably would would have noticed if it had (laughs) but it hasn't been, certainly when when I when we hug and kiss, there's nothing sexual about it, it's warm and it's lovely and it's it's comforting and all that sort of thing but it's not sexual. (2:766) now for me I wouldn't want any sort of sexual relationship now anyway, because it would feel weird with the roles, I don't know it just it wouldn't feel right to me(2:773) I think sort of it it's a different sort of love, it's a different sort of you know, when when you've been together as long as X and I have, so much of your relationship is is is based on mutual experience, it's not you know it's not it's not physical attraction and sex, it's not it's not kind of that kind of love's young dream kind of thing (laughs) we're not lovey dovey at all erm it's it's that sort of depth of feeling that you get with family where all your experience, all that shared experience and all that shared mutual support and things and that's what we've been together 25, 26 years, that's what builds it and thankfully long term memory is really good so he, we've still got all	Some feelings of warmth still there but in different way- more like as a carer, protective, dependent, mothering like relationship Perhaps not loving partnership but caring relationship- change of roles- relationship redefined- loss of certain feelings Doesn't miss sex life- not something have talked about as couple so has limited understanding whether partner feels the loss of this element, this loss doesn't seem as strongly felt Although offer affection, this isn't sexual- more care? Showing warmth as friend rather than love? "when I" changed to "when we" suggests participant doesn't feel sexual feelings. Feels warmth from partner but not sexual feelings- like carer role of family rather than partner- participant seems accepting/content with this Content with absence of sex and doesn't seem to want this- relationship redefined through role change- not feeling "right" *Seems like come to terms with this*- feelings are still there but different Feelings based on strength of relationship before injury- preinjury person/life together Affection/sex less important- solid relationship more about experiences/support "depth of feeling"- suggests solid grounding that can't be eroded- family life brings them together and holds connection Memory intact so still able to share old memories together to hold on to connection
Humour as element that builds strong connection	we click on that (humour)(1:296), I'll think it's hilarious and he doesn't realize he's been funny he'll do what he used to do before, the sense of humour is still largely the same(1:304) we still find a lot of the same things funny, we'll share videos or something so you know as I say we will watch stuff together and talk about that (1:546) a lot of the humour that we had before he's he still does, although I'll be honest, I think sometimes he doesn't do it deliberately(2:503)	sense of being couple, connection ?feels natural, unforced Has confidence that partner knows what he is doing is funny- ?like his brain is working the same as before Humour brings closeness- actively try and do things to be closer Although humour still there, participant unsure if this is deliberate or type of humour exacerbated by injury
Warmth shown through practical over emotional elements	neither of us were lovey dovey in any way, we've always been quite sort of I don't know you know we don't we don't say I love you all the time. Nothing like that. It's erm but we'd erm yeah a cuddle and a kiss as you are going past each other. You know I would say, I would say, that would happen every day, it's just you know kind of passing in the kitchen erm (pause) other than that I suppose not really just just practical just how you how you deal with each other, it's how you sort of give each other space or do stuff together or and judge judge each other's mood. That sort of thing to me that that's the kind of how you work around each other and consider the other person's feelings(1:418) he would be able to say what can I help with, what do you want me to do or he might just quietly go and deal with the kids, recognizing emotional strain just the day to day wear and tear and be able to do something practical to help give me a hug, do something practical to help or bring chocolate back with him, you know just something(1:780)	Not overly affectionate before injury- *?i wonder if judging on comparing to other couples and how they may show love?* Showed warmth in passing to each other- reciprocal- ?sounds more like done thing rather than spontaneous? Way showed care through practical things that partner has trouble with now from injury- perhaps more discontinuous as now unequal partners? Partner having to read cues to be able to do this successfully Related to being in tune with partner- ?higher level process, less display, more innate/instinctive feeling? Support with practical needs which showed participant he cared ?like a team before, appreciated partner's actions Partner would be able to offer support without being told

