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Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

How People Make Sense of their Partner's Cognitive and Emotional Difficulties

Following Acquired Brain Injury

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Abstract

The primary focus of the research is caregivers of people who have had an acquired brain injury (ABI); the literature review collated evidence in relation to caregiver resilience and the empirical paper focussed on partners in particular.

Section one details the systematic literature review. It aimed to review all of the quantitative research exploring resilience and related constructs (RARCs: resiliency, posttraumatic growth [PTG], and hardiness) in caregivers of people with ABI. There was a particular emphasis on how authors defined their constructs, and the quantitative relationships of RARCs that were elucidated. Three databases were searched: CINAHL, MEDLINE and PsychINFO. Inclusion criteria were broad: papers must have used a measure for their RARC construct, and have used this to perform some type of statistical analysis. Twenty-six papers were included. Findings showed that resilience and resiliency were not narrowly defined, and often crossed over, or became confused with other RARCs. Generally, high RARCs scores were associated with good outcomes, and low RARCs scores were associated with poorer outcomes.

Section two details the empirical paper, exploring people's sense-making of their partner's cognitive and emotional difficulties following ABI. Six working-age partners of people who had an ABI were interviewed and transcribed data was analysed using interpretive phenomenological analysis. Five themes were constructed: (1) "I don't know...it's a weird thing to describe": The complicated nature of ABI; (2) "So you try and work around it": The exhausting task of taking on the extra cognitive and emotional load; (3) "You're not the partner anymore": Finding a new relational dynamic; (4) "It's like this ultimate patrol": The need to protect; (5) The lack of effective support is isolating. Clinical implications were discussed.

Section three appraises sections one and two critically, including further strengths, challenges, clinical implications and some of the author's reflections through the process.

Declaration

This thesis documents research undertaken for the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Hayley Butler

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Date: 15th May 2022

Acknowledgements

I would firstly like to extend my thanks to the participants who took the time to take part in this research. Thank you for sharing your stories; the positive bits and the emotional, which have all inspired me. I know that not everything is represented here, for the narratives were so rich, that it was beyond the scope of the word count here. I hope I have caught the main threads, however, which cross over several narratives, as well as the differences.

I would like to also thank my supervisors, Fiona, Will, Alan, and Dave, without whom, I wouldn't have the first idea about how to even go about starting such a project. Thank you for helping me with all of the practical things, as well as helping me to organise my time. Thank you for your direction, expertise, and support when things got emotional. You have helped improve my researching skills from that of an undergraduate dissertation level to that of a doctoral candidate. I am forever in your debt!

I would like to extend the biggest thanks to my family, particularly my partner, Andrew. Firstly, for all helping me take care of my basic needs while I spent extended days working on this project – whether that meant cooking meals, bringing drinks, or encouraging breaks. This would not have been what it is without that. Thank you also for being there to hear my rants and stresses during the course, and for the love and care which helped me maintain my wellbeing over the past three years. Thank you to my step-kids for the laughs, love and kindness, which have been flickers of light when the tunnel seemed dark, and to my wider family, whose support has been the foundations of my resilience.

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Section One: Systematic Literature Review

**The role of resilience in caregivers of Adults living with Acquired Brain Injury: A
Quantitative Systematic Literature Review**

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Abstract: 193

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Abstract

This paper aimed to investigate how resiliency and related constructs (RARCs) have been conceptualised in research with caregivers of people who have an acquired brain injury (ABI). It also aimed to review all the quantitative work undertaken using RARCs in this particular group. A systematic search of three academic databases was performed focusing on the overlapping concepts of resilience, resiliency, hardiness and post-traumatic growth (PTG) in informal caregivers of people with ABI. Papers were selected based on broad inclusion criteria. PTG and hardiness had narrow and defined definitions but there was still much heterogeneity in 'resilience' and 'resiliency' definitions. Generally, correlational research found that higher RARCs were associated with positive outcomes in ABI caregivers (Small-large effect-sizes) and lower RARCs were associated with negative outcomes (Small-medium effect-sizes). Complex statistical modelling highlighted that resilience did not always have direct effects on outcomes, but that it was mediated by other constructs. It was a conclusion that there is a continued need for a clearer definition of resilience, and consensus around which skills are most important in resiliency. Review strengths and limitations, clinical implications and future research are discussed.

Keywords: Brain Injury, Caregivers, Resilience, Resiliency, Hardiness

The role of resilience in caregivers of Adults living with Acquired Brain Injury: A Quantitative Systematic Literature Review

Acquired brain injury (ABI) is defined as any damage or injury to the brain, which has occurred after birth (Giustini et al.2013; United Kingdom ABI Forum [UKABIF], 2013). There are various sub-categories, which describe cause, including traumatic brain injury (TBI; road accidents, falls), and non-traumatic (stroke, tumour etc.). Injury can be classified as mild, moderate or severe. Various classification systems are available. One of the most common is the Mayo (Malec et al., 2007), which determines severity based on the level of consciousness at the time of the injury (using the Glasgow Coma Scale (Teasdale & Jennett, 1974)), length of unconsciousness, length of post-traumatic amnesia (PTA) (Entwistle & Newby, 2013) and neuroimaging. ABI is the biggest cause of death and disability in young people. For example around 1.4 million people per year are admitted to hospital as a result of their injuries in the UK (National Institute for Health and Care Excellence, NICE, 2019).

ABI sequelae can include physical impairment, as well as behavioural, cognitive and emotional changes, which are extremely heterogenous (Doppenberg et al., 2006; Goldstein et al., 2010; Lippa et al., 2020; Murherjee et al., 2006). Behavioural and personality changes are commonly reported (Azouvi et al., 2016) even after mild traumatic brain injury (Kreutzer, et al., 2001), where there is typically no loss of consciousness (American Congress of Rehabilitation Medicine 2016). Aggression and irritability are cited as the most difficult and problematic changes for individuals (with insight into these complications) and their family members. Emotional reactions such as grief and loss (Coetzer, 2006), depression and anxiety are also typical for people who have had an ABI, and there is some evidence to suggest that cognitive sequelae can impact this further (Levin et al., 2007).

Cognitive changes following ABI are wide-ranging, and can include memory problems (Wammes et al., 2016; Vanderploeg et al., 2014), attentional difficulties (Mangels

et al., 2002; Slovarp et al., 2012), language impairments (Vas et al., 2015), insight problems (Prigatano & Schacter, 1991) and executive function impairments (Engstad et al., 2013; Ord et al., 2009). It is thought to be a combination of these cognitive impairments, which cause some of the most problematic and long-lasting, day-to-day difficulties for people with ABI. Once physically stable and out of the hospital, it is generally left to family members to provide much-needed day-to-day support, as 'informal caregivers' (Powell et al., 2016), which saves health services considerable sums of money (e.g. Buckner & Yeandle, 2015).

Support needed can vary widely because of the heterogeneity of difficulties after ABI. Furthermore, caregivers of loved ones with ABI can provide benefit to rehabilitation programmes (Fisher et al., 2015), with evidence that their involvement helps to improve community reintegration and increased adaptive functioning in their relatives with ABI (Godwin et al., 2011).

Carer psychological distress, and burden in providing this care however, is well reported in the literature (see Baker et al., 2017; Kreutzer et al., 1992 for reviews), with meta-analyses using data from 1,755 stroke caregivers reporting a rate of 40.2% for depression and 21.4% for anxiety (Loh et al. 2017). Low health-related quality of life (Caro et al., 2017; McPherson et al. 2011; Saban, 2016), stress (Walker et al., 2020), poor relationship satisfaction (Burrige et al., 2004; Gosling & Oddy, 1999) and poor perceived family functioning (Schönberger et al., 2010) are also negative outcomes for family caregivers of people with an ABI.

Research has thus far been unable to pin-point specific causes of these wide-ranging negative outcomes (Wells et al., 2005). Some argue a cumulative impact of distress from the symptoms of the ABI (Bayen et al., 2013), like personality change (Wood & Yurdakul, 1997), neurobehavioural difficulties (Allen, et al., 1994; Yasmin & Riley, 2021), social-cognitive difficulties and lack of awareness of impairment (Burrige et al., 2004; Grayson et

al., 2021). Others point to intrapsychic factors within the caregiver, such as mastery (Cox et al., 2018) and coping styles (Liu & King, 1999). Some also explore external contributions to caregiver distress, like lack of emotional support (Tverdov et al., 2016) and financial burden (van Beusekom et al., 2015). More recently, however, there is some consensus that burden and psychological distress are multi-faceted concepts, that are likely contributed to by a combination of all of the above (Kavga et al., 2021; Stevens et al., 2016; Wu et al., 2020)

Historically, much of the research base has focused on the negative outcomes for caregivers of people who have had an ABI (Baker et al., 2017). It is clear however, that not all caregivers of people with ABI suffer negative outcomes (Machamer et al., 2002). More recently, there seems to have been a shift to the exploration of positive traits, elucidated in positive psychology, such as resilience, which may act as protective factors or buffers against burden and psychological strain. This may provide some indication as to why some people suffer negative outcomes and others do not (King et al., 2020).

Resilience as a construct has been gaining traction in psychological research for the last couple of decades (King et al., 2020; Omer et al., 2014). It was initially studied scientifically in children who had overcome early childhood adversity and trauma (Garmezy & Nuechterlein, 1972; Werner, 1989). These authors all used the term resilience to describe children who, after experiencing multiple adversities, seemed to adapt and become more successful than peers who were reared in similar environments. Resilience has since been explored as a protective factor against long-term psychological distress in a variety of populations including adults and caregivers (Dias et al., 2015; Palacio et al., 2019; Scaffers et al., 2019).

Ostensibly, resilience seems like a straightforward construct, however, a recent review of how the term 'resilience' has been conceptualised in adult mental health highlighted several discrepancies (Ayed et al. 2019). Two main differences were found: resilience as a

personal characteristic or trait (personal and social resources) and resilience as a process (bouncing back from adversity, immunity to adversity and growth after adversity). Although all of these concepts of resilience point towards a protective effect or barrier against poor mental health after adversity, the authors highlighted that the constructs are indeed different. For example, immunity is similar to the construct of hardiness (Kobasa, 1979), growth to the construct post-traumatic growth, first described by Tedeschi and Calhoun (1995) and 'bounce back' as the more widely acknowledged meaning of 'resilience' described by O'Leary and Ickovics, (1995), as a return to baseline or homeostasis. Although these processes are different constructs, there is likely significant overlap in the underlying mechanisms which, together, all contribute to protection against long-term psychological distress in ABI caregivers.

In summary, there are high levels of burden and distress reported in family caregivers of people living with ABI but no clear picture showing what causes this distress, or what helps caregivers to adjust and manage. Elucidating the effects of resilience and related constructs (RARCS) such as hardiness and PTG might be helpful in further understanding coping and adjustment in this population. This research therefore aims to examine the available quantitative research exploring resilience and its similar conceptualisations (hardiness and PTG) and their relation to ABI caregiver outcomes. This will help us understand the relationship between resilience and psychological distress. It is only then that we may come to a deeper understanding of protective factors, which might potentially be used in interventions for caregivers to reduce such distress. The review aimed to answer the questions 1) How have RARCS been conceptualised in studies with caregivers of people with ABI; 2) What are the quantitative relationships of RARCS in studies with caregivers of people with ABI?

Methods

Search Strategy

The search for relevant literature was conducted on 14/09/2021 (No date limits), using a systematic approach. Research Databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and Medline were searched following advice from an academic librarian. Other similar reviews have used these databases (see Anderson et al., 2015). Each database's "suggest terms" function was used to expand the major concepts: 'Brain injury', 'family caregiver' and 'resilience', so that similar and alternative terms were included in the search. BOOLEAN operators 'OR' and 'AND' were used to combine the search terms and major concepts. Words used to form the major concepts and search strategy are included in Appendix B. Furthermore, reference lists of the included papers were searched by hand for other relevant articles. Results from each database were uploaded and combined in referencing software, EndNote, before exact duplicates were removed.

The inclusion criteria for included papers were kept broad intentionally, to ensure that all papers exploring quantitative relationships of RARCS were included. The only inclusion criteria were: papers must use a measure of resilience, resiliency, PTG or hardiness to measure these constructs in family caregivers of adults with an ABI, and perform some type of quantitative statistical analysis, which included observational studies or interventions. Papers with caregivers of people who have a degenerating brain disease were not included.

Search Results

The database search yielded 7443 records, reducing to 4580 after duplicate removal. After the title and abstract screen, 98 papers were full-text screened. Reference list searching further identified 6 potentially relevant papers. The author screened 101 papers (98 from database searching and 3 from reference lists), to check they met criteria, which identified the final 26 papers. The PRISMA diagram (Figure 1) illustrates this process.

[INSERT FIGURE 1 HERE]

Data Extraction and Quality Appraisal

Data including demographics, participant recruitment, aims, design, results and construct definitions were extracted from the final studies by the author (see Tables 1 and 2). The quality of the included studies was appraised using the 14-item Quality Assessment Tool for Diverse Studies (QUATDSS; Sirriyeh et al., 2012; see appendix C). Each criterion is rated between 0 and 3, with the overall quality score converted into a percentage. The QUATSDD was employed because of the heterogeneity of quantitative study designs utilised in the final papers. Its efficacy as a quality appraisal tool has been reviewed and by Harrison et al. (2021), with the authors finding the tool ‘strongly reliable’ for appraisal of studies with a mix of methodologies. A second rater applied the QUATSDD to 10% of the final papers. Raters agreed on 98% of the scores, with disagreement on a single item. This discrepancy was resolved through discussion. The average quality rating was 70.2% (range = 57%-88%). Ratings for each paper are included in Table 3. The largest limiting factors were lack of explicit theoretical framework and consideration of sample size. No studies were excluded on the basis of their quality appraisal score, rather, quality assessment was employed to guide critical analysis.

[INSERT TABLE 1 HERE]

[INSERT TABLE 2 HERE]

[INSERT TABLE 3 HERE]

Results

There were 26 studies included, but two of these used the same participants (Anderson et al., 2020; Simpson et al., 2021), as well as three other studies sharing a set between them (Meyers et al., 2020a; Meyers et al., 2020b; Meyers et al., 2020c). This review includes data from all the studies where relevant, but only considered these participants once when counting total participant numbers. Please refer to Table 1 for detailed information about participant numbers, aims, and results.

Brief Overview of the Studies

Half of the studies came from the USA (13/26) and were primarily published between 2018 and 2021 (19/26). Ten studies used relative caregivers of people with TBI specifically, while twelve utilised a sample of mixed ABI caregivers and six focussed on stroke caregivers. Thirteen studies used dyads of caregivers and people with ABI, but then split the data between caregivers and persons with ABI. For the most part, researchers used convenience sampling, with the majority of participants recruited through clinics and hospitals (12), rehabilitation units (3), support groups (3) or a mix of these sources (5). Studies were mostly observational (23/26), including one factor analysis (Las Hayas et al., 2014) and there were 3 intervention studies.

Participants

This review represents 2,905 informal caregivers of people who have had an ABI: 648 (22.3%) males, 2111 (72.7%) females and 38 (1.3%) not recorded. They were made up of 1704 spouses, 533 parents, 215 adult-children, 46 siblings and 431 unknown or 'other' family members or relations. The weighted average age of participants is $M = 50.92$, $SD = 10.65$ for those that reported (21 papers). Approximately 77% of the sample were married, with 58% having at least a high school education, 49% at higher education and 30% having completed a

university level qualification. Only two studies represented a large proportion of participants from primarily low educational groups (Las Hayas et al., 2015 and Jia et al., 2021).

Characteristics of the Person with ABI

People with ABI were typically male (70% of the 19 studies that reported gender), with a weighted average age of $M = 47.9$ (17 studies reported age), $SD = 9.41$ (14 studies reported SD). Only 14 studies reported time since injury and averaging methods were heterogeneous, with $\frac{3}{4}$ of the studies reporting standard deviation, which was typically very high. Where reported (10 studies), the ABI population was generally highly educated with 73.4% being educated beyond high school. Fifteen papers noted injury severity: Eight used Activities of Daily Living Scales (ADLS). Three studies used measures of PTA (the majority of people with ABI were in the ‘extremely severe’ range), and a further 3 used hospital notes. There seemed to be an even mix of mild and severe injuries.

Key Findings

This review found thirteen studies on resilience, nine studies on resiliency, two on PTG and a further two explicitly looking at hardiness. Please refer to Table 1 for a breakdown of which studies fit into each category. Findings were split into these themes of resilience following Ayed et al. (2019). Consideration was given to how each paper defined their construct and how each measured them. Quantitative relationships were then explored and synthesised.

Resilience

Construct definition

From the studies reviewed, 11/13 gave a definition of resilience. Several studies gave some evidence of being aware of the debates surrounding the vague nature of the resilience construct in research. Ten papers defined resilience as being a form of ‘adaptation’ or a construct which ‘promotes’ adaptation. Three of the papers focused on the facing of adversity

or stress, and then gaining something from this, or surpassing the baseline state: words used are “growth” (Brickell et al., 2020) and “ability to thrive” (Scholten et al., 2020). Six of the definitions focused on the multi-faceted nature of resilience. Resilience was described as including the ability for “resource mobilisation” (Migliorini et al., 2018; Bricket et al., 2020; Simpson et al., 2013) with one suggesting resilience as “an expression of personal resource” only, giving no acknowledgement to wider resources (Scholten et al., 2020). Many of these definitions pointed towards resilience comprising of personal skills and external resources, which can be acquired by anyone. Resources and skills specified amongst the resilience papers were psychological resources, reappraisal coping, spirituality, self-efficacy and social relationships. Four papers seem to place resilience, or the skills needed for resilience, as attributes of the individual (or family).

Finally, three papers conceptualised resilience to buffer or protect against psychological distress after an adverse event. There were several measures of resilience utilised. For details, and further details about individual paper definitions of resilience, please see Table 2.

Concerning resilience measures used, they were fairly homogenous. The most common was the Connor Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) used by four papers. There were a further six measures used by other papers (See table 1 for details).

Correlates with psychosocial factors

Several of these studies looked at resilience and its association with other psychosocial constructs. There were significant positive correlations, with large effect-sizes, between resilience and constructs such as hope (Anderson et al., 2020; Simpson et al., 2021; Simpson et al., 2020), self-efficacy (Jia et al., 2021; Carlozzi et al., 2020; Anderson et al., 2020; Simpson et al., 2021; Scholten et al., 2020) and spirituality (Simpson et al., 2020).

Positive correlations were also found with coping styles: problem focussed and problem solving with medium effect-sizes (Anderson et al., 2020; Simpson et al., 2021), emotional suppression and social support seeking with small effect-size (Sander et al., 2020; Anderson et al., 2020; Simpson et al., 2021). Negative correlations were seen with passive coping and escape/ avoidance coping, with medium and small effect-sizes respectively (Scholten et al., 2020; Anderson et al., 2021).

Other significant positive correlations with moderate effect-sizes were found between resilience and extraversion, social support (Anderson et al., 2020; Simpson et al., 2021) and posttraumatic growth: philosophy of life (Las Hayas et al., 2015). Other negative correlations with resilience (medium effect-sizes) were neuroticism (Anderson et al., 2020; Simpson et al., 2021) and caregiver negative appraisals of life events (Scholten et al., 2020).

Predictors of resilience

Anderson et al., (2020) and Simpson et al. (2020) both used structural equation modelling (SEM) approaches to see which variables accounted for variance in resilience. The former model explained 63%, with self-efficacy, problem-focussed coping and extraversion as predictors, while the latter explained 35% with spirituality and hope as predictors.

Correlates with positive outcomes

Positive associations were identified between resilience and quality of life (QOL) (Bermejo-Toro et al., 2020; small effect-size) and health-related quality of life (Anderson et al., 2020; medium effect-size). Similar associations with small-medium effect sizes were also found for the QOL subscales: physical, psychological, environmental and social health (Jia et al., 2021).

Moreover, resilience correlated with positive affect, with a large (Anderson et al., 2020; Simpson and Jones, 2013) and medium (Simpson et al., 2020) effect-size. Similarly, a

high resilience group had higher levels of positive affect than a low resilience group (Simpson & Jones, 2013).

Other correlations were between resilience and ‘wellbeing’, with large effect-size (Carlozzi et al., 2020) and positive aspects of caregiving (moderate effect-size; Bermejo-Toro et al., 2020; Las Hayas et al., 2015). Resilience correlated significantly with the positive aspect of optimism only, with a large effect-size in Bermejo-Toro et al.’s (2020) paper, but also to outlook on life, acceptance and social support with moderate effect-size in Las Hayas et al.’s (2015) study, which had more participants.

After controlling for demographic factors and self-efficacy, linear regression showed that resilience also accounted for a significant (albeit small) proportion of variance in all QOL subscales (Jia et al., 2021). This was broadened with an SEM, which showed a significant direct relationship between resilience and QOL, as well as a significant indirect one mediated by self-efficacy.

SEM also showed that resilience had a significant direct effect on positive affect (Anderson et al., 2020; Simpson et al., 2020), as well as a significant indirect effect on this and positive mental health, through hope (Anderson et al., 2020). Simpson’s SEM presented a similar picture, only, resilience was the mediator between hope and positive affect, and there was no direct relationship between hope and positive affect.