G.3: Summary of emergent themes from participant

P6 Themes
Transitioning relationship *Old to new- making adjustments* *Complicated to simple/easy*
Same person, same feelings *Humour as element that builds strong connection*
Grief for old life -intellectual -response to needs
A different sort of love/warmth *Warmth shown through practical over emotional elements* *Mothering- childlike* *Solid foundations/pre injury person as grounding for acceptance with changes*
Understanding *Partner insight/understanding of his difficulties* *Understanding- brain areas affected- locus of control away from partner?* *Natural instinct before in emotions- brain affected this* *Lack of understanding*
Relationship redefined- One sided *Change in roles* *Reciprocity (conversation, understanding feelings)* *Impact/burden of difficulties e.g., communication, carer role, loss* *Lack of talking about feelings- impact*
Injury as traumatic, unexpected recovery for injury
Impact of visible (physical) vs invisible (emotional) injury- links to perception of others

G.4: Notes relating to superordinate theme development

How does this loss of warmth manifest itself in the relationship? What kinds of things are the participants dealing with?

- Reduced empathy/consideration for partner's needs/loss of emotional support
- Lack of reciprocity- communication, affection
- Closeness & connection: sex/intimacy, reduced activity/shared interests, changes to humour
- Some elements of warmth still present/stable despite injury/improved?

What is their <u>immediate</u> experience of these changes?

- Positive: love remains (same person), hope for recovery (seems to impact on seeing positive changes)
- Negative: guilt, dissatisfaction/frustration, sadness/grief for old life/loss of sense of self, isolation from others (hidden disability), isolation from partner (one sided), hopeless for change/future

What sense do they make of them?

- *Changes as result of areas of brain*: empathy for partner- locus of control away from partner at "fault".
- *Lack of information/limited understanding* heightens difficulties – exacerbated by lack of support from services
- *Elements that are still there as fundamental to who the person was before*
- *Unknown/uncertainty regarding intent behind actions and meaning of warmth or function of behaviour* shown by partner with brain injury. This is exacerbated through change in roles- more functional/practical relationship rather than emotion behind, partner queries if affection is one sided or lacking meaning and imposing on person with brain injury. Person with brain injury being told by participant what they need e.g., hug- link to automatic/instinctive response. Link to "like a shell" as to helping understanding behind lack of warmth. contrast: Acknowledgement person/relationship priorities change over time.

How do these changes impact on the relationship?

- *one sided partnership*- Change to roles- parenting, protector and advocate, loss of "teammate"- emotional wellbeing- trapped, burden/duty, isolation. Impact of carer support. Contrast- spending more time together>built connection. (*Link to relationship redefined/loss of couplehood)*
- *Transitioning relationship*- 'a different sort of love'- mother-child- protection, secret language (non-verbal) hug more important than words (Helen), less complicated, realisation that relationship has changed/reduced expectations from partner *(link to different feelings)*

- *Attempts/adjustments to maintain warmth* e.g., “making do”, hold on to memory, reconnection in other ways, acknowledgement of elements of same person. ?lack of support exacerbates difficulties, ‘like a shell’ (uncertainty of the response from the partner) *(Link to Different person vs Same person/loss)*
- *Growing together*-Acceptance & gratitude, “adjust & achieve” to help cope with changes, *link to “same person”/couplehood*

G.5: Combining Participant quotes into final superordinate themes

Retention/presence of warmth, e.g. humour, shared interests, content with relationship as it is, feelings of love and couplehood still present	
I was really quite touched coz I wasn't sure whether he just saw me as somebody who looked after him but er there is, there is still something there. It er surfaces now and again(2:311)	June
it's (time in bed together) one of the few times when I feel life's a bit normal(2:551), it (reciprocal physical affection) makes me feel all is not lost(2:639)	June
So for him to hug and hold that hug with meaning, I know it's in there(2:267)	Helen
you know, there are things that have happened that have you know consolidated that warmth(2:30)	Isabella
sometimes she'll you know touch my arm in a very you know affectionate way (1:419) which you know seems like a minor thing, but for me it's quite a big thing, she is acknowledging the relationship(1:899)	Isabella
one of the things that most attracted me to him is his sense of humour, he makes me laugh and he still does(1:290), always has been there, in some areas we can still joke around and and he can still chat as though there's nothing different(2:466), a lot of that is still there, and imagination is still the same in a lot of ways(2:512)	Emma
I think I probably would would have noticed if it had (laughs) but it hasn't been, certainly when when I when we hug and kiss, there's nothing sexual about it, it's warm and it's lovely and it's it's comforting and all that sort of thing but it's not sexual. (2:766)	Emma
oddly it's like a reset button, kind of like it cleared mess (laughs). But took a lot of other stuff with it as well, unfortunately, (laughs) but you know so it's an odd situation. There's a lot of stuff lost but there's also in a weird way some stuff gained(1:458)	Emma
I'd say that, in terms of intimacy and stuff there's still that sense in which you know, a couple has their way of going about you know just demonstrating affection and and being close and you know having sex and stuff like that(1:488)	Otis
there's something meaningful in how she she offers support you know with not too many words but a reassurance that everything is going to be okay, you're okay, and so she has a way of doing that(2:890)	Otis

Changes to/loss of warmth behaviours	
Lack of consideration/insensitivity to partner needs/lack of empathy/loss of emotional support	
It's not gone completely but erm he can't sort of make allowances(1:721), he was very good you know if he saw that I was struggling in any way(1:735)	June
I can think I'm being really obvious about how I'm feeling and he really hasn't got a clue(1:816), I just don't think he does like respond to my emotions, I could have a full on meltdown cry {pause} and he'd probably say what should we have for lunch (2:835), like the filter that most of us have before we speak out loud sometimes isn't, isn't there (1:810)	Rosie
He did definitely show that he cared(1:403), initially he would just say exactly whatever came to his mind whether it was appropriate or inappropriate to whomever (1:451) I'd probably have to say first", responds if directed now he would just ask me if I wanted a glass of wine	Sally
there's no empathy there (2:41), it took like for me to like crying my eyes out for him and to not get that back when you're upset(2:660), he was actually annoyed I was upset weirdly enough, just tried to ignore it as well (2:227) think with the emotional side of things as well, it looks It just seems, it seems alien to him (1:794)	Helen
we bought each other flowers we you know we were we organized to go out, you know, without telling the other person what we were doing(1:378), now a lot of what she's you know a lot of what she's concerned with Is you know, understandably her own needs(1:436)	Isabella
emotions puzzle him just delude him in a way that they didn't used to(1:129) before: I would say he was naturally very empathetic(1:440) now: he doesn't anticipate what I'm feeling, he doesn't empathise, he doesn't notice when there's other stuff going on(1:475), obviously he's not able to think about my emotions and feelings in the way he could because he doesn't understand them(2:356)	Emma
In terms of emotional warmth it's it's the lack of empathy is the most difficult for me. Okay there's two, lack of empathy and (pause) that he doesn't tend to initiate anything even even like I say, he'll hug me if it's very obvious that that's what's expected(2:802)	Emma
I think that you know there's a sense in which I am thought about, I don't think I don't think there's a sense in which it is overly articulated though(1:698)	Otis
Lack of reciprocity: communication	
it's (closeness) changed, mainly because of his speech and understanding (1:688), I think the worst thing is not being able to discuss things with him(2:51), our conversations are rather erm sort of essential(2:127)	June
he likes talking about the things he used to do. When he was younger and when he was able to do things. {pause} So he tends to kind of go over his old memories and things that he used to do quite a lot. I try and talk about the future and things I'd like to do. But he's less interested in that so there's not much to talk about (1:783)	Sally