Correlates with Negative Outcomes

Burden

Five studies looked at correlates of resilience and caregiver burden. Generally, there was a consensus that resilience played a ‘protective’ role against burden in caregivers of people with an ABI. All significant correlations between resilience and burden were negative, with a medium effect-size (Las Hayas et al., 2015; Simpson &) or a small effect-size (Simpson et al., 2020; Anderson et al., 2020). Similarly, Brickell et al. (2020; N=365) split

participants into low, moderate and high resilience, based on resilience scores. They found that the low resilience group scored higher than either the moderate or high groups on perceived burden (moderate effect-size). Contradicting this however, is the lack of difference in burden between the low and high resilience group in the Simpson and(2013; N=30) paper, although this was a weaker paper with small sample size.

Depression and Anxiety

Resilience was found to correlate with depression but not anxiety. Bermejo-Toro et al. (2020) measured correlates of resilience with anxiety and depression separately, finding a negative correlation between resilience and depression (medium effect-size), and no significant relationship between resilience and anxiety. Scholten et al. (2020) grouped anxiety and depression and termed the combination ‘psychological distress’. They initially also found a significant, negative correlation between resilience and psychological distress. This effect was not significant however, when mediators and moderators were added into a larger model. Bermejo-Toro et al. (2020) however, found a significant negative association between resilience and depression, after demographic factors were taken into account in stepwise regression analyses.

Other authors exploring the relationship between resilience and negative affect, are Simpson and Jones (2013), Anderson et al. (2020) and Simpson et al. (2020). The former showed a significant, negative correlation between resilience and negative affect (Medium effect-size), while the latter papers explored the relationship between them in SEMs. Anderson et al. (2020) describe resilience as providing a ‘buffering effect’, through its complex relationship with negative affect through mediating variables hope and mental health.

Stress

Resilience was also looked at in relation to stress, perceived stress and strain.

Resilience was negatively correlated with stress (Simpson et al., 2020) and strain (Simpson & Jones, 2013) with small effect-size. Similarly, a high resilience group had less perceived stress than those in a moderate resilience group (Brickell et al., 2020).

Mental Health

Finally, resilience was associated with mental health in one study. Rasmussen et al. (2020) used multiple linear regression with mental and general health (combined) as the outcome measure. They found that resilience contributed a significant proportion of the variance in mental health when added into a model with depression and anxiety.

Several direct relationships between resilience and negative outcomes reduced when they were entered into more complicated statistical models, such as SEMs, with several other variables. Scholten et al. (2020) ran multiple mediation regression analyses, finding that the relationship of resilience and psychological distress was *moderated* by resilience's negative relationship with caregiver appraisals and appraisals' positive association with passive coping. This in turn, had a positive association with psychological distress. A similar picture is seen in Simpson et al.'s (2020) work: the initial negative correlation between the resilience and depression, anxiety and stress was reduced when *mediating* variable, positive affect and *moderating* variable, negative affect were added into an SEM.

In another SEM, Anderson et al. (2020) showed that social support mediated the relationship between resilience and burden. Simpson et al.'s (2020) model however, found no path between resilience and burden, only a direct path between spirituality and burden (in the negative direction), with spirituality accounting for a significant proportion of the variance in resilience. Simpson et al. (2020) did not measure social support. Similarly, Anderson et al. (2020)'s model showed no direct path from resilience to any negative caregiver outcomes,

but hope and mental health were mediators between resilience and both negative affect and ‘psychological distress’.

Resiliency

Construct definitions

For a more comprehensive description of how each study defined their resiliency constructs, see Table 2. Briefly, of the nine papers that looked at resiliency, two papers did not give a clear definition before going on to measure “resiliency skills”. Nearly all of the other papers defining resiliency referred to the construct of adaptation, and resiliency being a form of adaptation to adversity, or providing the skills to help one to adapt. Four of the resiliency papers defined resiliency as the ability to “bounce back” after adversity, or as a set of “adapt and recover” skills, suggesting a suffering, followed by a return to baseline state. Finally, four made reference to resiliency as a construct, which spans the biological, the psychological and the social, while three others placed resiliency skills within the person.

Despite some defining resiliency as a construct in, and of itself, no papers included a measure of ‘resiliency’ as a whole construct. All studies measured skills, which were defined as dynamic and changeable, including two intervention studies (Bannon et al. 2020; Vranceanu et al., 2020). Mindfulness and coping were the only resiliency skills that all papers had in common; all used the same measures. There was little agreement about other resiliency skills, which included (with the number of studies referencing these in brackets):

- Mindfulness (9)
- Coping arsenal (cognitive, behavioural and emotional) and ability to use such (9)
- Caregiver self-efficacy (3)
- Preparedness for caregiving (PFC; 2)
- Intimate Bond (2)

- Intimate care (1)
- Dyadic Relations (2)

Measures used for each skill are included in Table 1.

Correlates of resiliency

Correlates between the skills

Nearly all of the resiliency papers reported correlations between resiliency skill scores: mindfulness and coping were generally significantly positively correlated with a large effect-size (between $r = .70$; Shaffer et al., 2016a, and $r = .796$; Meyers et al., 2020b). PFC correlated positively with the other resiliency factors with a moderate effect-size (Lin et al., 2020; Zale et al., 2018). Shaffer et al. (2016a), found a positive correlation between self-efficacy and both coping and intimate bond (moderate effect-sizes) and PFC with a large effect-size, but little correlation with mindfulness.

Positive Outcomes

QOL was the only positive outcome for resiliency and it was measured in one study. Zale et al., (2018) showed that all resiliency factors (coping, mindfulness and PFC) correlated positively with the QOL domains (physical, psychological, social and environmental) with moderate to large effect sizes. They then performed hierarchical linear regression to see resiliency's effect on QOL, after accounting for demographic and mental health variables. They found a significant effect of resiliency skills after entering these at a third level, showing resiliency skills accounted for a significant proportion of the variance, over and above depression and demographic variables.

Negative Outcomes

Depression, anxiety and posttraumatic stress (PTS) were the most commonly measured negative outcomes in resiliency studies. Resiliency skills were negatively correlated with depression; effect-sizes ranged from small (Shaffer et al., 2016b) to large

(Zale et al., 2018; Meyers et al., 2020; Lin et al., 2020). Similarly, skills were negatively correlated with anxiety; effect-sizes ranged from medium (Shaffer et al., 2016b) to large (Zale et al., 2018; Meyers et al., 2020b; Shaffer et al., 2016a). The same story is also seen with PTS symptoms, with resiliency skills correlating significantly and negatively with large effect-sizes (Meyers et al., 2020c; Lin et al., 2020). Longitudinal studies showed that baseline coping and mindfulness ratings continued to correlate negatively with depression measured at 3 and 6 month follow-up from intensive care unit (ICU) admission (Meyers et al., 2020a), with similar findings for anxiety (Meyers et al., 2020b) and PTS symptoms (Meyers et al., 2020c) albeit with medium effect-sizes. These authors report that resiliency skills at baseline were predictive of lower depression (Meyers et al., 2020), anxiety (Meyers et al., 2020b) and PTS (Meyers et al., 2020c) over time with small effect-sizes.

Other negative outcomes reported in caregivers were anger and stress. Anger had a significant negative correlation with resiliency skills, coping and mindfulness with medium (Shaffer et al., 2016b) to large (Zale et al., 2018) effect-sizes. Considered individually, stress and distress were also significantly negatively correlated with resiliency skills, with moderate effect-sizes (Zale et al., 2018).

In line with these results, Lin et al. (2020) completed a median split of their sample, forming high and low mindfulness, coping, intimate care and PFC groups. Caregiver resiliency skills were measured when people with ABI left the ICU, and depression was measured three times over 6 months. ANCOVA (with gender as covariate) showed that the higher coping, mindfulness and PFC groups had significantly lower depression scores than the corresponding low score caregiver groups at baseline. At 3-month follow-up, baseline coping was the only significant main effect; high coping at baseline, was linked to lower depression at 3 month follow-up. An interaction was seen between high and low intimate care

groups. Male caregivers who provided higher levels of intimate care to their loved one with ABI reported less depression than females in this group at 3 and 6-month follow-up.

Intervention studies

Resiliency intervention studies showed that interventions increased coping skills (small to large effect-sizes; Bannon et al., 2020; Vranceanu et al., 2020) and mindfulness skills (Bannon et al., 2020) when compared to controls, who saw no improvement when treated using standard care (education program). These authors reported that intervention groups saw a decrease in anxiety, depression and PTS symptoms between baseline and post-treatment with medium to large effect-size. These results remained stable at 12-week follow up for Vranceanu et al. (2020; 58 participants) however, although there was a trend for decreasing anxiety, depression and PTS symptoms at 3-month follow-up for Bannon et al. (2020), none of these were clinically significant (16 caregivers).

PTG

Construct definitions

PTG was defined as a positive “change” or “transformation” after an adverse event or trauma. Both papers (Las Hayas et al. 2014; Hallam & Morris, 2013) gave heed to “benefit finding” and the former mention an incorporation of the traumatic event, which is integral to the creation of a new viewpoint on the world. Both PTG papers suggested a suffering after the traumatic event, followed by a growth, which culminated in a state beyond that of the baseline. Both used the posttraumatic growth inventory (PTGI; Tedeschi & Calhoun, 1996; Weiss, & Berger, 2006) to measure PTG.

Predictors of PTG

Several factors were associated with PTG. There was a strong positive association with deliberate rumination, a moderate positive correlation with social support, (Hallam et al., 2013), positive affirmation and outlook on life (Las Hayas et al., 2014) and a small positive

correlation with avoidance coping (Hallam et al., 2013). Regression analysis confirmed that deliberate rumination, avoidance coping, and social support all individually predicted a significant proportion of variance in PTG (Hallam et al., 2013).

Correlates of PTG

Only Hallam et al. (2013) measured caregiver positive outcome, QOL, finding a positive correlation with PTG, but with only a small effect-size. Neither paper looked at correlates with negative outcomes.

Hardiness

Construct definitions

Both studies measuring ‘hardiness’ defined it in the context of the family, or ‘family hardiness’. Niyomthai et al. (2003) used the Family Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996) as a basis for their definition of hardiness as an internal resource characterised by a perception of control over events. They define this as a ‘resiliency’ factor, which a family needs in order to adapt. Inci and Temel (2016) also use the McCubbin and McCubbin (1996) model and note hardiness as being ‘protective against the effects of stressful events’, as well as a “feeling of control” over events and circumstances. Hardiness in these studies is suggestive of a buffer to adverse events. Studies were homogenous in their measures of family hardiness.

Correlates of Hardiness

Niyomthai et al. (2003) found that hardiness had a significant positive correlation with caregiver wellbeing and a significant negative correlation with significant stressful family life events (medium effect-size). They also showed that life events accounted for the largest proportion of the variance in caregiver wellbeing (24%) and that hardiness accounted for an extra 7%.

Interventions

Inci and Temel (2016) conducted an RCT, testing a support program (with a heavy focus on increasing ABI knowledge and social support) aiming to increase hardiness (or ‘family resiliency’). ANOVA found an increase in family hardiness and social support over the experimental period and a significant decrease in family distress (large effect-sizes), all of which remained stable for the experimental group after 6-months.

Discussion

This review aimed to gather, synthesise and appraise the findings of quantitative research studying resilience in caregivers of people with ABI. In particular, the review sought to identify definitions of RARCs in the ABI caregiver literature and then examine the quantitative relationships explored, for instance, predictors of RARCs and how RARCs related to outcomes.

Quality Appraisal

There were varying strengths in the quality of the papers reviewed here and although ratings were not used to exclude papers, it is important to highlight the best quality research when considering their findings. Those rated highest by the QUATDS were Anderson et al. (2020), Bannon et al. (2020), Inci and Temel, (2016), Zale et al. (2018) and Hallam et al. (2013), who all scored above 80%. However, the majority of the included studies were actually of good quality, where average quality rating was 70.2% (range = 57%-88%) thus these are mainly high quality papers and there is some confidence about the results. The most limiting factor was a lack of explicit consideration of sample size or power calculations. Many of the studies reviewed did not base their research on a pre-existing theoretical framework or model as a guide, or they did not explicitly mention this. This is important because, with such a widely operationalised construct such as resilience, theoretical frameworks help to keep research focussed and theory driven. This lack of a theoretical basis is likely to confuse the resilience literature further. Moreover, not all studies reviewed

statistically assessed validity and reliability of measures in their own samples. This is a problem because it raises questions about whether the measures are measuring the constructs they are supposed to be measuring, reliably, in ABI caregivers. Finally, many seemed to lack inclusion of experts by experience in development and design of the project. This is an important consideration because research has shown that including individuals with experience of the issue being researched makes mental health research more service-user focused (Minogue et al., 2005) and thus more applicable to clinical settings (Ennis & Wykes, 2013).

RARC definitions

Although most of the papers reviewed here explicitly included a clear definition of the RARCs they were measuring, not all did. Despite previous reviews suggesting a clearer operationalisation of resilience is needed (Ayed et al., 2019; Tusaie & Dyer, 2004; Windle et al., 2010; Windle et al., 2011; Aburn et al., 2016), in this review a lack of a clear and narrow definition across resiliency and resilience papers remained. This made it difficult to separate and fully understand the two constructs. Resilience was sometimes seen as a single construct ‘as one thing’ to be measured, whereas resiliency seemed to be a group of improvable skills (with a lack of consensus on what these skills were). Resiliency skills were the basis for intervention studies.

The findings here enhance conclusions by Ayed et al. (2019) who explored conceptualisations of resilience in mental health literature. Viewing outcomes in relation to the baseline state is a useful way of separating RARCs. While the majority of resilience papers pointed to a period of suffering after an adverse event, followed by a return to baseline, in line with the ‘bounce-back’ meaning of resilience (Ayed et al. 2019; Bonanno et al. 2007), others crossed into ‘posttraumatic growth’ and ‘hardiness’ construct definitions. In terms of the baseline, PTG was understood here as an experiencing of adversity, followed by

a growth, or ‘surpassing’ of the baseline. Hardiness was understood as a construct which buffers and protects people from adversity, or maintains the baseline state. As perhaps anticipated, PTG and hardiness papers were more homogeneous, containing definitions that are narrow and well defined.

This confusion was mirrored in measures of resilience. This is something that has been the focus of review, although across childhood studies, which used the same measures as the current review (Windle et al., 2011; Ahern et al., 2006). They found that although most of the scales measured different facets of resilience, scale designers rarely compared them against others already established for convergent validity. Those that did compare against others (3 of the 19 original validation studies), found correlations of only 0.59 (Brief Resilience Scale [BRS] and the Connor-Davidson Resilience Scale [CD-RISC]) and 0.51 (BRS and Ego Resilience Scale-89). Both of these would not be acceptable according to Campbell and Fiske (1959)’s cut-off of .60, although the CD-RISC and BRS approached this. It was also noted that two studies in the current review (Carlozzi et al., 2020; Las Hayas et al., 2015) failed to show appropriate convergent validity, with the former using self-efficacy measures to validate their resilience measure and the latter only using one subscale of the PTGI and health-related quality of life measures. Only Las Hayas et al. (2015) broached this in their limitations. Furthermore, nearly all resilience scales reviewed across the lifespan by Smith-Osborne & Bolton, (2013), included factors in personal competence and some form of acceptance, with the CD-RISC (Connor & Davidson, 2003) also claiming to measure tolerance to negative effects, which seems like the basis for hardiness, and ‘strengthening effects’ which is more in line with PTG. It can be argued that the measures of resilience, are not, in fact, measuring a clear construct of ‘resilience’, but also aspects of PTG and hardiness.

Relationships to Resilience

Because of the heterogeneity of resilience constructs and measures, and diversity in correlates studied, it would not have been appropriate to compare results using meta-analysis. The heterogeneity also made it difficult to draw definitive conclusions about what makes up resilience in caregivers of people with ABI, and its impact on possible outcomes. That said the review shows that regardless of the concept of resilience considered and measure used resilience generally related negatively to negative caregiver outcomes, such as burden (small-medium effect-sizes), psychological distress (small-large effect-sizes), and positively related to positive outcomes like wellbeing (medium-large effect-sizes), quality of life (small-medium effect-sizes) and positive affect (large effect-size). This is in line with much of the wider resilience literature across a diversity of populations (Dias et al., 2015; Fontes & Neri, 2015; Harmell et al., 2011; McKenna et al., 2022; Palacio et al., 2020). Moreover, Rasmussen et al.'s (2020) regression analyses showed resilience accounting for a significant proportion of variance in mental health, on top of variance already accounted for by anxiety, depression and demographic factors. This further advances the case that this resilience construct added something significant to positive mental health.

Studies using complex statistical modelling approaches established factors contributing to resilience, and the relationship between resilience and caregiver outcomes. Relationships were identified between resilience and hope, spirituality, self-efficacy, social support, coping skills and personality, all of which are found across the resilience literature as a whole (Satici, 2016; Ledesma, 2014; Taheri & Falavarjani, 2019; Balgiu, 2017, Raghavan & Sandanapitchai, 2020). Through resilience's interaction with these other skills and constructs, some of which, like self-efficacy have similar problems with conceptual confounds (Curvis, et al., 2016), a more complicated picture of the role of resilience in outcomes emerges. There was disagreement amongst these models in terms of causal effects – for example whether resilience had a direct effect on outcomes, or whether it acted as a

mediator between variables, or other constructs took a mediating role. Hope accounted for a proportion of variance in resilience in Simpson et al. (2020)'s model for example and resilience was the mediator between hope and positive affect. In the Anderson et al. (2020) model however, hope was the mediator between resilience and positive mental health and positive affect (as well as having its own, direct path to positive affect). It is likely that the methodological approach of such papers affected these conclusions; many were cross-sectional in design and it was difficult to ascertain causality in terms of these variables. However, they do begin to build up a picture of the complex role that resilience plays, in relationship with other variables, in predicting wellbeing.

Most of the papers made the argument that resilience is protective, and something that should be the focus of skill building interventions for caregivers after their loved one has had a brain injury. Those studies that did increase 'resiliency' skills (mostly coping and mindfulness) in intervention RCTs showed general trends for the decrease of psychological distress such as depression, anxiety and PTS. It is noted however, that again, there was some heterogeneity in these interventions; some built on aspects of social support (Inci & Temel, 2016) and some increasing self-efficacy (Bannon et al., 2020) as resiliency skills. This made it difficult to draw conclusions about which parts of the interventions were more effective, but overall, interventions had some positive outcomes. Methodologically, most had relatively small samples.

Strengths and Limitations

This review has brought together all the available quantitative literature on resilience constructs, resilience, resiliency, PTG, hardiness, and their quantitative relationships in samples of caregivers of people who have had a brain injury. There are strengths in its appraisal of quality of included papers, broad search terms and inclusion criteria, ensuring that the research relating to these overlapping constructs (Ayed et al., 2019) were captured. It

also allowed the inclusion of RCTs, which looked at the development of caregiver interventions. These aimed to measure the impact of increasing resiliency skills on levels of negative caregiver outcomes over time, giving some directionality to reviewed relationships. Furthermore, care was taken to find all relevant papers from appropriate academic databases; hand searching of reference lists strengthened this and ensured all relevant papers were gathered and included in this review.

Considering limitations, firstly, grey literature, including theses, were not included. While the initial search identified four potentially relevant theses, grey literature is not peer reviewed and, therefore, quality is not assured. In addition, the scope of this project prohibited an extensive search of other grey literature. This could mean that important findings were missed. It was also the case that only English language studies were included, which again may have excluded important information. Also acknowledged is the publishing bias of western research. It is expected that further research on resilience in caregivers of people with brain injury exists in different countries' journals, which are not in English and which the academic databases do not include.

Furthermore, a mixed-methods quality appraisal tool was selected because of the heterogeneity of methods and designs of the quantitative studies reviewed. The appraisal tool itself has some drawbacks (Fenton et al., 2015) including awarding up to 3 points to studies for including service-user involvement in the design of the project. Some might argue this as a limitation, as some studies with service-user involvement may have scored the same or higher, despite being more methodologically flawed, than others with better methods and analyses. Others would argue the strengths of service-user involvement however, such as involvement making research more service-user focussed (Minogue et al., 2005) and increasing recruitment success (Ennis & Wykes, 2013). In the current review, only two papers scored the full 3 points on this. It could also be argued that using this tool took away

some of the more important methodological considerations needed for appraising each design (i.e. randomisation being important for an RCT, but not a cross-cohort study, or more nuanced differences in quantitative analyses), which the tool is not sensitive enough to capture.

Finally, sense of coherence (SOC) is a term that was highlighted in some of the included papers as being similar to resilience. This is another construct, which has links with resilience and is commonly used interchangeably with and confused with resilience (Almedom, 2005; Fossion et al., 2014). Further reviews may wish to include SOC studies to see if there is overlap with the definition of resilience in the ABI caregiver population, and explore correlates to see if they are similar.

Clinical Implications and Future Research.

This review highlights that resilience is not a straightforward and static construct. Many of the studies here included a number of other factors, some of which, like social support, are not simply internal mechanisms. These were often dynamic and changeable, like coping, spirituality and hope, and accounted for significant variance in resilience or resiliency constructs (Anderson et al., 2020; Simpson et al., 2020). Resilience viewed as a dynamic process, facilitated by biological, psychological and sociological processes, is a more useful view clinically. It takes the blame away from the individual. If someone who is suffering with poor outcomes following a significant trauma or adversity, such as a family member having a brain injury, feels they do not have enough 'resilience', there is likely to be a sense of internalisation and shame, and a sense of that person being at fault. This review highlights a need for clinical teams to work with caregivers to increase dynamic factors such as sense of hope, social support, participation in mindfulness etc., drawing blame away from the individual, and this in itself, lends hope that poor outcomes can be reduced.

Following from this, more research using complex modelling techniques such as structural equation modelling and regression analysis should be done. This may help to confirm dynamic factors that are related to resilience (like hope, social support, spirituality etc.), which can be used as a basis for new resilience-increasing interventions in this population. A secondary benefit of such work is that it may help to find a more narrow and better defined conceptualisation and understanding of resilience as a construct.

Some intervention studies included here are promising. Although using modest sample sizes, they have shown that increasing resiliency skills and resources may reduce distress in caregivers of people who have had a brain injury. Future research should focus on conducting RCTs, which build known resiliency resources and skills, and track their impact on both validated and reliable scales of resilience, which are sensitive to change. An example of such a measure might be the CD-RISC (Connor & Davidson, 2003), although as discussed, the measure also contains some aspects of hardiness and PTG. However, developing ABI caregiver specific resilience measures may also be a useful future direction where convergent validity is appropriately explored using other validated resilience measures.

Finally, further resilience research should also address directionality of resilience correlates. Only 7 studies here were longitudinal, including the 3 intervention studies. It is not clear whether positive outcomes in ABI caregivers are as a result of having increased resilience, or whether high levels of resilience are only possible when people are not living with negative outcomes such as anxiety and depression. This will help us to have more of an understanding about where resilience fits within a wider picture of adversity and outcomes in individuals who care for people with brain injury.

Conclusion

This review sought to gather all quantitative papers, which explored resilience and its related constructs: resiliency, PTG and hardiness in caregivers of people who have an ABI. Although the construct definition of resilience and resiliency varied widely, definitions of PTG and hardiness were narrow and well defined. Overall, it would seem that resilience and related constructs are broad in terms of how they are defined and constructed. Several papers here showed dynamic processes and skills such as coping, hope, spirituality, social support and self-efficacy accounting for significant proportions of variance in resilience concepts, rather than them being simple, internal, and un-modifiable constructs. Although there are some limitations of this review to consider, most of the research reviewed linked high rated resilience and its related constructs with positive outcomes in caregivers, and low resilience and related constructs with poorer, more negative caregiver outcomes. This has clinical implications in terms of supporting caregivers by capitalising on and helping to build some of the multiple resources feeding into resilience, thus increasing outcomes such as wellbeing, quality of life, positive affect and decreasing outcomes such as burden, depression, stress and negative affect.

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Tables and Figures

Figure 1

PRISMA Flow Diagram indicating the audit trail from the initial search.

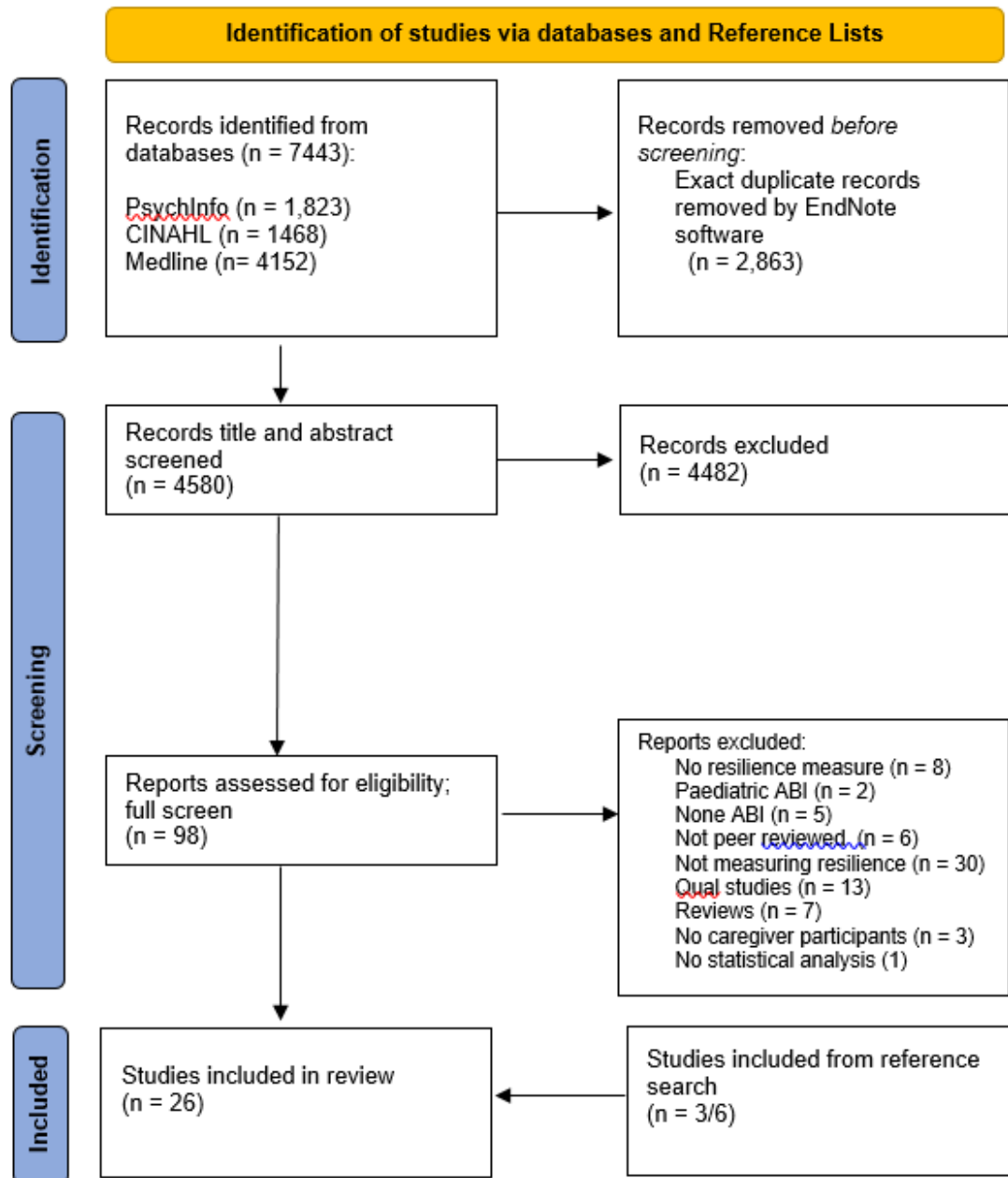


Table 1

Studies quantitatively exploring resilience or related constructs (RARCS), using a RARCS measure, in caregivers of people with acquired brain injury.

| Paper | Aims | Caregiver N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|--------------------------|--|---------------------------|---|-----------------|---|---|-------------------------------|--|
| Resilience Papers | | | | | | | | |
| Anderson et al. (2020) | To look at resilience, self-efficacy and hope in family members of those with TBI and model the impact of these variables on outcomes well reported in the literature (burden, QOL and psychological distress) | 131 (TBI) | Inpatient: Consecutive series; 6 rehab centers; everyone on caseload contacted that met inclusion | Cross-sectional | Connor-Davidson Resilience Scale (CD-RISC); (Connor & Davidson, 2003) | Personality factors, coping, functional independence of person with injury, self-efficacy, hope, physical health of caregiver, social support, burden, general health, positive and negative affect | Structural Equation Modelling | Model accounts for 63% of variance in resilience, 33% variance in burden, 53% variance in Mental health, 58% variance in psychological distress. Extraversion had small link with resilience; self-efficacy (SE) had had a strong link to resilience. Resilience has a moderate direct effect on positive affect. Also has a ' protective role ' against burden, but this is effect is mediated by social support. Resilience is a moderately linked to hope, which in turn, increases positive affect, decreases negative affect, decreases psychological distress (buffering effect) and increases positive mental health. Used goodness of fit indices to show that the model had strong agreement with the data. Problem focused-coping linked with resilience directly, and through SE. |

| Paper | Aims | Caregiver N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Sander et al. (2020) | To look to see how hyper vigilance (HV) and emotional suppression (EE) affect positive and negative affect in TBI carers: hypothesis - higher EE and HV would be linked to higher negative affect | (165) TBI | From a pool of participants from a larger, multi-center study (support organizations, hospitals, universities) | Cross-sectional | Outcomes: TBI-QOL Resilience; (Carlozzi et al. 2020); Family Resilience Scale for Veterans, (Finley et al., 2016) | Emotional Suppression, Caregiver vigilance; Negative affect; <u>Patient</u> Depression, Patient anger, CG anxiety, physical health, Perceived Stress, Positive Affect, wellbeing, Self-efficacy, life satisfaction | Correlation and Linear regression (accounting for covariate demographics). | EE and HV both correlated (small-moderate) with affect measures bar self-efficacy. First model: This is EE on it's own - small negative correlation between EE and resilience (B=-.20, SE=0.07), p=.0043, SE (B=-.20, SE=0.08) P=.0168, Fam resilience (B=-.06,SE=0.02) p=.0069 and Life satisfaction (B=-.27, SE=0.08), P=.0006. Model 2: Caregiver Vigilance: More strongly associated with negative affect in CGs. This one is also less associated with positive affect. Those with higher resilience scores and SE seemed to be unaffected by level of vigilance. Third Model: Combined EE and HV - HV more associated with the negative and EE more associated with the Positive outcomes. In the combined model, CG resilience was not associated with HV, but retained a small correlation to EE (B=-.18, DE0.08) p=.02, along with SE, B=-.24 SE=0.09, p=0.009 and life satisfaction: B=-.24, SE 0.09, P=0.005. More anxiety = more impairment of HV and EE |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Rasmussen et al. (2020) | To see which family-related factors are associated with poorer mental health in TBI patients and their caregivers | 63 (TBI) | Inpatient rehab center Outpatient rehab centre | Cross-sectional | The Resilience Scale for Adults (RSA; Frieberg et al., 2005) | Physical health, mental health, Family Adaptability and Cohesion, Patient physical health, Generalized Anxiety, Self-Efficacy, QOL | Multiple regression analysis/ Univariate linear regressions | Final model showed 56.2% variance of mental health accounted for by resilience $B=0.12$, $p=0.007$ (CI: 0.04, 0.21), depression $B=-0.79$, $p<0.001$ (CI-1.16,-0.43) and anxiety $B=-0.64$, $p=0.003$ (CI -1.06,-0.22) scores. Only 17% family members reported poor mental health as measured by the scale's cut-off. |
| Jia et al. (2021) | To look at factors that are associated with QoL and construct models based on those that are in Chinese stroke CGs - to look at the relationship between resilience and QoL and look at the mediating role of SE. | 305 (Stroke) | Cluster Sampling - 2 hospitals | Cross-sectional | Ego Resilience Scale (ERS) | Quality of Life, Self-Efficacy | Structural Equation Modelling and linear regression analysis (hierarchical multiple regression) | ERS correlated significantly with all QOL scores: physical health $r = .221$, $p<.01$, psychological health, $r = .216$, $p<.01$, social health, $r = .381$, $p<.01$ and environmental health $r = .306$, $p<.01$. ERS correlated with SE $r = .527$, $p<.01$. Resilience and SE both positive association with the QOL after controlling for demographic factors. Resilience and SE contributed 22.5% variance to physical, 24.5% of psychological, 36% to social and 30% to environmental health. Resilience has a direct positive effect on QOL, SEM ($B=.17$, $p<.01$). Resilience also associated positively with SE, ($B=0.49$). The authors noted about SE: "The path coefficient of resilience with QOL decreased significantly ($\beta= 0.17$, $P< 0.01$) when the indirect pathway was mediated by self-efficacy. Self-efficacy played significant mediating effect between resilience and QOL ($a \times b= 0.198$, bias-corrected and accelerated 95% confidence interval: 0.112-0.301) after an estimate was by using the bootstrap test. Thus, resilience not only directly influences QOL, but it also affects QOL score by indirectly mediating self-efficacy." |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|----------------------------|--|-----------------------|--|-----------------|---|---|-------------------------------------|---|
| Bermejo-Toro et al. (2020) | To see if demographics of the person with the ABI or the resilience of the CG differently affect QOL in the CG | 78 (ABI) | support groups/hospitals/federations / purposive/convenience | Cross-sectional | IV: Questionnaire of Resilience in Caregivers of Acquired Brain Injury (QRC-ABI); (Las Hayas et al. 2015) | Functional independence, neurobehavioral sequelae, QOL, Anxiety and Depression, Positive Aspects of Caregiving (PACS) | Correlation and stepwise regression | Total resilience correlated positively with QOL, (Pearson = .257, P<.05), PACS, (Pearson= .384, p<.01) and negatively with depression (Pearson = -.381, p<.01). All other domains were negatively associated with depression except spirituality: optimism -.37, p<.01, acceptance -.377, p<.01, social support -.318, p<.01. The resilience total did not correlate with anxiety but subscales acceptance and SS did weakly, .29 p<.01 and .275, p<0.05 respectively. only optimism of the subscales correlated with PACS, = .532, p<.01. And optimism and social support for QOL, = .229, p<.05 and .324, p<.01 respectively. Stepwise regression analysis found a negative relationship between resilience and depression (B=-.331, p=.003) and patient behavioural problems positively associated (B=.373, P<.001). |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Carlozzi et al. (2020) | To look at the reliability and validity of a new scale, TBI-CareQOL, including resilience subscale. | 385 (TBI) | Research registries and Model systems databases to find people with TBI to ask their caregivers and support groups (convenience?) | Cross-sectional survey and 3-week re-test (N=267) | TBI-careQOL Resilience (Carlozzi et al. 2020) | Anxiety, strain, loss, sleep impairment, positive affect, wellbeing, physical health, Life Satisfaction, Stress, Self-efficacy. Health related QOL, Caregiver appraisal (TBI anxiety, fatigue, social isolation, ADL functioning, ability to participate in social roles and activities) | Internal consistencyCronbach's alpha and IRTB internal consistency reliability. Retest R - intraclass correlation coefficient. Convergent and discriminant validity: Pearson correlations | Used the self-efficacy and positive affect and well-being for convergent validity = .62 and .66 respectively - both strong according to authors benchmarks. TBI-QOL resilience is positively associated with the CG satisfaction (.32), mastery (.35) negatively with CG ideology (-.04) and .25 with physical health. Test-retest reliability >=.73. All measures had excellent test-retest reliability, >.8. SE-RT reliability adequate. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-------------------------|---|-----------------|---|-----------------|---|---|---|--|
| Las Hayas et al. (2015) | To create a measure of resilience in people who care for people with ABI. To investigate psychometric properties in a sample of Spanish caregivers. | 237 (ABI) | Participants recruited from Federation of ABI associations or those admitted to ABI day-centers | Cross-sectional | Questionnaire of Resilience in Caregivers of Acquired Brain Injury (QRC-ABI); (Las Hayas et al. 2015) | Post Traumatic Growth, Quality of Life, Positive Aspects of Caregiving (PACS), caregiver risk, burden | Confirmatory factor analysis and correlation analysis | To create the QR-ABI, the authors reviewed 15 papers which looked into resilience in CGs in the health literature, including previous resilience measures. 4 subsections developed (spirituality, Social Support, Acceptance and outlook (on life)). Other measures were used to assess convergent validity. Participants have a mean QRC-ABI of 43.24/68SD=11.21 a=.88. Intercorrelations of the four subscales are: r=.75** outlook in life, .62** acceptance, .62** social support and .62** spirituality to the total score. There is a positive correlation between QRC-ABI and all the subscales of the QOL: 0.19 physical*, .49** psychological, .45**social relationships, and .28* environmental. Negative correlation with the burden scales at the ** level (.01), -.43 ideology, -.44 CARE expectation and -.26 CARE impact and positive correlation at the ** level to the PACS subscales: total .44, outlook on life .34 and self-affirmation .48 and PTGI philosophy on life .48. Outlook on life in the PACS only weakly correlates with outlook on life in the QRC-ABI .27 p<0.1. and philosophy on life with the PTGI .31, P<.01. QRC-ABI subsections acceptance and social support quite strongly correlated with QOL psychological (.55** and .55** respectively) and CARE total and expectation (.55/.56** and .48/.44** respectively. Social support of the resilience scale also highly correlated .52** with the QOL social relationships. Spirituality subscale of the QRC-ABI only weakly correlated with PACS total* .2 and PACS self affirmation .21 and moderately correlated with PTGI philosophy of life, .41** social support and acceptance significantly correlated with all outcomes bar spirituality domain. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|------------------------|---|-----------------------|---|-----------------|--|---|--|---|
| Brickell et al. (2020) | "To examine factors related to resilience in military caregivers across caregiver health-related quality of life (HRQOL), caregiver sociodemographic variables, and service member/veteran (SMV) injury and health status." | 346 (TBI) | Recruited from medical treatment facilities and through charity events and flyers | Cross-sectional | The traumatic brain injury caregiver quality of life (TBI-CareQOL); (Carlozzi et al. 2020) | Caregiving appraisal; adaptability of the person with TBI; Perceived stress. | ANOVA and Chi-sq for differences in resilience groups and demographics | Firstly, there were differences in the demographics between the moderate resilience and moderate-high resilience groups in terms of employment, out of pocket expenses, number of dependents and SMV neurobehavioral presentations. With regard to the quality of life measures: low resilience group had significantly less mastery, $p < .01$ than the other two groups. High resilience had more mastery than moderate $p = .013$ $d = .34$. low group has more perceived burden than moderate and high, $p < .001$ and relationship satisfaction, $p < .001$. Low group scored significantly worse on all areas of the TBI-QOL measure than the other two. The moderate group also had more perceived stress than the high group, $p < .001$, $d = .52$ and sleep impairment, $p = .016$, $d = .33$ - all correlations between the moderate and high, bar the perceived stress, have small effect sizes (.27-.34) and were therefore discounted as being meaningful by the authors. |
| Simpson et al. (2021) | To build a model of burden and psychological adjustment with explanatory and mediating variables and test it, using brain injury caregivers and caregivers of people with spinal chord injury. | 131 (TBI) | same participants | Cross-sectional | Mediating: Connor-Davidson Resiliency Scale (CD-RISC); (Connor & Davidson, 2003) | Personality factors, coping, functional independence of person with injury, self-efficacy, hope, physical health of caregiver, social support, burden, general health, positive and negative affect | ANOVA and Structural Equation Modelling | Same as Anderson et al. (2020) |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-----------------------|---|-----------------------|---|-----------------|--|--|--|---|
| Simpson et al. (2013) | Between resilience and outcome measures, including measures of affect | 30 (TBI) | Convenience sample, using medical records of the facility and staff caseloads At a specialist brain injury rehabilitation unit | Cross-sectional | The resilience scale (RS); (Wagnild & Young, 1993) | Positive and negative aspects of caring (PACS), caregiver burden, carer's assessment of managing | Spearman's correlation, Mann-Whitney U test. | Mann-Whitney U test showed no significant differences in terms of demographics between the traumatic brain injury caregivers and their spinal cord caregivers. People with SCI significantly older than TBI. With regard to the quant measures, there was only one difference: TBI CGs scored higher on emotional involvement (burden measure) ($z = 2.98$, $P = 0.003$; Mann-Whitney U). This is about being ashamed and embarrassed about behavior of the loved one. Because there were no other significant differences the SCI group and TBI group were both put together for the final correlation analysis. Strong correlations found between the resilience scale and personal competence ($r=.94$, $p<.01$) And life acceptance ($r=.89$, $p<.01$), which are both subscales the resilience total. Other strong correlations are between resilience scale and positive affect ($r = .67$, $p<.01$). There was a moderate negative correlation between resilience and negative affect ($r=-.47$, $p<.01$). A weak negative correlation with burden total, ($r=-.32$, $p<.05$), as well as subcategories general strain, ($r=-.33$, $p<.05$), disappointment, ($r=-.31$, $p<.05$) and emotional involvement ($r=-.31$, $p<.05$). No correlation with independence measure at all or other demographic characteristics. High resilience group had significantly higher positive affect scores ($z=-6.71$, $p<.005$ with bonferroni) and higher scores on the caregiver management measurement ($z=-3.26$, $p<.005$). There was no difference in the high/ low resilience groups in terms of burden or negative affect. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Scholten et al. (2020) | To look at the relationship between resilience and distress, looking at the mediating effect of coping | 106 (ABI) | recruited from several rehabilitation centers around Utrecht Between April '16 and July '18 | Cross-sectional | Connor-Davidson Resilience Scale-10 (CD RISC-10); (Connor & Davidson, 2003) | Anxiety, depression, Appraisals of Life Events, threat, loss and coping. | Spearman's rho and t-test initially, followed by serial multiple mediation regression analysis with sociodemographic factors as covariates | t-tests show the ABI CGs as more resilient than the SCI CGs, $t(226)=-2.01, p<.05$. ABI CGs also had less threat and loss appraisal, $t(225.6)=4.01, p<.001$. CGs in SCI had significantly more distress, $t(226)=1.95, p=.05$ both groups had higher anxiety than depression in subacute. Correlations: appraisals - resilience = $-.40, p<.001$, passive coping-resilience = $-.44, p<.001$, psych distress-resilience = $-.42, p<.001$, high education-resilience, = $.14, p<.05$ Mediation model: in the ABI group, the model explained 47% of the variance in psych distress, $s(F(3,102) = 21.15, p < .001)$. There was no direct relationship between resilience and psychological distress after the indirect relationships (mediators) of passive coping, threat and loss appraisals in ($c = -.53, p < .001$; $c' = -.08, p > .05$). Resilience was moderated by appraisals (small negative correlation 8%) and passive coping (small negative association 13%) and through appraisals, which had a strong association with passive coping, which had a strong association with psych distress. There were no correlations of the person's independence level with distress, or resiliency factors. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-----------------------|--|------------------------|--|---------------------|---|--|--|---|
| Simpson et al. (2020) | To use structural equation modelling to explore the relationships between hope, resilience and spirituality and their effects on various caregiver outcomes. | 76 (TBI) 23(SCI) | Oct 2013- May2016. Six rehab centers in Australia everyone that met inclusion asked. | Cross- sectional | Connor- Davidson Resilience Scale (CDRS); (Connor & Davidson, 2003) | Functional assessment of person with TBI/SCI; spiritual wellbeing; Hope; Caregiver Burden; Positive and negative affect Depression, Anxiety, Stress | descriptive SEM; t-tests using bonferonni; chi square goodness of fit to test the model | No group differences between the SCI and TBI group on any of the measures, so both were grouped together for the SEM. Correlational analyses used first to determine which variables should be entered into the model. They chose anything with correlation above .3 (medium). Spirituality and hope accounted for 35% of the variance in resilience according to the SEM. Spirituality had a direct impact (B=.39) and an indirect impact through hope: (B = .67 to hope and then .26 to resilience) and hope had a direct impact on resilience (B=.26). Resilience only had a direct effect on positive affect, (B = .23). Resilience mediated spirituality's effect on positive affect. Resilience's effect on depression was mediated by positive affect (B= -.24), which then had a strong positive effect on negative affect (B=.51), which then had impacts on stress, anxiety, and depression (B = .60 .72, and .51). Resilience did not explain any of the variance in burden. Resilience, hope and spirituality explained 37% variance in positive affect, 56% of the variance in depression, 52% of the variance in anxiety and 50% of the variance in stress. Incremental fit were all above the .9 benchmark. Pearson correlations showed spirituality was positively associated with resilience measure, $r = .561$, $p < .01$ and also hope as being associated with resilience measure, $r = .520$, $p < .01$ and positive affect, $r = .483$, $p < .01$. There was a weak negative correlation with burden, $r = -.257$, $p < .05$, negative affect, $r = -.286$, $p < .01$, stress, $r = .259$, $p < .05$ and anxiety, $r = -.218$, $p < .05$ and a moderate association with depression, $r = -.436$, $p < .01$ |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Resiliency Papers | | | | | | | | |
| Vranceanu et al. (2020) | To look to see if there are better outcomes in a resiliency promoting intervention against an educational program intervention, in terms of PTSD, depression and anxiety | 58 (Variou s) | Direct referrals of everyone that came in with stroke (neuro-ICU) hospital - 2 week window | Single Blind RCT: measures at baseline, 6 and 12 weeks "All study staff besides the statisticians were blind to the allocation algorithm" | The Measure of Current Status Part A (MOCS-A)(Carver, 2006); The Cognitive and Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Dyadic Relationship Scale (DRS)(Sebern & Witlatch, 2007) | Anxiety, depression, PTSD | "separate shared-baseline, mixed-model repeated-measure ANOVA estimated by restricted maximum likelihood" | No statistical differences in the group demographics. CG BL-PI depression reduction (-3.8 vs 0.6; difference, -4.5; 95% CI, -6.7 to -2.3; P < .001), which was over the MCID for anxiety and depression scale and anxiety reduction (-5.0 vs -0.9; difference, -4.1; 95% CI, -6.7 to -1.5; P = .002). PTS scores in caregivers also improved (-11.4 vs 5.0, difference, -16.4; 95% CI, -21.8 to -10.9; P < .001) - this was better than the MCID too. Patients in the RT group also shared improvements in all symptoms. At 12 weeks, the CG post trauma group continued to show improvement in symptoms (difference, -3.7; 95% CI, -7.3 to 0.0; P = .02), while the education-only group's symptoms remained stable. The only resiliency variable that the intervention significantly improved for the caregivers was increase in positive coping, namely relaxation (0.6; 95% CI, 0.2 to 1.0; P = .008). No other significance was found for caregivers. Positive coping and improved dyadic interactions increased for the patient of the RT group after the intervention compared to the control, but not the same for CGs. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Bannon et al. (2020) | To explore the feasibility of the resiliency intervention, and to look at the improvement of the distress variables and resiliency skills before, after and follow-up from the intervention. Compared against a 'minimally enhanced normal care' control. | 16 (Stroke) | Approached everyone who was referred into the neuro ICU (Hospital) | RCT (Baseline, Post-intervention and 3 months) - no blinding after assessment | The General Self-Efficacy Scale (GSE)(Luszczynska et al. 2005); The Measure of Current Status Part A (MOCS-A)(Carver, 2006); The Cognitive and Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Intimate Bond Measure (IBM)(Wilhelm & Parker, 1988). | Anxiety, depression, PTSD | Cohen's d to measure the effect sizes of the improvement in resiliency skills and reduction of psychological distress measures | Cohen's d shows a reduction in anxiety, post trauma symptoms and depression in the CG recovering together program (d = -.63, -.81, and -.98). Authors report that these are large-medium ES - between the baseline and PI measures. The minimal normal care group had increases in depression, anxiety and post trauma symptoms ((d = .71, .48, and .46) medium-large (baseline-post test). RT group had some gains in the resiliency skills after the intervention and these ranged from high ES to low ES; non of the standard care group made gains in this 6 weeks. There are a number of variations which show movement in the numbers at the end of the intervention and the 3 month follow-up for all the groups (RT-SE, d = -.7 at BL-PT, -.26 at PT-3M, -.37 at BL-3M), but non of these are 'clinically significant'. Trend for the intervention group to decrease in psychological distress from baseline to 3 month follow up and the standard care group to increase. |
| Meyers et al. (2020c) | To look at the relationship between PTS and resiliency factors over time after someone comes into the neuro intensive care (both patients and caregivers) | 103 (ABI) | From a tertiary care medical center over 1 year | Longitudinal prospective cohort study (BL and 3, 6 months) | Cognitive Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Measure of Current Status (MOCSA) - Part A (coping)(Carver, 2006) | Posttraumatic stress symptoms | Dyadic analysis (APIM) and multi-level modelling; Pearson's r, chi square and paired-samples t-test. | 16% clinical posttraumatic stress in caregiving sample - baseline. At 6 months, 14% caregivers showing PTS clinically. The bivariate analysis showed that BL caregiver mindfulness was strongly correlated with CG coping r=0.796, p<.001. Coping negatively correlated with PTS symptoms at baseline r=-.665 (large effect size), at 3 months, r=-.449 (medium ES), and 6 months, r=-.416 (medium ES). Mindfulness negatively correlated with PTS at BL -.531 (large ES), 3 months, r=-.374 and 6 months r=-.329 (medium ES). Actor/ partner independence showed that mindfulness and coping predictive of less PTS symptoms over time, p<.001 |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Meyers et al. (2020b) | To look at anxiety and its trajectory in patients and CGs after neuro-critical care and to explore how resiliency skills mindfulness and coping affect these. | 103 (ABI) | From a tertiary care medical center over 1 year | Longitudinal prospective cohort study (BL and 3, 6 months) | Cognitive Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Measure of Current Status (MOCSA) - Part A (coping)(Carver, 2006) | Anxiety | Dyadic analysis; actor partner independence modelling (APIM) Pearson's r, chi square and paired-samples t-test. | Patients had significantly more anxiety than CGs ($\chi^2(1)=9.01, p<0.001$) and 6-month follow-up $\chi^2(1)=9.82, p=0.002$). Negative correlation between CG baseline anxiety and coping scores $r=-.568, p<.001$ (large ES), 3M $r=-.418$ (medium ES), $p<.001$ and 6M $r=-.398, p<.001$ (Medium ES). Mindfulness also negatively correlated with BL anxiety $r=-.618, p<.001$ (large ES), 3M $r=-.460$ (Medium ES), $p<.001$ and 6M, $r=.453, p<.001$ (medium ES). Both coping and mindfulness highly correlated $r=.796, p<.001$ (large ES). APIM showed that BL mindfulness and coping related to lower anxiety at 3M and 6M. The higher the patient mindfulness, the lower the CG anxiety at 3M, after accounting for the individual factors (actor effects) $B=-.107, p=.008$ and the same for the other way around. |
| Meyers et al. (2020a) | To see what the trajectory of depression is in CGs and patients at the Neuro-ICU and the impact of resiliency factors on this. | 103 (ABI) | From a tertiary care medical center over 1 year | Longitudinal prospective cohort study (BL and 3, 6 months) | Cognitive Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Measure of Current Status (MOCSA) - Part A (coping)(Carver, 2006) | Depression | Dyadic analysis (APIM) and multi-level modelling; univariate relationships: Pearson's r, chi square and paired-samples t-test. | Bivariate analysis to look at actor effects (CG) showed a negative correlation between coping and mindfulness and depression at BL (CG coping and depression at BL $r=-.605, p<.001, 3m, -.399, p<.001, 6m, r=-.355, p<.001$, CG mindfulness and depression at BL $r=-.559, p<.001, 3 month r=-.363, p<.001$ and 6 month $r=-.355, p<.001$ mindfulness. Coping and mindfulness correlated at $.796$. BL depression in CGs predicted depression at the other 2 time points, $B=.419, p<.001$ BL-3m, and $B=.736, p<.001$ 3m-6m. BL mindfulness predicted lower depression at BL, $B=-.293, p<.001, 3m, -.249, p<.001$ and 6m, $B=-.253, p<.001$ and coping predicted lower depression: BL: $B=-.209, 3m, B=-.144$ and 6m, $B=-.121, p<.001$. CG BL depression more predictive of depression at 3m, $r=-.410$ (medium ES) and 3months - 6months, $r=-.663$ (large ES) |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
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| Shaffer et al. (2016a) | To look at resiliency factors (coping and mindfulness) and how they correlate to various forms of psych distress (anxiety, depression and PTS symptoms) in the early stages of neuro-ICU in px and caregivers. | 92 (ABI) | Everyone admitted to the neuro ICU that met criteria was approached | Cross-sectional correlation | Cognitive Affective Mindfulness Scale Revised (CAMS-R) (Feldman et al. 2007); The Measure of Current Status (MOCSA) - Part A (coping)(Carver, 2006) | Posttraumatic symptoms, Anxiety and depression | Pearson's r and paired samples t-test. Cohen's d | Coping was significantly and negatively correlated with PTS $r=-.52$, $p<.001$ (large ES), anxiety, $-.58$ (large ES) and depression, $r=-.48$, $ps<.001$ (Medium ES). Also mindfulness negatively correlated with PTS, Anxiety and Depression, $r=-.54$, $r=-.47$, $r=-.42$, $ps<.001$. CG depression and anxiety correlated $r=.63$, $p<.001$. Anxiety and PTS symptoms correlated, $r=.70$, $p<.001$. CG coping was significantly related to mindfulness, $r=.70$, $p<.001$. --- Actor/partner interdependence modelling results: only higher mindfulness was associated with less PTS symptoms ($B=-1.05$, $-.48$ [standardized], $p<.001$). Anxiety was related to both mindfulness ($B=-.12$, $p<.001$ -.22 [standardized]) and coping ($B=-.12$, $p<.001$, $-.38$ [standardized]). Depression in CGs, only coping was related ($B=-.05$, $p=.02$, $-.31$ standardized). Higher mindfulness = lower depression in the partner. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-----------------------|--|-----------------------|---|-----------------------------|---|---|---|---|
| Zale et al. (2018) | To see which factors are associated with greater QOL in caregivers of patients in the neuro-intensive care unit. | 79 (ABI) | Everyone admitted to the neuro ICU that met criteria (March 15 - December 16) caregivers noted on discharge | Cross-sectional correlation | The Preparedness for Caregiving Scale (PFCS) (Archbold et al. 1990), The Cognitive and Affective Mindfulness Scale (CAMS-R) (Feldman et al. 2007), The Measure of Current Status-A (MOCS-A) (Carver, 2006) | Quality of life, Emotion thermometers, Anxiety and depression | Correlations and ANOVA. Multivariate regression models. Hierarchical linear regressions | Coping positively correlated with QOL domains (r=.521 physical, r=.589 psychological, r=.478 social and r=.357 environmental, ps<.01), mindfulness also (r=.649, r=.627, r=.323, r=.382 respectively, all ps<.01) and preparedness for Caregiving (r = .509, r=.347, r=.393, and r=.571 respectively. All ps<.01). PFC only correlated at .438 to coping and .322 to mindfulness, where as coping and mindfulness was .739, ps<.01. Resiliency and distress all sig. negative correlations: Coping: (r=-.574[depression], -.540 [anxiety], -.378 [anger], -.319 [stress], and -.321[distress]. Mindfulness (rs = -.523, -.531, -.291, -.395 and -.387) ps<.01. Preparedness for caregiving: (rs= -.439[depression], -.455[anxiety], -.365[anger]) ps<.01 stress and distress non sig. (rs= -.215 and -.177). Physical QOL regression: psychological distress accounted for variance at step 2: ($\Delta R^2= 0.39$, $F(5, 71) = 9.54$, $p < 0.001$) and resiliency at step 3: ($\Delta R^2= 0.21$, $F(3, 68) = 13.17$, $p < 0.001$), with mindfulness and preparedness associated with physical QOL on their own ($sr^2 = .12$, $p < .001$) and $sr^2 = .07$, $p = .001$ respectively. Psychological QOL: psych distress accounted for ($\Delta R^2= 0.33$, $F(5, 71) = 7.04$, $p < 0.001$). resiliency accounted for ($\Delta R^2= 0.17$, $F(3, 68) = 7.84$, $p < 0.001$) with mindfulness being individually positively associated ($sr^2= 0.07$, $p = 0.004$). Social QOL, psych distress ($\Delta R^2= 0.25$, $F(5, 71) = 5.12$, $p < 0.001$). resiliency = ($\Delta R^2= 0.11$, $F(3, 68)$, $p = 0.010$), PFC was the only unique significant positive association ($sr^2= 0.05$, $p = 0.021$). Environmental QOL: distress: ($\Delta R^2= 0.31$, $F(5, 71) = 6.79$, $p < 0.001$). resiliency ($\Delta R^2= 0.16$, $F(3,68) = 7.34$, $p < 0.001$). with preparedness also uniquely associated $sr^2=.14$, $p < .001$.) |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|------------------------|---|-----------------------|--|-----------------------------|--|--------------------------------------|--|---|
| Shaffer et al. (2016b) | Using dyadic analysis, to see the effect of resiliency factors on psychological distress (anxiety, depression, anger and distress) in caregivers of patients on the Neuro ICU | 99 (ABI) | looked at everyone admitted to the neuro ICU and approached within the first 2weeks. | Cross-sectional correlation | The Cognitive and Affective Mindfulness Scale (CAMS-R) (Feldman et al. 2007), The Measure of Current status-A (MOCS-A)(Carver, 2006), The Intimate Bond Measure (IBM)(Wilhelm & Parker, 1988); Revised Caregiver Self-Efficacy Scale (CSES-R)(Steffen et al. 2002) | Emotion Thermometers | ANOVA within subjects and bonferonni correction, t-test, Cohen's d measure of effect size. | Only CG SE significantly negatively correlated with distress, ($r = -.27, p < .01$). Coping and CG SE negatively associated with anxiety ($r = -.39, p < .001$) and ($r = -.27, p < .01$) respectively. Mindfulness and coping negatively correlated with depression ($r = -.28, p < .01$) and ($r = -.36, p < .001$). Mindfulness, depression and CG SE negatively correlated with anger ($r = -.28, p < .01, r = -.36, p < .001$ and $r = -.37, p < .001$ respectively). No partner effects. T-test looked at CGs with clinically significant emotional distress and those without. Those at clinical cut-off were likely to have lower SE ($t = 3.47, d = .74, p < .001$) and coping ($t = 3.32, d = .72, p < .01$) scores. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|----------------------|---|-----------------------|--|--|--|--------------------------------------|---|--|
| Lin et al. (2020) | To see if gender interacts with resiliency factors measured at baseline and depression measured at BL, 3months and 6months. | 96 (ABI) | Between March-August 2016 (neuro-ICU) hospital | Longitudinal prospective cohort study (BL and 3, 6 months) | The Preparedness for Caregiving Scale (PFCS); (Archbold et al. 1990), The Cognitive and Affective Mindfulness Scale (CAMSR) (Feldman et al. 2007), The Measure of Current Status-A (MOCS-A)(Carver, 2006); The 12-item intimate care dimension of the Intimate Bond Measure ; 15-item Revised Scale for Caregiver Self-Efficacy | Depression | Pearson r for correlation of continuous and ANOVA/ chi square for categorical, and cont. ANCOVA | Intimate care only correlated with coping and SE scores (r=.239 and .316 resp. p<.05). Intimate care had no relation to depression at any time. Coping negatively correlated with depression at BL, 3 and 6 months (r= -.574, -.369, and -.350, all ps<.01). Mindfulness also negatively correlated with depression (r= -.493, -.271*, -.273*, p<.01 *p<.05. SE also negatively correlated with depression at all time points (r = -.309, -.427, and -.293*, p<.05and *p<.01). PFC and depression negatively correlated at BL (r= -.424, p<.01) and 3 months (r= -.480, p<.01) and not sig with 6 months. Depression at BL is sig correlated with 3 and 6 month depression (r= .589 and .574, p<.01). 3 month depression highly correlated with 6 month depression score (r = .757, p<.01.). Mindfulness highly correlated with coping (r= .702). SE and intimate care not correlated with mindfulness. PFC moderately correlated with other resiliency factors between r=.307 and .431, ps<.01 and also highly correlated with SE, r=.60, p<.01. ANCOVA BL results: High coping group had lower depression scores F(1, 89)=16.81, p<0.001, η2=0.16. Also higher mindfulness group had lower depression compared with low mindfulness: (M=5.45, SE=0.55), F(1, 89)=14.36, p<0.001, η2=0.14 and there was a PFC groups main effect: (M=5.02, SE=0.53), F(1, 89)=8.23, p=0.005, η2=0.09. At 3 months, only the coping score at baseline (high coping group) reported less depression at 3m: F(1, 73) = 4.12, p=0.046, η2=0.05. Male CGs who reported high levels of intimate care of their partner at BL had lower levels of depression than their low IC group: F(1, 73)=5.29, p=0.024. this ANCOVA also controlled for relationship of the CG. ANCOVA 6 months: significant interaction: baseline intimate care, |

gender and depression at 6months: $F(1, 67)=4.53, p=0.037, \eta^2=0.06$. Males that had higher scores of intimate care of their partner at BL had lower levels of depression 6 months later than women who gave their family members intimate care.

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-------------------------|--|-----------------|---|---------------------------------------|---|---|---|--|
| PTG Papers | | | | | | | | |
| Las Hayas et al. (2014) | To translate the PACS, and measure construct validity, reliability and factor analysis with a sample of caregivers of people with ABI. Used measures of burden and PTG to look at correlations | 141 (ABI) | Convenience Sample - ABI associations contacted their members, and CGs attending day centers were contacted | Factor Analysis/ cross-cohort surveys | The Post-Traumatic Growth Inventory (PTGI; Weiss, & Berger, 2006) | Positive Aspects of Caregiving, QOL, caregiver risk | Factor Analysis of the PACS and "comparative fit index (CFI), non-normed fit index (NNFI), Pearson correlation to test validity with other measures | PACS total correlated with the PTGi ($r=.54, p<.01$ [large ES]), with the PACS self-affirmation factor ($r=.41, p<.01$ [medium ES]) and PACS outlook on life factor ($r=.55, P<.01$ [large ES]). Both the PACS self-affirmation and PACS Outlook-on-life are almost moderately correlated ($r^2=.46, p<.001$) and this model is a good fit. The PACS had moderate, positive correlation with QoL psychological ($r^2=.31, p<.01$), weak correlation with QOL social relations, ($r=.22, p<.01$), negative weak relationship with the CARE burden factors (expectations of caring and caring impact) ($r=-.31, P,.01$ and $r=-.23, P<.001$ respectively) and CARE total ($r=-.37, p<.01$ [medium ES]). |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|------------------------|---|-----------------------|-------------------------------------|-----------------|---|--|---|---|
| Hallam & Morris (2013) | to test two theories of PTG (explore explanatory power of both) and look at variables which are associated with it. | 71 (stroke) | convenience Sample - stroke groups. | Cross-sectional | The Post-Traumatic Growth Inventory (PTGI; Weiss, & Berger, 2006) | The Barthel Index (BI); The Coping Orientation to Problems Experienced (COPE); Multidimensional Scale of Social Support (MSPSS); The Rumination Scale (RS); Adult Carer Quality of Life (AC-QOL) | Correlation, linear regression and mediation analysis | Based on the PTGI inventory scoring, (6-104 range), the authors note that all CGs experienced some growth. Strong positive correlation of PTG with total rumination ($r = .63$, $P < .05$ [large ES]) and deliberate rumination ($r = .62$, $p < .01$ [large ES]). Lots of correlations within the rumination subscales, with the smallest being between deliberate and intrusive rumination ($r = .31$, $p < .01$ 1 tail). Only a small correlation of PTG with QOL ($r = .2$, $p < .05$ [Small ES]). Avoidance coping also significantly correlated with PTG ($r = .25$, $P < .05$ [Small ES]). No other coping measures correlate (active or acceptance). PTGI also correlated with social support ($r = .34$, $p < .01$ [Medium ES]). Regression analysis shows support for Tedeschi and Calhoun model of PTG ($R^2 = .49$; $F(5, 63) = 12.08$; $p < .0000$) with deliberate rumination accounting for the biggest proportion of the variance, followed by avoidance coping and social support. In the other analysis, with Schefer and Moos model of PTG as predictor, the model was significant but only social support explained some of the variance in PTG significantly. social support as a mediator of deliberate rumination and PTG in this model. |

| Paper | Aims | N (Injury Type) | Sampling | Design | Measures of resilience Construct | Comparing constructs/ outcomes | Statistical Analysis | Results Outline |
|-------------------------|--|-----------------------|--|---|--|---|---|--|
| Hardiness Papers | | | | | | | | |
| Inci & Temel (2016) | To test the efficacy of a support program (designed using the resiliency model and from the pre-test data) by measuring resilience before and after in a treatment group (comprising of educational sessions [5] and social support sessions [5] comprising of problem-solving, expressing of emotion and feelings about caregiving and coping...and control group (routine home care) | 70 (stroke) | Convenience (from a hospital and clinic) | RCT (Baseline, Post-intervention and follow-up) - single blind (participants) | The Family Hardiness Index (FHI); (McCubbin & McCubbin, 1996). | Family Regenerativity and Adaptation, Family Stressors, Family Strains, Relative and Friend Support, Social Support, Family Coping-Coherence, Family Distress | Chi-Square; two-way repeated measures ANOVA; Friedman ANOVA, paired t-tests with bonferonni and wilcoxon signed ranks | No statistical differences in the group demographics. Significant differences between the experimental and control groups at the pre-test in Family hardiness (control group had statistically higher hardiness and statistically lower family distress). Family hardiness significantly increased over the intervention for both groups (post-test) ANOVA, p=.001 (experimental) and p=.009 (control); with a large effect size = -.89, P<.01 (for the experimental) and remained stable in follow-up (increased slightly but non-significant after bonferonni correction (p=.024)). After the bonferoni corrections, cohen's d for control group was minimal d=.16 and non-sig; similarly, family distress decreased from pre-post-test in experimental group (d = 0.67, p=.01) and remained stable at follow-up. There was no change in distress for the control group. There were no group differences as intervention seemed to bring hardiness and distress to the same level as the control group. Family coping-coherence changed significantly in the ANOVA for experimental group, p=.001. Only the pre-intervention and follow-up difference had a notable effect size, d=-.83, p<.01 in the experimental with the pre-post intervention just outside the significance range (p=.019). The ANOVA showed that social support increased in both groups over time (p<.01), although effect size was only significant in the experimental group for pre-post intervention and pre-intervention - followup (d=1.05 and d=1.3 resp. P<.01). Relative and friend support increased in the experimental group: ANOVA p = 0.015 between pre-intervention and follow-up, (d=-.79, |

| | | | | | | | | |
|--------------------------------|---|---------------------|--|------------------------|---|---|---|---|
| <p>Niyomthai et al. (2003)</p> | <p>Looking at duration of care, family stressful events and hardiness scores and how they relate to caregiver wellbeing</p> | <p>120 (stroke)</p> | <p>From out-patients clinic, and 2 other hospitals in south Thailand</p> | <p>cross-sectional</p> | <p>The Family Hardiness Index (FHI); (McCubbin & McCubbin, 1996).</p> | <p>Family inventory life events and changes, Family member well-being</p> | <p>Pearsons correlation and stepwise multiple regression analysis</p> | <p>p=.005). There was a significant group difference in family strain at post-intervention, $p < .01$, with a reduction between some time points in the experimental group, $p = .021$, however, no significant ES between time points after the bonferoni corrections.</p> |
| | | | | | | | | <p>FILE showed that the majority of families came under the low life-events category (58.3% of caregivers). only 13 (10.8%) had high scores. Mean hardiness scores ($M = 45.0$, $SD = 8.99$), were in the moderate hardiness range. Co-orientated care was the highest score ($M = 20.47$), then confidence, challenge and control ($M_s = 7.75, 9.40$ and 5.17 respectively). Family member wellbeing scores were "relatively good" but authors note a wide range amongst the families. Nothing correlated with caregiving duration. Life events scores significantly, negatively correlated with hardiness ($r = -.41$, $p < .01$) and wellbeing ($r = -.494$, $p < .01$) with medium ES, indicating that the higher life events, the lower the score on both hardiness and wellbeing. Wellbeing also significantly, positively correlated with hardiness ($r = .442$, $p < .01$ [medium ES]) indicating that as hardiness increased, so did wellbeing. Multiple regression: Hardiness, duration of caregiving, and wellbeing were standardized due to violating the assumption of normality. Life events accounted for 24% variance in Family member wellbeing, F change = 1,118 = 38.16, $p \leq .001$. Hardiness added 7% variance (F change 2,117 = 11.72, $p \leq .001$). both account for 31.3% in wellbeing $B_s = -.376$ and $.288$ respectively.</p> |

Table 2*RARCS definitions of each paper*

| Authors | Title | Construct definition |
|--------------------------|---|---|
| Resilience papers | | |
| Anderson et al. (2020) | A predictive model of resilience among family caregivers supporting relatives with traumatic brain injury (TBI): A structural equation modelling approach | “the ability to adapt in the face of tragedy, trauma, adversity, hardship and ongoing significant life stressors” (Newman, 2005, p. 227)’ and ‘White and associates (2008) observed that it was a multi-dimensional construct comprising a mix of personal skills and attributes, social competence, social resources and spirituality, which may be associated with reductions in morbidity and increased positive well-being’ |
| Sander et al. (2020) | Emotional suppression and hypervigilance in military caregivers: Relationship to negative and positive affect. | No clear definition of resilience |
| Migliorini et al. (2018) | Family and TBI: an investigation using the Family Outcome Measure – FOM-40 | Discussed in relation to the findings: ‘Capacity to mobilise needed social and economic resources in order to meet challenge is a key component of resilience (Windle, Bennett, & Noyes, 2011)’; Family resilience: ‘Set of processes which assist a family to "rally in times of crisis, to buffer stress, reduce the risk of dysfunction and support optimal adaptation, Walsh et al. 2011)’ |

| Author | Title | Construct definition |
|----------------------------|---|--|
| Rasmussen et al. (2020) | Mental Health and Family Functioning in Patients and Their Family Members after Traumatic Brain Injury: A Cross-Sectional Study | No clear definition of resilience |
| Jia et al. (2021) | Positive effects of resilience and self-efficacy on World Health Organization Quality of Life Instrument score among caregivers of stroke inpatients in China | ‘Windle et al. and Bannonet al. defined resilience as people’s adaptability to maintain mental and psychology well-being when facing a traumatic event or frustration.16, 17; Resilience is associated with lower levels of suffering, better ability to adjust, and better QOL among caregivers of patients with stroke, and it could help individuals respond to care-related psychological challenges.18”. "Self-efficacy as necessary for resilience to occur (22)’ |
| Bermejo-Toro et al. (2020) | Quality of life, psychological well-being, and resilience in caregivers of people with acquired brain injury (ABI) | ‘Resilience thus acts as a protective factor against stress and increases the positive consequences resulting from caring’...’A considerable amount of research about resilience has suggested that people with higher resilience avoid the potentially adverse effects of stress [e.g. (44,45)], are more protected from the experience of depression (46), and report healthier levels of psychological adaptation and functioning when facing either acute or chronic traumatic events’ |
| Carlozzi et al. (2020) | Reliability and Validity Data to Support the Clinical Utility of the Traumatic Brain Injury Caregiver Quality of Life (TBI-CareQOL) | No clear definition of resilience |

| Author | Title | Construct definition |
|-------------------------|---|--|
| Las Hayas et al. (2015) | Resilience in Family Caregivers of Persons With Acquired Brain Injury | 'The factors that facilitate a positive and healthy adaptation are recognized in the literature as resilient qualities'... 'For our present work, we understand resilience as the process of positive adaptation in the face of adversity, trauma, tragedy, threats, or significant sources of stress (American Psychological Association [APA], 2010) or, more specifically, as a dynamic process in which psychological, social, environmental, and biological factors interact to enable an individual at any stage of life to develop, maintain, or regain his or her mental health despite exposure to adversity (Wathen et al.,2012). Resilience may be acquired and modified in anyone(Connor & Davidson, 2003) and at any point in life (APA,2010;Flach, 1988).' |
| Brickell et al. (2020) | Resilience is associated with health-related quality of life in caregivers of service members and veterans following traumatic brain injury | 'The process of personal adaptation and growth in response to significant adversity, and the ability to use resources and maintain healthy functioning is often referred to as resilience [19–21].' They acknowledge the difference in conceptualisations of resilience. Based on Windle et al. (2011, cited in [22], p. 268) 'as the process of successfully adapting to significant sources of stress or trauma, facilitated by an individual's psychological resources, life experiences, and environment'"...this measure is one that was adapted for ABI |
| Simpson et al. (2021) | Testing a Model of Resilience in Family Members of Relatives with Traumatic Brain Injury vs spinal Cord Injury: Multigroup Analysis. | 'the ability to adapt in the face of tragedy, trauma, adversity, hardship and ongoing significant life stressors' (Newman, 2005, p. 227)' and 'White and associates (2008) observed that it was a multi-dimensional construct comprising a mix of personal skills and attributes, social competence, social resources and spirituality, which may be associated with reductions in morbidity and increased positive well-being' |
| Simpson et al. (2013) | How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury? | 'Resilience is a multidimensional construct constituting a range of thoughts (e.g. positive outlook), feelings (e.g. hopefulness, sense of humour), and behaviours (e.g. capacity to mobilise social and economic resources).16 Resilience can be defined as a "dynamic process encompassing positive adaptation within the context of significant adversity".19. Such a definition reflects a growing consensus that resilience does not consist of fixed personality traits, but rather is a set of skills which can be learned.16,20,21" ... "resilience, a range of generic skills (e.g. personal and social competence, personal structure)16' |

| Author | Title | Construct definition |
|------------------------|--|--|
| Scholten et al. (2020) | Appraisals and coping mediate the relationship between resilience and distress among significant others of persons with spinal cord injury or acquired brain injury: a cross-sectional study | 'resilience – which reflects one's ability to thrive in the face of adversity – seems to be an important expression of personal resource' |
| Simpson et al. (2020) | Do spirituality, resilience and hope mediate outcomes among family caregivers after traumatic brain injury or spinal cord injury? A structural equation modelling approach. | 'Resilience can be defined as "the ability to adapt in the face of tragedy, trauma, adversity, hardship and ongoing significant life stressors" (Newman, 2005, p. 227)'...'resilience was also linked to positive affect, with resilience also acting as a buffer against depressive symptoms (Jones, Simpson, et al., 2019).' |

Resiliency Papers

| | | |
|-------------------------|---|---|
| Vranceanu et al. (2020) | Feasibility and Efficacy of a Resiliency Intervention for the Prevention of Chronic Emotional Distress Among Survivor-Caregiver Dyads Admitted to the Neuroscience Intensive Care Unit: A Randomized Clinical Trial | Authors describe that their definition is in another paper - referenced the below paper, Bannon et al. (2020) |
|-------------------------|---|---|

| Author | Title | Construct definition |
|--------------------------|---|---|
| Bannon et al. (2020) | Recovering together: building resiliency in dyads of stroke patients and their caregivers at risk for chronic emotional distress; a feasibility study | 'Resiliency skills include Self-Efficacy, mindful skills, coping, interpersonal bond': described in a different paper, which was referenced - this was difficult to find |
| Meyers et al. (2020a) | Baseline resilience and depression symptoms predict trajectory of depression in dyads of patients and their informal caregivers following discharge from the Neuro-ICU | 'Resiliency is a biopsychosocial construct defined as the ability to adapt and recover when faced with adversity' |
| Meyers et al. (2020b) | The Impact of Resilience Factors and Anxiety During Hospital Admission on Longitudinal Anxiety Among Dyads of Neurocritical Care Patients Without Major Cognitive Impairment and Their Family Caregivers | 'Resiliency, or successful adaptation in the face of adversity or trauma,'...'Here, we conceptualize resiliency in terms of 2 modifiable factors, mindfulness and coping. Mindfulness, the ability to remain present and defer judgment in the face of adversity'...'Coping, the arsenal of cognitive, behavioral, or emotional skills that an individual can rely on to manage stress, is also associated with improved physical and mental health outcomes.' |

| Author | Title | Construct definition |
|------------------------|---|---|
| Meyers et al. (2020c) | Baseline Resilience and Posttraumatic Symptoms in Dyads of Neurocritical Patients and Their Informal Caregivers: A Prospective Dyadic Analysis | as above in Meyers et al. (2020b) |
| Shaffer et al. (2016a) | Mindfulness and Coping are Inversely Related to Psychiatric Symptoms in Patients and Informal Caregivers in the Neuroscience ICU: Implications for Clinical Care | 'Resiliency, defined as the ability to bounce back from stressful and adverse situations'... 'Mindfulness, the ability to remain attentive to the present moment without becoming overwhelmed, is one skill that enhances resilience to stressors including traumatic experiences.'... 'Resiliency also depends on the breadth and accessibility of one's coping arsenal, or one's bank of behavioral (e.g., use of social support, employment of relaxation techniques), cognitive (e.g., adaptive thinking), and emotional (e.g., ability to regulate emotions) strategies to manage stress (28)' |
| Zale et al. (2018) | Resiliency is independently associated with greater quality of life among informal caregivers to neuroscience intensive care unit patients | Resiliency– 'the ability to bounce back when faced with stressful situations [18]–is a multidimensional construct. Within a biopsychosocial framework, resiliency can be conceptualized as an interplay of biological, psychological, and social processes (e.g. [18,20])'. |
| Shaffer et al. (2016b) | Psychosocial resiliency is associated with lower emotional distress among dyads of patients and their informal caregivers in the neuroscience intensive care unit | 'Resiliency, or the ability to adapt effectively under significant adversity [15]'... 'Although resiliency is a multidisciplinary construct with environmental, genetic, epigenetic, and neural mechanisms that evolve through an individual's lifetime [15], research has identified several modifiable psychosocial factors that promote successful adaptation to stress. Mindfulness - the ability to stay present and defer judgment in the face of adversity [16]; coping – the arsenal and application of one's behavioral, cognitive, and emotional strategies to manage stress [17]; social support – empathetic interpersonal interactions that meet one's emotional |

and functional needs [18]; and self-efficacy – one’s perceived resourcefulness to adapt under adversity [19].’

| Author | Title | Construct definition |
|-------------------------|--|--|
| Lin et al. (2020) | Gender Differences in Longitudinal Associations Between Intimate Care, Resiliency, and Depression Among Informal Caregivers of Patients Surviving the Neuroscience Intensive Care Unit | ‘Resiliency—the ability to “bounce back” when faced with adversity—is a multidimensional construct that encompasses skills for successful adaptation to stress or trauma [11] and is protective against depression in caregivers of heterogeneous patient populations [12–14]. Several modifiable resiliency factors’...‘Mindfulness (the mental state of being aware of present experiences while describing them non-judgmentally), caregiver self-efficacy (the perceived ability of accomplishing caregiving responsibilities), preparedness for caregiving (perceived readiness for managing the caregiving role), and intimate care (physical and emotional affection with another) may prevent caregivers from developing depression [4, 12–16].’ |
| PTG Papers | | |
| Las Hayas et al. (2014) | Positive Aspects of Caregiving in Spanish Caregivers of Individuals With Acquired Brain Injury | PTG - ‘Wong, Ussher, and Perz (2009), working with caregivers of cancer patients, concluded that finding benefits in response to experiencing adverse events serves the important function of allowing individuals to incorporate difficult experiences into their worldview in a meaningful way.’ |
| Hallam & Morris (2013) | Post-traumatic growth in stroke carers: A comparison of theories | ‘post-traumatic growth (PTG), which is defined as ‘positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events’ (Calhoun & Tedeschi, 1999, p. 1). Such growth encompasses finding benefit and meaning after trauma” |

| Author | Title | Construct definition |
|----------------------------|--|--|
| Inci & Temel (2016) | The effect of the support program on the resilience of female family caregivers of stroke patients: Randomized controlled trial | 'It [family hardiness] is a resilience-focused process, with specific focus on several post-crisis or adaptation-oriented elements in an effort to explain the family's behavior and functioning in the process of adaptation...'Resilient families can grow stronger from stressful and difficult conditions they face (McCubbin, McCubbin, & Thompson, 2003)'...'family members' ability to cope with stressful life cycles in the family and to ensure family cohesion is defined as family resilience (Black & Lobo,2008).' ...'It is possible to improve a family's support systems, communication and compliance or other resilience factors through a therapeutic or group intervention program in the family'.</td |
| Niyomthai et al. (2003) | Caregiving duration, family life events, family hardiness, and well-being of family caregivers of stroke survivors. | 'in this study, therefore, focusing on three components that related to the adaptation process: family life events, family hardiness, and family adaptation.'... 'In the study of family adaptation, hardiness within the context of the family as a unit is specifically characterized by a sense of control over the outcomes of the life events and hardships. Family hardiness helps a family to adjust and adapt over time. Thus, using hardiness as a family internal resource for readjustment to cope with additional changes, can reflect family adaptation'...'changing to maintain equilibrium. Hardiness may not be an "internal resource" but one that can be built.' |

Table 3*Quality appraisal QUATDSs scores for included papers*

| Authors | Theoretical framework | Statement of aims | Research setting descript. | Sample size consideration | Representative sample/ reasonable size | Description of procedure | Rationale for data collection tool(s) | Detailed recruitment data | Statistical assessment of measurement tool(s) | Fit between question and method of data collection | Fit between question and method of analysis | Justification for analytical method selected | Evidence of user involvement in design | Strengths and limitations critically discussed | Total Score (out of 42) | Total % quality score |
|--------------------------|-----------------------|-------------------|----------------------------|---------------------------|---|--------------------------|--|---------------------------|--|---|--|---|---|---|-------------------------|-----------------------|
| Scholten et al. (2020) | 3 | 3 | 3 | 0 | 2 | 2 | 3 | 2 | 3 | 3 | 2 | 3 | 0 | 2 | 31 | 73.81 |
| Anderson et al. (2020) | 3 | 3 | 3 | 2 | 2 | 3 | 3 | 3 | 1 | 3 | 3 | 3 | 0 | 2 | 34 | 80.95 |
| Simpson et al. (2021) | 1 | 3 | 3 | 2 | 2 | 3 | 2 | 3 | 1 | 3 | 3 | 3 | 0 | 2 | 31 | 73.81 |
| Shaffer et al. (2016a) | 1 | 3 | 3 | 1 | 1 | 3 | 2 | 3 | 0 | 3 | 2 | 3 | 0 | 1 | 26 | 61.90 |
| Meyers et al. (2020a) | 0 | 3 | 3 | 0 | 1 | 2 | 1 | 2 | 0 | 3 | 3 | 3 | 0 | 3 | 24 | 57.14 |
| Rasmussen et al. (2020) | 0 | 3 | 3 | 3 | 2 | 2 | 3 | 3 | 1 | 3 | 2 | 3 | 0 | 2 | 30 | 71.43 |
| Migliorini et al. (2018) | 0 | 3 | 3 | 1 | 2 | 2 | 2 | 3 | 0 | 2 | 3 | 2 | 0 | 2 | 25 | 59.52 |
| Vranceanu et al. (2020) | 0 | 1 | 3 | 2 | 2 | 3 | 1 | 3 | 0 | 3 | 3 | 2 | 2 | 3 | 28 | 66.67 |
| Meyers et al. (2020b) | 0 | 3 | 3 | 0 | 1 | 3 | 2 | 3 | 1 | 3 | 3 | 3 | 0 | 2 | 27 | 64.29 |
| Meyers et al. (2020c) | 1 | 3 | 2 | 0 | 1 | 2 | 2 | 2 | 0 | 3 | 3 | 3 | 0 | 2 | 24 | 57.14 |
| Bannon et al. (2020) | 2 | 3 | 3 | 1 | 2 | 3 | 3 | 3 | 3 | 3 | 2 | 2 | 3 | 2 | 35 | 83.33 |
| Sander et al. (2020) | 1 | 3 | 3 | 1 | 2 | 3 | 2 | 3 | 1 | 2 | 3 | 3 | 0 | 2 | 29 | 69.05 |
| Shaffer et al. (2016b) | 0 | 3 | 3 | 0 | 2 | 3 | 1 | 3 | 0 | 3 | 3 | 3 | 0 | 2 | 26 | 61.90 |
| Zale et al.(2018) | 1 | 3 | 3 | 3 | 2 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 0 | 3 | 36 | 85.71 |
| Simpson et al. (2013) | 1 | 3 | 3 | 0 | 2 | 2 | 2 | 2 | 1 | 3 | 2 | 2 | 0 | 2 | 25 | 59.52 |
| Las Hayas et al. (2014) | 0 | 3 | 3 | 0 | 2 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 2 | 2 | 33 | 78.57 |
| Hallam et al. (2013) | 3 | 3 | 3 | 3 | 2 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 0 | 2 | 37 | 88.10 |
| Carlozzi et al. (2020) | 0 | 3 | 3 | 0 | 2 | 3 | 2 | 2 | 3 | 2 | 3 | 3 | 1 | 2 | 29 | 69.05 |

Appendices

Appendix A: Neuropsychological Rehabilitation Guide for Submissions

About the Journal

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Appendix B: Database Search Terms

| | Subject Headings | OR | Free text Title Search | OR | Free text Abstract Search |
|-----------|--|-----------|---|-----------|--|
| PsychInfo | <p>[Concept of brain injury]: (DE "Cerebellum" OR DE "Cerebral Ventricles" OR DE "Frontal Lobe" OR DE "Prefrontal Cortex" OR DE "Limbic System" OR DE "Occipital Lobe" OR DE "Parietal Lobe" OR DE "Cerebrum" OR DE "Cerebral Cortex" OR DE "Rhinecephalon" OR DE "Forebrain" OR DE "Gray Matter" OR DE "Mesencephalon" OR DE "Left Hemisphere" OR DE "Right Hemisphere" OR DE "Temporal Lobe" OR DE "Cerebrovascular Accidents" OR DE "Dysexecutive Syndrome" OR DE "Encephalitis" OR DE "Encephalomyelitis" OR DE "Intracranial Abscesses" OR DE "Kluver Bucy Syndrome" OR DE "Brain" OR DE "White Matter" OR DE "Leukoaraiosis" OR DE "Brain Injuries" OR DE "Traumatic Brain Injury" OR DE "Traumatic Brain Injury" OR DE "Brain Damage" OR DE "Brain Disorders" OR DE "Head Injuries" OR DE "Brain Lesions" OR DE "Neural Lesions" OR DE "Cerebral Ischemia") AND [concept of resilience]: (DE "Openness to Experience" OR DE "Adaptability (Personality)" OR DE "Posttraumatic Growth" OR DE "Psychological Endurance" OR DE "Positive Psychology" OR DE "Resilience (Psychological)" OR DE "Hope" OR DE "Optimism" OR DE "Psychological Capital") AND [concept of caregiver]: (DE "Caregivers" OR DE "Caregiving" OR DE "Same Sex Couples" OR DE "Dyads" OR DE "Cohabitation" OR DE "Sexual Partners" OR DE "Interpersonal Relationships" OR DE "Partners" OR DE "Brothers" OR DE "Sisters" OR DE "Husbands" OR DE "Wives" OR DE "Couples" OR DE "Fathers" OR DE "Homosexual Parents" OR DE "Mothers" OR DE "Single Parents" OR DE "Stepparents" OR DE "Family Members" OR DE "Family" OR DE "Adult Offspring" OR DE "Biological Family" OR DE "Daughters" OR DE "Grandchildren" OR DE "Grandparents" OR DE "Inlaws" OR DE "Parents" OR DE "Siblings" OR DE "Sons" OR DE "Spouses" OR DE "Military Families" OR DE "Significant Others")</p> | OR | <p>[concept of brain injury]: TI (((cerebr* OR brain OR hemespher* OR "frontal" OR "temporal" or parietal or occipital OR "white matter" or "gray matter" or "diffuse axon*" OR cerebellum OR Forebrain OR Cortex OR cortical OR subcortical) N5 ((damage OR injur* OR insult* OR ablat* OR lesion* OR stroke* OR accident* OR inflam* OR death OR "penetrating inj*" OR fracture OR hypox* OR anoxi* OR ischemi* OR herniat* OR abcess* OR oedema OR swell* OR infection)) OR or stroke OR encephalitis OR hypox* OR ABI OR TBI OR CVA OR aneurysm OR neuro-ICU OR "diffuse axona*"), AND [concept of resilience]: TI (hope or optimism or resilien* or hardiness or hardin* or hardy or PTG or ((posttrauma* or post-trauma* or "post trauma*") N5 (growth)) or adapt* or "psychological adjust*" or thrive*) AND [concept of caregiver]: TI (caregiv* or care-giv* or "care giv*" or spous* or marit* or partn* or girlfriend* or boyfriend* or husband* or wife or wive* or "significant other" or significant-other or "loved one*" or cohabit* or parent* or mother* or father* or</p> | OR | <p>[concept of brain injury]: TI (((cerebr* OR brain OR hemespher* OR "frontal" OR "temporal" or parietal or occipital OR "white matter" or "gray matter" or "diffuse axon*" OR cerebellum OR Forebrain OR Cortex OR cortical OR subcortical) N5 ((damage OR injur* OR insult* OR ablat* OR lesion* OR stroke* OR accident* OR inflam* OR death OR "penetrating inj*" OR fracture OR hypox* OR anoxi* OR ischemi* OR herniat* OR abcess* OR oedema OR swell* OR infection)) OR or stroke OR encephalitis OR hypox* OR ABI OR TBI OR CVA OR aneurysm OR neuro-ICU OR "diffuse axona*"), AND [concept of resilience]: TI (hope or optimism or resilien* or hardiness or hardin* or hardy or PTG or ((posttrauma* or post-trauma* or "post trauma*") N5 (growth)) or adapt* or "psychological adjust*" or thrive*) AND [concept of caregiver]: TI (caregiv* or care-giv* or "care giv*" or spous* or marit* or partn* or</p> |

| | | | | | |
|---------|--|-----------|--|-----------|---|
| Medline | <p>[Concept of brain injury]: (MH "Brain+") OR (MH "Brain Infarction+") OR (MH "Brain Abscess") OR (MH "Brain Injuries+") OR (MH "Fornix, Brain") OR (MH "Brain Edema") OR (MH "Hypoxia, Brain+") OR (MH "Hypoxia-Ischemia, Brain") OR (MH "Brain Diseases") OR (MH "Brain Contusion") OR (MH "Brain Concussion") OR (MH "Meninges+") OR (MH "White Matter") OR (MH "Prosencephalon+") OR (MH "Limbic System+") OR (MH "Cerebral Ventricles+") OR (MH "Brain Stem") OR (MH "Intracranial Hypertension") OR (MH "Leukoencephalopathies") OR (MH "Hydrocephalus") OR (MH "Encephalitis+") OR (MH "Brain Injuries, Traumatic") OR (MH "Brain Injuries, Diffuse+") OR (MH "Brain Hemorrhage, Traumatic+") OR (MH "Basal Ganglia Diseases") OR (MH "Neuroaxonal Dystrophies") OR (MH "Stroke+") OR (MH "Ischemic Stroke+") OR (MH "Hemorrhagic Stroke") OR (MH "Intracranial Hemorrhages+") OR (MH "Cerebrovascular Trauma+") OR (MH "Brain Ischemia+") OR (MH "Intracranial Embolism and Thrombosis") OR (MH "Head Injuries, Penetrating") OR (MH "Brain Stem Hemorrhage, Traumatic") OR (MH "Gray Matter") OR (MH "Telencephalon+") OR (MH "Diencephalon+") OR (MH "Cerebrum+") OR (MH "Cerebral Hemorrhage+") OR (MH "Intracranial Hemorrhage, Traumatic+") OR (MH "Temporal Lobe+") OR (MH "Parietal Lobe+") OR (MH "Occipital Lobe+") OR (MH "Frontal Lobe+") OR (MH "Prefrontal Cortex+") OR (MH "Cerebellar Cortex") OR (MH "Cerebellum+") OR (MH "Cerebellar Diseases") OR (MH "Cerebral Infarction+") AND [concept of resilience]: (MH "Resilience, Psychological") OR (MH "Adaptation, Psychological") OR (MH "Mental Competency") OR (MH "Posttraumatic Growth, Psychological") OR (MH "Emotional Adjustment") OR (MH "Sense of Coherence") OR (MH "Psychosocial Functioning") OR (MH "Survivorship") OR (MH "Hope") OR (MH "Optimism") AND [concept of caregiver]: (MH "Family") OR (MH "Family Relations") OR (MH "Military Family") OR (MH "Grandparents") OR (MH "Adult Children") OR (MH "Sibling Relations") OR (MH "Parenting") OR (MH "Spouses") OR (MH "Siblings") OR (MH "Parents") OR (MH "Caregivers") OR (MH "Mothers") OR (MH "Fathers") OR (MH "Interpersonal Relations") OR (MH "Sexual Partners") OR (MH "Marriage")</p> | OR | sibling* or brother* or sister* or family* or couple* or dyad*) | OR | girlfriend* or boyfriend* or husband* or wife or wife* or "significant other" or significant-other or "loved one*" or cohabit* or parent* or mother* or father* or sibling* or brother* or sister* or family* or couple* or dyad*) |
| | | | “” | | “” |

| | | | | | |
|--------|--|-----------|----|-----------|----|
| CINAHL | <p>[Concept of brain injury]: (MH "Brain Injuries") OR (MH "Right Hemisphere Injuries") OR (MH "Left Hemisphere Injuries") OR (MH "Brain Diseases") OR (MH "Basal Ganglia Diseases") OR (MH "Brain Diseases, Metabolic") OR (MH "Brain Concussion") OR (MH "Brain Contusions") OR (MH "Pneumocephalus") OR (MH "Cerebellar Diseases") OR (MH "Cerebral Edema") OR (MH "Cerebrovascular Disorders") OR (MH "Encephalitis") OR (MH "Hydrocephalus") OR (MH "Hypoxia, Brain") OR (MH "Intracranial Hypertension") OR (MH "Encephalitis, Viral") OR (MH "Myelitis") OR (MH "Meningitis") OR (MH "Meningoencephalitis") OR (MH "Head Injuries") OR (MH "Skull Fractures") OR (MH "Stroke") OR (MH "Ischemic Stroke") OR (MH "Hemorrhagic Stroke") OR (MH "Stroke, Lacunar") OR (MH "Cerebral Ischemia") OR (MH "Intracranial Embolism and Thrombosis") OR (MH "Intracranial Hemorrhage") OR (MH "Cerebral Infarction") OR (MH "Hypoxia-Ischemia, Brain") OR (MH "Reperfusion Injury") OR (MH "Temporal Lobe") OR (MH "Parietal Lobe") OR (MH "Frontal Lobe") OR (MH "Occipital Lobe") OR (MH "Cerebral Hemorrhage") OR (MH "Intracranial Thrombosis") OR (MH "Intracranial Embolism") OR (MH "Brain") OR (MH "Cerebral Ventricles") OR (MH "White Matter") OR (MH "Cerebellum") OR (MH "Diencephalon") OR (MH "Limbic System") OR (MH "Telencephalon") OR (MH "Brain Hemispheres") OR (MH "Cerebral Cortex") AND [concept of resilience]: (MH "Hardiness") OR (MH "Optimism") OR (MH "Adaptation, Psychological") OR (MH "Posttraumatic Growth, Psychological") OR (MH "Hope") AND [concept of caregiver]: (MH "Family") OR (MH "Adult Children") OR (MH "Extended Family") OR (MH "Family Relations") OR (MH "Sibling Relations") OR (MH "Siblings") OR (MH "Sons") OR (MH "Spouses") OR (MH "Daughters") OR (MH "Parents") OR (MH "Mothers") OR (MH "Fathers") OR (MH "Biological Parents") OR (MH "Significant Other") OR (MH "Caregivers") OR (MH "Sexual Partners") OR (MH "Interpersonal Relations")</p> | OR | “” | OR | “” |
|--------|--|-----------|----|-----------|----|

Appendix C: QUATDSS Appraisal Tool

| Criteria | 0 = Not at all | 1 = Very slightly | 2 = Moderately | 3 = Complete |
|--|-------------------------------|--|--|---|
| Explicit theoretical framework | No mention at all. | Reference to broad theoretical basis. | Reference to a specific theoretical basis. | Explicit statement of theoretical framework and/or constructs applied to the research. |
| Statement of aims/objectives in main body of report | No mention at all. | General reference to aim/objective at some point in the report including abstract. | Reference to broad aims/objectives in main body of report. | Explicit statement of aims/objectives in main body of report. |
| Clear description of research setting | No mention at all. | General description of research area and background, e.g. 'in primary care'. | General description of research problem in the target population, e.g. 'among GPs in primary care'. | Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands. |
| Evidence of sample size considered in terms of analysis | No mention at all. | Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design. | Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements. | Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements. |
| Representative sample of target group of a reasonable size | No statement of target group. | Sample is limited but represents some of the target group or representative but very small. | Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine | Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace. |

| Criteria | 0 = Not at all | 1 = Very slightly | 2 = Moderately | 3 = Complete |
|--|---------------------------|--|---|---|
| | | | <p>what sample is required to be representative.</p> | |
| <p>Description of procedure for data collection</p> | <p>No mention at all.</p> | <p>Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.</p> | <p>States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.</p> | <p>Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.</p> |
| <p>Rationale for choice of data collection tool(s)</p> | <p>No mention at all.</p> | <p>Very limited explanation for choice of data collection tool(s).</p> | <p>Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.</p> | <p>Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.</p> |
| <p>Detailed recruitment data</p> | <p>No mention at all.</p> | <p>Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.</p> | <p>Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.</p> | <p>Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.</p> |
| <p>Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)</p> | <p>No mention at all.</p> | <p>Reliability and validity of measurement tool(s) discussed, but not statistically assessed.</p> | <p>Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test-retest reliability is unsuccessful but no action is taken.</p> | <p>Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.</p> |

| Criteria | 0 = Not at all | 1 = Very slightly | 2 = Moderately | 3 = Complete |
|---|------------------------------|--|--|---|
| Fit between stated research question and method of data collection (Quantitative) | No research question stated. | Method of data collection can only address some aspects of the research question. | Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition. | Method of data collection selected is the most suitable approach to attempt answer the research question |
| Fit between research question and method of analysis | No mention at all. | Method of analysis can only address the research question basically or broadly. | Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail. | Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc. |
| Good justification for analytical method selected | No mention at all. | Basic explanation for choice of analytical method | Fairly detailed explanation of choice of analytical method. | Detailed explanation for choice of analytical method based on nature of research question(s). |
| Evidence of user involvement in design | No mention at all. | Use of pilot study but no involvement in planning stages of study design. | Pilot study with feedback from users informing changes to the design. | Explicit consultation with steering group or statement or formal consultation with users in planning of study design. |
| Strengths and limitations critically discussed | No mention at all. | Very limited mention of strengths and limitations with omissions of many key issues. | Discussion of some of the key strengths and weaknesses of the study but not complete. | Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis. |

From: Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of evaluation in clinical practice*, 18(4), 746–752. <https://doi.org/10.1111/j.1365-2753.2011.01662.x>

Appendix D: PRISMA Checklist

| Section and Topic | Item # | Checklist item | Location of item in report |
|-------------------------------|--------|--|----------------------------|
| TITLE | | | |
| Title | 1 | Identify the report as a systematic review. | |
| ABSTRACT | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | |
| INTRODUCTION | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | |
| METHODS | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | |

| Section and Topic | Item # | Checklist item | Location of item in report |
|--|--------|--|----------------------------|
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | |
| RESULTS | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | |
| Study characteristics | 17 | Cite each included study and present its characteristics. | |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect <u>estimate</u> and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | |
| DISCUSSION | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | |
| | 23b | Discuss any limitations of the evidence included in the review. | |
| | 23c | Discuss any limitations of the review processes used. | |
| | 23d | Discuss implications of the results for practice, policy, and future research. | |
| OTHER INFORMATION | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | |
| Competing interests | 26 | Declare any competing interests of review authors. | |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be <u>found</u> : template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | |

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

Section Two: Empirical Paper

How People Make Sense of their Partner's Cognitive and Emotional Difficulties

Following Acquired Brain Injury

Word count (excluding references, tables and appendices):7758

Abstract: 199

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[†]See Appendix A in Section 1 for submission guidelines

Abstract

This interpretive phenomenological analysis aimed to understand working-aged people's sense-making of their partner's cognitive and emotional difficulties after acquired brain injury (ABI) and what impact this sense-making had on their relationship. Interviews with working-age partners of people who have an ABI formed the data, from which five interrelated themes were constructed. Themes were: (1) 'I don't know...it's a weird thing to describe': The complicated nature of ABI; (2) 'So you try and work around it': The exhausting task of taking on the extra cognitive and emotional load; (3) 'You're not the partner anymore': Finding a new relational dynamic; (4) 'It's like this ultimate patrol': The need to protect; (5) The lack of effective support is isolating. Participants who benefitted from specialist ABI support found that this often alleviated some of the cognitive and emotional load, and helped them step back from protective roles. All participants noted the heterogeneity of ABI and caregiving experiences. It was concluded that post-discharge ABI support services should be available to all partners of people with ABI to provide individualised ABI-education, support for mental health difficulties and relational support. A further recommendation was for charitable ABI support groups to be smaller, and more homogenous.

Keywords: Brain Injury, Caregivers, Sense-making, IPA, Relationship

How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury

Acquired brain injury (ABI) is among the leading causes of death and disability in people under 40 years old (Johnson & Griswald, 2017; Majdan et al. 2016). Each injury is unique with wide ranging difficulties, including neurobehavioral sequelae, cognitive, language and physical impairments (Lezak, et al., 2004). The economic cost of brain injury, including support and care related to ABI is significant (Humphreys et al., 2013; United Kingdom ABI Forum [UKABIF], 2019).

Family members (predominantly partners and parents) often become informal caregivers of people with ABI (Ergh et al. 2002; McIntyre et al. 2018). Their responsibilities vary from help with personal care to transportation, providing memory aids and even becoming their family member's rehabilitation assistants, which can sometimes mean giving up occupational roles (Turner et al. 2007). Caregivers can experience high levels of psychological distress (Kreutzer et al. 1992; Higginson et al., 2010; Laratta et al., 2020). This can include depression, anxiety (Loh et al., 2017) and post-traumatic symptoms (Meyers et al., 2020). Psychological distress is thought to affect as many as 40% of caregivers (Loh et al., 2017).

Caregivers are often studied as a group but the impact of caregiving on different family members may differ. For example, couples may experience difficulties, which are particular to them and different from parent carers, such as marital dissatisfaction, perceived loss of empathy, and increasing social isolation (Anderson et al. 2009; Godwin et al., 2011; Kratz et al., 2017; Yeates, et al. 2013). A recent survey from a UK ABI charity, Headway (2018) found that as many as 38% of romantic relationships broke down after one partner sustained an ABI; lack of understanding of the injury and social isolation of the uninjured

partner were considered key contributors to relationship breakdown. Furthermore, a review of studies looking at the divorce rate and separation after one partner had had an ABI found a range of 15-78% (Godwin et al., 2011). Those with more severe injuries were more likely to be divorced or separated (Kreutzer et al., 2016), and both older age and greater length in relationship prior to the injury were found to be protective factors (Kreutzer et al., 2007). Grigorovich et al. (2015) also found that younger partners of people with strokes who need increased assistance with day-to-day activities were less likely to participate in wellbeing-keeping activities than older partners. These caregivers were then more likely to be depressed and had lower levels of mastery compared to older caregivers.

Kreutzer et al. (2016) considered marriage stability and relationship distress, rather than divorce rates or relationship breakdown in the earlier stages after ABI. Out of 42 partners of people with ABI (80% of which were less than 3 years post-injury), 29% rated their relationships as unstable and 50% felt that their relationship was in distress. The authors concluded that more research was needed to explore the experiences of those whose marriage was stable, but in distress. Lesser-known cognitive sequelae of the ABI such as difficulties in emotional control (irritability and anger), personality and mood changes create increased strain on relationships (Brooks et al. 1986) with reduced deficit awareness are also a source of tension among affected couples (Yeates et al. 2007).

Cognitive models (e.g. focused on attribution theory (Heider, 1958; Kelley, 1971; Weiner, 1979) or family resilience (McCubbin & McCubbin, 1996)) may go some way to explain factors which predict partners' relational distress. However, such models often do not address the in-depth experience of couples including relational and contextual factors. Whiffin et al.'s (2021) meta-synthesis of families' experiences after TBI shows the importance of drawing on subjective experiences, which can reveal more complex and often contradictory positions co-existing when understanding and adjusting to TBI.

In order to take an active role in rehabilitation, gain a sense of mastery and engage in a process of adjustment, people must first have an understanding of the underlying cognitive and emotional problems experienced by their partners with ABI. This will help them to develop skills and strategies to overcome problems in an effective way. It is well documented that information about ABI sequelae is one of the most unmet needs for ABI caregivers (Manscow & Arntzen, 2018), with many unaware of the cognitive sequelae of their partner's injuries until after discharge home from hospital (Perry & Middleton, 2011). However, gaining such knowledge and skills takes place within complex circumstances, while potentially negotiating change in the couple relationship (Bowen et al. 2010) as well as wider family, work and social life (Daisley et al. 2014; Gracey et al., 2009).

Consequently, this study will take a qualitative approach to gain an insight into partners' perceptions, understanding, and beliefs about cognitive and emotional sequelae after ABI and how they cope within the couple relationship. Doing this will help us learn how best to meet these needs in the partner population. The research question for this study is, therefore: how do people make sense of their partner's cognitive and emotional difficulties following ABI? This study focusses on the experience of working age partners of people living with ABI.

Method

Ethics

Ethical approval was granted by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (see Appendix A).

Design

Interpretative phenomenological analysis (IPA) was chosen as an appropriate methodology because of its phenomenological roots and focus on in-depth, individual

experiences of people who share a common life experience (Smith, Flowers & Larkin, 2009). ABI is a unique experience, requiring a methodology that is sensitive enough to capture the individual meaning-making experience, as well as that of the collective. In trying to understand how partners of people with ABI make sense of the injury, the researcher interprets participants' interpretations (the double hermeneutic; Smith, 2004).

The researcher collected data using semi-structured interviews. These loosely followed an interview schedule, including eight topic areas, to keep the interview close to the research question, while allowing conversations to flow naturally. Demographics included questions based on the Mayo classification system for traumatic brain injury (TBI; Malek et al. 2007), alongside questions about day-to-day difficulties, to judge ABI severity. Open-ended question prompts were included to promote rich responses (Ogden & Cornwell, 2010) in line with the IPA approach (Smith & Osborn, 2003). An expert by experience and field supervisors reviewed the study materials for the appropriateness of their content and level of understanding.

Participants

Partners of people with ABI were recruited using purposive sampling, from independent neurorehabilitation practices and online advertising.

Participants had to:

1. Live with their partner who had a moderate-severe ABI acquired in working age (below 67), with cognitive difficulties that affect day-to-day functioning.
2. Have been in a relationship with the person before their ABI.
3. Have been with their partner for at least one year before the interview.
4. Live in the UK and speak English at a sufficient level for an hour-long interview.

Partners with ABI / cognitive impairment themselves and partners of people with degenerative brain injury/ disease were excluded.

Six participants were recruited. Four came through neurorehabilitation professionals and two responded to the Twitter advertisement (see recruitment). This is sufficient for IPA (Murray & Wilde, 2020). A description of participants and their partners with ABI are presented in Table 1. Two participants were male and four were female. All were in heterosexual relationships. At the time of injury, the mean age of participants was 35 (Range: 26-57), four participants had children under the age of 10 and two had no children.

[TABLE 1 HERE]

Procedure

Recruitment

A staged recruitment method was adopted. Stage 1 involved recruitment from independent ABI and neurorehabilitation organisations (January 2021-December 2021). Neurorehabilitation professionals were contacted via email. Client-lists were screened for potential participants against inclusion criteria. Professionals discussed the project directly with clients and researcher details were passed on, or participant details were passed to the researcher to arrange a time for interview.

For stage 2 a study advertisement was posted on a professional twitter account and promoted to various neurorehabilitation and ABI agencies (June 2021-December 2021).

Participants who expressed interest were sent study documents via email, and an interview was arranged if participants consented.

For stage 3 the researcher attended some third sector ABI family support groups to discuss the research with potential participants. No partners in these groups met the inclusion criteria.

Data collection

Consent was gained and recorded via Dictaphone, by reading the consent form over the telephone (n=5) or Microsoft Teams (n=1). These files were recorded separately from interviews. After ensuring participants had a private space, they were interviewed by the researcher, using their chosen medium. Interviews lasted 1h17m on average (Range = 54m to 1h44m) and two interviews were split into two sessions.

Analysis

Data was analysed by the author, following guidance from Murray and Wilde (2020). All interviews were transcribed verbatim, before starting the coding process. The first interview was re-listened to and re-read to facilitate immersion in the data. Initial coding of transcript one was completed, keeping as close to the participant's words as possible (see Appendix B). Then initial codes were transferred into Microsoft Excel, where an iterative process ensued, of grouping codes into 'thematic threads'. Once individual participant themes were developed, an interpretive, narrative summary of each theme was written (Appendix C). Once the first participant's narrative summaries were completed, this process began again with the second interview, and so on. The final phase included merging individual themes (Appendix D) across participants, using a similar iterative process of grouping, to produce the final IPA themes.

Rigor

Following Yardley's (2008) guidelines for high quality qualitative research three supervisors with expertise in neurorehabilitation and an expert by experience enhanced sensitivity to context, ensuring the project was suitable for the intended audience and remained relevant to the context of working age adults. To ensure commitment, rigor and sensitivity in data analysis, extracts of the first transcript, and interpretive paragraphs were read through by one supervisor, with expertise in IPA, and resulting themes were discussed with two supervisors (Yardley, 2008). Reflexivity is also an important part of qualitative research to ensure transparency (Dodgson, 2019; Yardley, 2008). The author is female and in the same age category as the participants interviewed here. She has worked in the field of ABI rehabilitation for six years and has been an informal caregiver to a family member, living with traumatic brain injury, since adolescence. She had no prior research interview experience. A reflective journal used throughout the process helped bracket researcher reflections to keep as close to the participant experience as possible. Participant quotes were also used to illustrate themes and audit trails were utilized for transparency (Yardley, 2008).

Results

The analysis culminated in five inter-connected themes of how people made sense of their partner's cognitive and emotional difficulties following ABI. They were: (1) "I don't know...it's a weird thing to describe": The complicated nature of ABI; (2) "So you try and work around it": The exhausting task of taking on the extra cognitive and emotional load; (3) "You're not the partner anymore": Finding a new relational dynamic; (4) "It's like this ultimate patrol": The need to protect; (5) The lack of effective support is isolating.

Theme 1: ‘I don’t know...it’s a weird thing to describe’: the complicated nature of ABI

A central theme through all of the narratives was the complicated nature of ABI. Participants expressed their struggle in understanding their partner’s cognitive and psychological difficulties, especially when thinking about how the two interacted. This began at the hospital, continued when their partner came home, and for some, the struggle was apparent in the interview.

Several participants discussed feeling completely perplexed by the invisible nature of the cognitive and emotional changes in their partner, particularly at the beginning. Anna captured this when talking about how she did not believe the neurorehabilitation team, when warned of the difficulties she might face if Adam left the unit before rehabilitation completion:

I was seeing the Adam that was fighting to do these sessions [neurorehabilitation], he didn’t seem to have fatigue, you didn’t see it, no. He was like, ‘no, I’m going to prove to you, you’re wrong (Anna)

She then reflected: *‘Oh my god, they were so right. It was so right. Last year [when he came home], was the worst year ever’ (Anna)*

Anna's reflections on seeing Adam in the hospital, seemingly at his best, was in complete contrast to how she saw him on returning home. Her use of ‘oh my god’ added stress to her point, highlighting the contrast to the listener, and the shock she felt at the realization that the rehab professionals’ perception was different to hers. She then went on to repeat this ‘it was so right’, further emphasizing a disbelief that she did not see the changes before this time.

Several participants shared that even when they were aware of some of their partner's cognitive difficulties, it was still a challenge to tease apart what was what. David highlighted this when trying to understand Anila's distress while in rehabilitation:

I would say it was sort of twofold...maybe there's more, probably more angles than that. So, basically, it was a combination of, er, being in an environment she didn't really understand, away from her family...yeah...and being, discovering that she was severely disabled, right? That's probably the first part...secondly, she had incredible...at that time, her memory was very, very severely impaired... (David)

It is clear here that David was sense-making-in the moment of the interview. Putting himself in Anila's shoes, he gained an empathic insight into how different aspects of Anila's injury and her environment exacerbated her distress. This showed an added complexity and understanding of the interweaving of the biological, the psychological and the social, which many of the other participants recognised; it is not all about the ABI, but the injury does make things harder to tease apart than they would have been before the injury. An example of this is from Maggie, who expressed her continued confusion many years after the injury:

Sometimes he just forgets. Or he just can't be bothered, one or the other...I don't know. Is he forgetting? Or is it he can't be bothered? You know? (Maggie)

The statement at the beginning showed a confidence in her sense-making. Another option followed this, not obviously linked to the injury, introducing doubt. Finally, Maggie settled her confusion 'I don't know.' Maggie repeated her questioning of the motivation for Dennis' behaviour, implying a struggling to square this, further emphasized by her

questioning directed to the listener. This illustrated the confusing nature of the injury effects, in the moment of the interview. This was a sense shared by most of the other participants - the journey to understanding the cognitive and psychological difficulties was one that is ongoing.

Strategies participants used to understand the cognitive and emotional changes were similar. All participants discussed a strategy of researching ABI: Anna, Rebecca, Eliza and Maggie all explicitly mentioned that they read around it, with an important emphasis on this being targeted, *'I didn't want to look at all of the brain injury side. I want to know what my husband's going to suffer with'* (Anna). David and Maggie both went on specific training that would go on to help their partners on the return home and nearly all participants mentioned a strategy of working with their partners to understand difficulties through their point of view.

Theme 2: 'So you try and work around it': the exhausting task of taking on the extra cognitive load

Participants felt the need to take on the extra cognitive load to help their partners manage day-to-day with their post-ABI difficulties. This often felt challenging and tiring. Most participants talked about an arduous trial and error approach to finding what worked, and this led to some sense of adjustment, but all continued to exert more effort, which made it more difficult to cope when other, normal stressors came up.

Because of the complicated nature of ABI, all the partners found the rehabilitation journey was one of trial and error. William talked about trying to find a satisfactory cognitive compensation strategy for Hannah's planning difficulties, and trying everything he could think of:

Ok well, I'll keep on trying that, but I'll take a bit of that [advice from others]...and we'll do this as well. (William)

Here, William indicated that something he tried initially was useful enough to keep some of, but that this was not completely effective, hence, 'I'll take a bit of that'. William went on to explain that he managed to build an external compensatory strategy so Hannah did not need him to go through common, every-day activities for her. Whenever something new needed planning however, he would need to take on this cognitive load again. Similarly, Maggie reported some adaptation to her role of needing to take on extra cognitive load to compensate for Dennis' struggle with emotional control post-ABI:

He don't like the word 'no'. If you say no, you know you're gonna get show off. So you try and work it round it. It's not a 'no', but it's not a yeah. And I've got ways to... do that like, because I've been doing it for so long...I had to put in it like 'Dennis terms' like so he wouldn't get angry. (Maggie)

Again, it seems the extra level of processing has evolved over time. 'I've been doing it for so long' implied an arduous journey of feeling her way through; a trial-and-error to find her current strategy, which she felt had now become a part of her. There were other examples however, where Maggie showed the relentless nature of taking on the extra load, 'You have to be one step forward with it all the time', in reference to Dennis' lack of risk awareness. Maggie found that she could not leave Dennis alone, through fear that he would come to further harm. The effort needed for this extra level of processing was also captured nicely by Eliza:

And it's certain things, which is quite frustrating, like I'll say to him, 'just grab the soya sauce out of the cupboard'. That wasn't good enough. I have to tell him in which cupboard, on what shelf and what... (Eliza)

Eliza illustrated the difference between how she would communicate with Anthony pre-ABI and how she now needed to break the process down for him, in real-time, to help her with the cooking. This process of having to adapt her communication felt draining. Rebecca felt similarly, in terms of frustration and expressing limited energy stores, when talking about Richard's difficulties with executive function:

I think of that frustration of he's, he's not cleaned the kitchen or you know he's not cooking dinner or whatever it is that I want him to do, and still struggling with that acceptance of me needing to be the one who kind of drives and organizes things, because I don't have that much headspace. (Rebecca)

Rebecca captured the exhausting nature here, of having to adopt the extra layer of processing for Richard, while also in the midst of her own battle between frustration and acceptance. There was a sense of futility in Rebecca's struggle. She used the word 'acceptance', implying a belief that Richard's difficulties were not going to change. Her sense-making of the struggle was that she had little 'headspace' and this induced a feeling of being stuck. This was something other participants experienced, especially when thinking about spreading of cognitive and emotional resources:

I would say that her [Anila] and Joseph [teenage son] have conflicting needs and it is impossible for me to fulfill both their needs equally...before, I would say that it was like

90-10 in Joseph's favor... and now it's probably more like 60-40 in Anila's favor, right? Maybe 70-30 in Anila's favor. (David)

Many of the participants shared that sense of simply not having the headspace when something else came up, particularly parents. Again, there was an underlying sense of a limited amount of emotional and cognitive energy, and that adapting to the changes in the partner takes a large proportion of this. William was not a parent, but thinking about having another person, needing a large proportion of his care, was something that felt nigh on impossible. There was a sense of sadness, and heaviness in his quote, and the ending felt as though there was not the capacity or headspace to process this.

The thought of just having kids and then having to cope erm, with looking after Hannah and a kid...Erm, it doesn't really bear thinking about. I try not to think about it too much. (William)

Theme 3: 'You're not the partner anymore': finding a new relational dynamic

While all participants saw a change in the relational roles, some compared the cognitive and emotional difficulties in their partner to those one might see in children, and saw their role change to one that seemed more paternal. For others, there was a felt sense of the partner being someone different but some parts remained the same. Nearly all participants discussed being in a state of figuring it out and finding a future together.

It sounds stupid say, but I tret Hannah very much like she was their age [young siblings]. (William)

Three participants talked about taking on more of a parental, nurturing role and there was typically shame around naming this, as above in William's quote. He noted later that this changed the dynamic in his and Hannah's relationship, 'it put a little bit of a strain on the relationship' before going on to describe the dynamic as one of 'teacher...child' and avoided the use of parent-child, perhaps because of the discomfort of this in a relationship, which was built on romance. Others similarly made this comparison of the injured partner to a child, to readjust slightly later:

Actually, with children, you might be more tolerant and let them make their mistakes and that. (Eliza)

You know, in order to parent, you've got to...contain your child's emotions and he can struggle with managing his own emotions...You know, I have to contain his emotions so that he can contain hers. (Rebecca)

Eliza and Rebecca both acknowledged here that their role was not entirely a parent-child one; Eliza described that she would treat a child differently, perhaps having more patience and flexibility if she were working with a child. Rebecca acknowledged that Richard is also a parent, and that she had to take a similar role towards him, so that he could take this role with their child. Although a parental strategy made sense, it did not fit well in terms of adjustment of the couples. This highlighted the complexity of the relational dynamics these partners found themselves in. Both felt the loss of the co-operative partner, the co-problem solver; there was now increased effort needed for the injured partner to partake, whereas

before, having this relationship would have reduced the cognitive effort through joint working.

Anna also shared this sense of loss of the pre-injury partner, and despite the role not feeling parent/ teacher-child, she expressed that Adam was and was not the same person: *'So I knew that my Adam was still in there'* (Anna); *'I sit and cry about who I've lost. I mourn him again.'* (Anna)

This sense of Adam being Adam, but not, was something that Anna grappled with throughout the interview, and emphasised the complicated nature of how the cognitive and emotional difficulties had changed him. On the one hand, Anna mentioned several times that Adam's 'soul' was the same, and on the other, there was a fundamental loss of the person he was pre-injury. Anna showed an understanding of Adam's sense of threat in this identity change, and the creation of a new, separate identity to Adam was formed to help her make sense of it, by naming the injury.

He's a part of us now, we are, we are threesome now, we are thruple, he isn't going anywhere. [ABI's name] is around until the end of Adam's days now. (Anna)

All participants discussed being in a process of finding a way forward, a new relational dynamic and Anna captured this nicely:

You know it's some sort of normality which we're just trying to find at the minute, like what's our new normal? (Anna)

Here presents an interesting juxtaposition; Anna acknowledged that they were searching and trying to hold on to a sense of 'normal', while at the same time acknowledging that things will be different. Some hope is felt, that this 'different' will become the new

normal, with the use of ‘we’, ‘us’ and ‘our’ suggesting that it will be a venture of co-operation. Other participants held a similar sense of keeping something, which tied them together pre-injury: laughing and sharing jokes was important (Maggie, Eliza, William and Anna), finding intimacy where they could (Maggie, William, David, Eliza) and communicating through problems, sometimes with the help of external support (Maggie, Rebecca and Anna).

Theme 4: ‘It’s like this ultimate patrol’: The need to protect

Many of the participants appraised the cognitive and emotional changes as making their partner more vulnerable in some way, forcing them (the participant) into the protective role. Anna captured this when she reflected on Adam’s time in the hospital:

I was like a lioness, and they probably all hated me, but they were, they weren’t doing the things that they should have been doing, so I was, you know people with brain injuries shouldn’t be left for long periods without loved ones and stuff, because they do sort of get left, and nobody takes them seriously because they’ve had a head injury.
(Anna)

The metaphor of ‘lioness’ provided a striking image of Anna as a ferocious guard. Her comment about the service staff probably hating her reinforced an idea that she was, in some way a nuisance in her constant vigilance. She then went on to explain her reasoning; she felt that Adam was not taken seriously, and left by staff because of his ABI, and that loved-ones were in a place to defend and advocate for their partners while they were unable to do so for themselves, for lots of different cognitive and emotional reasons. This was

something that generally followed participants through their journeys. David talked about how Anila was treated in a care facility:

To her, a party is at a club with drinks. Do you know what I mean? You, you don't put on party hats and string...this is ridiculous, she's disabled, she's not 4...to me, it's obvious, but it's not obvious to the majority of the world (David)

Again, David felt the need to advocate for Anila at the care facility she was in at a later stage in her ABI journey. He felt carers were infantilizing her because of her language difficulty and physical disabilities. There was an undertone of anger in David's words, similar to the image of Anna's 'lioness'; 'this is ridiculous' implied a sense of deep offence and the acknowledgement that this was not obvious to others reinforced his need to protect. It also gave the sense, almost, that if he did not protect, nobody else would, and this is exhausting; he described it as 'a relentless white noise'. It was this protective role, which several participants felt was one of the drivers for information seeking:

I did read up a lot and then I'd done a course on brain injury... 'cause...people were just being horrible to him and saying horrible things and I just wanted to be able to say to them, "but hang on a minute"... (Maggie)

Thus, Maggie felt that in order to protect Dennis, she needed to equip herself with understanding and knowledge.

Theme 5: The lack of effective support is isolating.

Most participants found that the complicated nature of ABI left them isolated, in terms of help to understand their partner's injury, a sense of empathic connection with others, and support for themselves. Nearly everyone acknowledged the heterogeneity of ABI:

With the brain injury, I think everybody is different...and different areas are affected differently. Some people have different, like reactions, or learning curves. (Eliza)

With this acknowledgement was an understanding that this might be the reason that effective support was so scarce, especially in statutory services:

I definitely don't think there's any guidance anywhere, I'm not even sure what that guidance would look like...which would never happen because there's never any funding for people... (David)

David suggested having services with 'exceptional' multi-disciplinary teams could help to manage the complicated nature of ABI, so that the families could simply take the family role and feel safe doing so. David had a positive experience with case management¹, where someone else managed Anila's care:

She's just continued to be phenomenal ever since [she started]. The, the fact that she's so good, has made me comfortable to step away, more so than perhaps I might have

¹ Case management is not part of NHS routine care in the UK. Case Management services sought by participants in the current study were sourced as part of ongoing litigation proceedings.

done. It's quite a hard thing to relinquish [control] when you care so much about somebody. (David)

'Continued to be phenomenal ever since' implied that throughout their journey, David had been surprised at how well the case manager supported Anila; she had surpassed expectations, and this has built enough trust for David to be able to step away from his protector role. 'Relinquish' almost sounded like a cautious 'letting go', an anxious letting go; David certainly used the word 'trauma' throughout to describe his and Anila's experience.

In contrast, Anna highlighted some areas of positive support after a period of feeling isolated in her role:

Then I go speak to my psychologist about it and they can sort of say "well this is how the brain works" and "this is what might have been damaged" and "now this is, this is now where, what we can do to work on this" (Anna)

support groups on Facebook...which is where, you know where people living and breathing the same things that I am living and breathing and who better to talk to to find...what works for whom then the people themselves (Anna)

Both quotes highlight the importance of finding people who really understand ABI, both from a professional and experiential point of view. Anna talked about psychology being pivotal in understanding her husband's cognitive difficulties and the use of 'we' showed a feeling of collaboration in thinking about strategies. The latter quote highlighted the benefits of shared experience for her. While most of the participants used support that Headway, an ABI charity, offered, nearly all commented on how these did not quite fit with their age, their

partner's injury, or status as a young partner, rather than a parent of someone who lives with ABI. Maggie found that an online group with thousands of people sharing a similar, complicated experience, was important for her wellbeing. She explained that they were on hand to help whenever she needed it, and she did not have to explain the difficulties, which she found, in itself, tiring. For those without this, loneliness was a common theme:

Yeah, we're all pretty different...It can make it quite hard sometimes to be honest, it's quite isolating. (David)

Many of the other themes tied into the feeling of loneliness that participants felt. The complicated nature of the injury, and lack of support to foster understanding (theme 1), the exhaustive nature of having to take on extra cognitive load, reducing time spent with loved-ones (theme 2), the loss of the decision-making/ planning/ empathic partner (theme 3), and the constant vigilance and protection role (theme 4), born from the sense that there is nobody else, who will take care of their significant other as well as they will. All this energy spent elsewhere left very little for self-care and help-seeking.

Discussion

This study has explored how people made sense of their partner's cognitive and emotional difficulties following ABI and found five interconnected themes.

The first theme related to how participants often found the cognitive and emotional difficulties related to the ABI difficult to understand and describe. This was regardless of the time since the injury and despite their efforts to gain understanding through a variety of sources. Previous research has identified similar themes including the invisibility of the

cognitive difficulties in ABI, and the complexity this brings for families (Atienza, 2020; Chamberlain, 2006; Saban et al., 2015). Similarly, "naivety" about these hidden difficulties is found elsewhere, particularly in the early stages of ABI (Jumisko et al. 2007), as is the shock of seeing a more realistic picture once the person is discharged home from the structured environment of the hospital (Nalder et al. 2012; Perry & Middleton, 2011; Fraser, 1999). The current work extends these findings to show that the sense-making is similar in working-aged partners of people with ABI and continues for years after the injury.

A similar theme of relational complication (theme 3) and ABI understanding is seen in a recent study exploring how wives of people with ABI make sense of change in their husbands: 'Lost and trapped in an unsolvable maze' (Ghosh-Cannell et al, 2022). The 'unsolvable maze' and 'lost' fit with the experience of some of the participants here, particularly Anna, Maggie and Rebecca. Similarly, to some participants in the current study, the perceived cognitive and emotional difficulties post-ABI changed the partner and the relationship, making some feel 'trapped'. Overwhelmingly for the majority of participants here, however, the sense was not one of 'trapped' but more of evolution, of growth, together as a pair – more in line with post traumatic growth (Tedeschi & Calhoun, 1995; Lyon et al., 2021). This was also evident in some participants from Ghosh-Cannell et al. (2022), where 'a new normal' was also mentioned in the theme 'Bravery to face changes'. This sense of growth more accurately mirrors the themes of 'relational identity reformations' and 'Nos omnes moriar' (Not all of us has died; Godwin et al. 2014). Here, participants are also holding onto parts of the relationship and pre-injury partner, which are still evident, while at the same time working out what has changed and why, as well as what works and what the new relationship looks like.

The loss some current participants described, of the pre-ABI partner and relationship, in the third theme, is 'ambiguous' (Boss, 1999). Similarly to Lond and Williamson (2020) and

Godwin et al. (2014) this loss is complicated, as the person with ABI is still living and in the majority of cases, still very recognisable. This is particularly difficult for the working-age participants in this current research, who are already shouldering many different responsibilities such as building careers and child rearing (Kreutzer et al., 1994). It is thought that the loss of this power-equivalent partner for some of the participants here makes everyday problems more difficult to manage. This supports Kreutzer et al.'s (1994) hypothesis that the loss of the 'peer-based reciprocal relationship' might be adding to emotional distress in couples, as compared to parents in their study. Time and energy are finite resources; with more spent understanding and compensating for their partners' difficulties (theme 2) and taking on different, more vigilant and protective roles (theme 4), there is less for their own help-seeking and emotional management.

In the fourth theme, many of the participants felt as though their partners were more vulnerable in some way because of their cognitive and emotional changes. This perception often started in the hospital, where many participants took on this protective role. Similarly, participants in Piccenna et al. (2016) and Oyesanya & Bowers, (2017) typically felt that their family members were not cared for adequately. For some participants in the current study, this role continued through their journey, and seemed to be one of the drivers for information seeking.

The final theme encapsulated the isolation participants felt in the sense-making process, with little support available. The sense for many was one of being forgotten; in most cases, participants took a step back from their own needs and self-care in favour of those of their partners. This sense of isolation is nicely captured in the 'isolating narratives' in Whiffin et al.'s (2021) meta-synthesis of experiences of family members after TBI. It is also not uncommon in the non-UK ABI caregiver literature (Piccenna et al. 2016). Some participants in the current study explicitly stated that there was no obvious effort of statutory services to

try to help them to understand their partner's injury in the acute stages. This led to many researching ABI for themselves, and accessing third sector services, in the longer-term, which were not typically tailored towards partners either.

The results here do not fit neatly into attributions theory (Heider, 1958; Kelley, 1971; Weiner, 1979) or the Stress-Appraisals model by Lazarus and Folkman (1984). These are primarily structured models of how people make attributions about a stressful situation, and how this affects emotion.

The Y-shaped model of rehabilitation after brain injury (Gracey et al. 2009), is a more natural fit to the current findings and describes a cyclical process of how an individual with ABI adapts and adjusts during rehabilitation. While it is focused primarily on the individual with the injury, it is important to recognise that when one partner in the relationship has an ABI, the lives of both are changed. The model takes into account the 'current context' of where somebody is with regard to their goals and relationships and an 'Aspired-to-self' which can be an 'Ideal Self' but is more typically, the 'Pre-injury self'. Discrepancy between the current context and the aspired-to-self contributes to psychological distress or 'self under threat'. The emotional journey to the 'adapted self-representation' and 'identification of new self-meanings and identities' comes through a cyclical process of understanding the injury through information sources, making predictions about what they are able to do, planning activity (including goals and steps), completing it, and reflecting on how it went.

After ABI, it makes sense that uninjured partners also go through a similar period of adjustment, and have to navigate the 'relationship under threat' in a similar, cyclical way, as Bowen et al. (2010) highlight in their chapter, which adapts the Y-shaped model to relationships. The results in the current paper map onto this adapted Y-shaped model. Participants were not typically aware of the change to their partner, or relationship in the early ABI stages. As more time passed, participants realised significant changes in their

partners, which were experienced as complicated and confusing (theme 1). This affected the relationship and their place in that relationship (theme 3; theme 4), causing threat to the 'relational identity', as it was compared to the pre-ABI relationship. Participants strived to understand cognitive and emotional difficulties using different resources. They planned and tried various strategies to compensate for them, using a trial and error procedure, and a continuous reflection to find what worked best (theme 2), alongside holding complex and changing attributions. Participants and partners often worked together in this process. Some had the help of case managers, psychologists, family and ABI charity support groups, who helped partners through this cyclical process to reduce the discrepancy between the relationship in the distressed state and the ideal, pre-injury relationship. Those that did not have this often felt very isolated in this journey (theme 5). All participants reported this journey as a continuous one and discussed a hope that this process would lead to a 'new normal', or the 'adaptive, realistic self-representation'.

Limitations and future research

The largest limitation of this research is possible heterogeneity of the sample. Ensuring the shared participant phenomenon is as similar as possible is important in IPA (Smith, Flowers & Larkin, 2009; Murray & Wilde, 2020) and thus heterogeneity could be seen as a threat to Yardley's (2008) principle of "commitment and rigour" for the research. Here, although all the participants were of working-age and living with a partner with an ABI, with whom they were in a relationship before their injury, there were some arguably important differences. For example, differences in having children (also at different ages), type of injury, and approximate area of injury. Differences were typically captured in individual themes, which did not fit with the collective enough to make it into the final themes. The difference in the experiences per ABI cause were not explored here and would

perhaps be a beneficial avenue to explore in future research, as evidence has shown that cause of ABI can change attributions of neurobehavioral sequelae (Redpath & Linden, 2009).

Finally, some participants came through private rehabilitation clinicians and had typically received private professional support. This leaves the potential for a biased sample.

Clinical Implications

A main finding in the current study is that uninjured partners find ABI difficulties confusing (theme 1), and this continues for years post-injury. This would suggest that additional information should be provided to uninjured partners to help them make sense of the difficulties. This is not an uncommon finding (Dahdah, 2016; Smith & Smith, 2000; Walker et al. 2021). Research examining caregiver education interventions have shown variable results (Hart et al., 2018; Kreitzer et al., 2018). Those that are active in nature and catered to the individual show more success in helping caregivers to understand difficulties, which fits with the results of the present study (theme 1). They also tended to yield better neuropsychological rehabilitation outcomes for people with ABI, because caregivers were able to take a more active role in rehabilitation, which seemed important to the participants here (theme 4; Forster et al. 2012; Zhang, Zhang, & Sun, 2019). Given the complexity and heterogeneity of caregiving partners, a 'one-size fits all' approach is not appropriate for this population (Cameron, 2021).

What seemed to be most helpful, for those that could access it, was the use of person-centred, specialist services such as neuropsychology, care co-ordination and case-management. Good case management took pressure off participants, helping them to step back from their protective roles (theme 4), and removing the extra cognitive load included in keeping track of appointments and arranging care (theme 2), which left more time and energy to invest in family and relationships (theme 3). Case managers were also described as large supports for uninjured partners (theme 5). This is consistent with wider literature about ABI

caregiver experiences (Turner et al. 2010). Neuropsychologists were portrayed as important for emotional and relational support (theme 5), and a profession that was able to effectively 'translate' some of the post-injury difficulties to uninjured partners after discharge (theme 1). They were also effective in helping to develop strategies with uninjured partners (theme 2). There are a number of international studies highlighting the positive impact of specialist, tailor-made support after ABI (Braaf et al. 2019; Cameron, 2021; Kanmani et al. 2021). Although this support has to be consistent (Braaf et al. 2019). Most participants discussed the importance of such support being available for them long after discharge from the hospital. This long-term post-ABI support is not typical in the UK however, despite ABI caregiver research from the USA, Australia and the UK, highlighting this need (Abrahamson et al., 2016; Foster & Degeneffe, 2019; Kitter & Sharman, 2015; Murray et al., 2006; Turner et al. 2010).

Most participants mentioned the ABI charity, Headway; one of the UK's leading ABI informational and support resources. Despite Headway being a place where injured individuals and uninjured family caregivers can come together, the majority of the working-age participants in this study felt that the typical demographic in their areas were not quite right. This often left them feeling more overwhelmed and isolated. Rethinking how support groups are formatted may be useful - Anna in particular found that having access to a larger group online, with a wide variety of family caregivers of different ages, helped her to feel less isolated and more understood. There is some evidence that peer support benefits caregivers of people with brain injury (Wobma et al., 2016). While there is strength in local area groups (allowing face-to-face interactions), perhaps the evolution in online technology, forced in the COVID-19 pandemic opens doors for more national and diverse support for people. Online platforms would allow ABI groups to be more personalised and catered to individual groups.

Further research is also needed to explore the effectiveness of online peer-support groups for caregivers of people with ABI.

Other highlighted gaps in services were relational support following ABI and finding appropriate mental health support for injured partners. The young partners here experienced a change in the dynamic of their relationships, which was felt as a direct result of the ABI and the sense-making of the resulting cognitive and emotional difficulties. Yeates et al. (2013) reviewed neuropsychologically informed couples interventions after ABI, which showed some positive outcomes. Further research is recommended to explore newer neuropsychologically informed couples' interventions and their effectiveness.

Additionally, for the participants that did seek mental health support for their partners, finding appropriate support in statutory services was experienced as exacerbating exhaustion. Some talked about feeling stuck in a cycle of being bounced from service to service, because few felt adequately resourced to manage the added complexity of ABI, and not meeting strict criteria for specialist ABI services (Odumuyiwa et al., 2019). This reinforced the idea of the injury being highly complicated and further added to feelings of isolation and exhaustion. This picture is also highlighted by Holloway et al.'s (2019) participants, who talked about the lack of specialist services and ABI knowledge in non-expert medical and mental health professionals in the UK. They found that sourcing appropriate support was something of a battle. In light of this, primary and secondary psychological services should be trained in ABI, or mental health services, as a whole, made less segregated and more cohesive.

Conclusions

This study sought to understand what sense people made of their partner's cognitive and emotional difficulties following ABI. Five themes emerged, which fitted with the Y-shaped model of rehabilitation after brain injury, and described how partners struggled to

make sense of post-ABI difficulties, years later. Uninjured partners dedicated significant time and energy in the sense-making process, typically adopting a trial and error-type strategy, which was experienced as exhausting. Elements of relational change, ambiguous loss, isolation, adaptation and working in partnership were also captured. Further research is needed around neuropsychologically-informed relational support after ABI and the effectiveness of couples' interventions. Clinical implications include easier access to longer-term, specialist post-ABI services such as neuropsychology and case management, non-expert medical and mental health professional training around ABI difficulties, and increased availability of more homogeneous peer support groups.

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Tables

Table 1

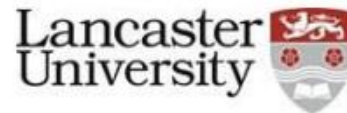
Further details about each participant and their partner with ABI

| | Participants* | Partners | ABI type | Time since Injury (Years) | Relationship Length pre-ABI |
|---|------------------|----------|-----------------|---------------------------|-----------------------------|
| 1 | William (Male) | Hannah | TBI | 5 | 1 |
| 2 | Anna (Female) | Adam | TBI | 2 | 11 |
| 3 | David (Male) | Anila | Brain tumour | 7 | 10 |
| 4 | Maggie (Female) | Dennis | TBI | 15 | 1 |
| 5 | Eliza (Female) | Anthony | TBI | 5 | 15 |
| 6 | Rebecca (Female) | Richard | Neuro-infection | 3 | 7 |

*** Pseudonyms were used to replace all names at the time of transcription.**

Appendices

Appendix A: Letter of Ethical Approval



Applicant: Hayley Butler
Supervisor: Fiona Eccles; Will Curvis
Department: DHR
FHMREC Reference: FHMREC21012

28 September 2021

Re: FHMREC21012
"How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Traumatic Acquired Brain Injury."

Dear Hayley,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "T. Morley".

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

Appendix B: Example of Initial Coding of Interview

[Included for examination but will be removed for final submission to preserve anonymity]

Appendix C: Theme 1 for Eliza. Cognitive changes are confusing: ‘He looked normal’ audit trail

[Included for examination but removed for final submission to preserve anonymity]

Example of theme 5 for Eliza: The frustration and exhaustion of the extra layer of processing audit trail

[Included for examination removed for final submission to preserve anonymity]

Appendix D: Illustration of how individual themes fit into the final themes (Colour Key of final themes underneath)

| Maggie and Dennis | William and Hannah | Rebecca and Rich | David and Anila | Anna and Adam | Eliza and Anthony |
|---|---|--|--|---|--|
| "You have to be one step forward with it all": post TBI difficulties mean Dennis is more vulnerable | "All of a sudden someone comes and erm takes it away from you." | "There is a lot of, probably what I use in my work, that I apply" | "I want to feel normal": Protecting Anila and Joseph from full the Impact of the injury: an ongoing challenge | "Hit by the brain injury train": The unpredictable emotional toll | Cognitive changes are confusing: "He looked normal" |
| "What's he going to do next time?": Less predictable and Feeling Unstable | Questioning: brain injury impacting relationship, or normal relational progression? | "Looking back...we were...naïve": Sense making over time | Attuned to Anila: Beyond the cognitive difficulties - the interweaving nature of the biological, the psychological, the social and the emotional | Health professional input to sense-making wasn't always helpful | Trying to tease apart what is cognitive change and what is emotional |
| Post-TBI changes are generally confusing | Navigating the role change: "pushing to help Hannah help herself"; you'll thank me when you're older" | It's complicated: it's not all about the cognitive difficulties | Support for Partners to make sense: "It's so Isolating" | Shifting perspectives/ seeing the world through Adam's eyes | Getting all the gears into motion: "I know you have to make things happen" |
| Being the one that has to adapt: "So you try and work around it" | Constant persistence: "I'll try it again tomorrow" | Support to help with things as a bit of a mixed bag | Understanding the changes through time: "they condition you to not expect something until after it's happened." | Grappling with Adam's identity - Adam but not Adam | "we went round and round...before we found our road" |
| "What about me?"; "It is lonely, a lonely place. Very lonely" | "I still feel I am largely to blame" | "Having to take on...": Wrestling with frustration, shame and acceptance - experienced as exhausting | "It's like this ultimate patrol... being Anila's champion at all times" | "I was like a lioness" | The frustration and exhaustion of the extra layer of processing |
| Psychology: "helped me...to like try and keep myself sane" | | | | Drawing on others to help make sense of the post-TBI difficulties | |
| Navigating the sudden change to the relationship | | | | Fighting together | |
| Looking with a compassionate eye | | | | | |

Final Themes of the Empirical paper

| | | | | |
|--|--|--|---|--|
| 'I don't know...it's a weird thing to describe': the complicated nature of ABI | "so you try and work around it": The exhausting task of taking on the extra cognitive load | "you're not the partner anymore": Finding the new relational dynamic | "it's like this ultimate patrol": Becoming the protector | The lack of effective support can be isolating |
|--|--|--|---|--|

Appendix E: COnsolidated criteria for Reporting Qualitative research COREQ

Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

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

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|--|----------|--|----------------------|
| Domain 1: Research team and reflexivity | | | |
| <i>Personal characteristics</i> | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 2-8 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 2-1 |
| Occupation | 3 | What was their occupation at the time of the study? | 2-1 |
| Gender | 4 | Was the researcher male or female? | 2-9 |
| Experience and training | 5 | What experience or training did the researcher have? | 2-1 |
| <i>Relationship with participants</i> | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 2-9 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 4-35 |
| Interviewer characteristics | 8 | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 2-9 |
| Domain 2: Study design | | | |
| <i>Theoretical framework</i> | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 2-6 |
| <i>Participant selection</i> | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 2-6 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 2-7 - 2-8 |
| Sample size | 12 | How many participants were in the study? | 2-7 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | 3-8 |
| <i>Setting</i> | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 2-8 |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | 2-8 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 2-7 |
| <i>Data collection</i> | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 2-6 |
| Repeat interviews | 18 | Were repeat interviews carried out? If yes, how many? | N/A |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 2-8 |
| Field notes | 20 | Were field notes made during and/or after the interview or focus group? | 2-9 |
| Duration | 21 | What was the duration of the interviews or focus group? | 2-6 |
| Data saturation | 22 | Was data saturation discussed? | N/A |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | No |

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|--|----------|--|----------------------|
| | | correction? | |
| Domain 3: analysis and findings | | | |
| <i>Data analysis</i> | | | |
| Number of data coders | 24 | How many data coders coded the data? | 2-8 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | 2-8 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 2-9 |
| Software | 27 | What software, if applicable, was used to manage the data? | 2-8 |
| Participant checking | 28 | Did participants provide feedback on the findings? | NO |
| <i>Reporting</i> | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 2-10 - 2-22 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 2-22 - 2-30 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 2-9 - 2-22 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 2-26 |

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

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

Section Three: Critical Appraisal

Word count (excluding references): 3,854

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Critical Appraisal

This appraisal is written in addition to sections one and two of this thesis. It will appraise both the author's quantitative literature review and empirical study, extending discussion about strengths, limitations, future research and clinical implications. It will also address some of the author's personal reflections on the work.

1 Main Findings

1.1 Literature Review

The literature review aimed to synthesis and appraise the quantitative evidence relating to resilience and related constructs (RARCs), namely resiliency, posttraumatic growth and hardiness, in caregivers of people with acquired brain injury (ABI). Inclusion criteria included: Papers must have explored RARCs in caregivers of people with ABI and used a measure of RARCs. Papers also must have used some statistical analysis with said measure. The review showed that higher rated RARCs were typically associated with positive outcomes in caregivers of people who have an acquired brain injury (ABI), and lower levels were associated with poorer outcomes. Positive outcomes elucidated were positive affect, quality of life (general and health-related), positive aspects of caregiving and positive mental health. Poor outcomes were typically psychological distress (anxiety, depression and posttraumatic stress symptoms), caregiver burden and poor quality of life. The review also highlighted the lack of a clear and consistent definition of both resilience and resiliency constructs in the ABI caregiver literature, and this was reflective of research in wider resilience literature (Tusaie & Dyer, 2004; Windle et al., 2010; Windle et al., 2011; Aburn et al., 2016).

1.2 Empirical Paper

The empirical paper focussed more narrowly on partners of people with ABI and their experiences of the sense-making process of the cognitive and emotional difficulties following the injury. The paper found five main themes, which all surrounded the complicated nature of ABI for uninjured partners. Uninjured partners typically felt exhausted by having to work out how to compensate for some of the changes in their injured partner through scaffolding and enhanced communication, and this often left less time for other caring responsibilities and their own help-seeking. Partners also discussed their journey through the changed relationship and how they adapted to new roles, with help from professionals being valued for half of the group who were able to access and engage with this work. Finally, nearly all uninjured-partners felt isolated in their journey of sense-making.

2 Research Decisions, Strengths and Challenges

There were many decision-making points throughout this thesis. These decisions formed some of the strengths and challenges of the above research papers. Points of decision were carefully discussed with my research supervisors and field supervisors. Some of the main decision points are outlined below, along with their strengths and challenges and my reflections through this process.

2.1 Literature Review

It was not until searching the wider literature on resilience that I realised the word ‘resilience’ was such a controversial term in psychological research, because of its lack of a coherent definition (Ayed et al., 2019). I had read a few papers about the protective effects of resilience in caregivers of people who have had a brain injury, and knew that I wanted my review to collate all the quantitative data in this area. After reading the review by Ayed et al. (2019) and their conclusions about the construct being confused in some research with PTG,

hardiness and Resiliency, I decided to use these terms in my own search. This led to the ‘resilience and related constructs’ (RARCs) of the literature review.

A university research librarian was approached to help with what to include in the search terms. They advised that I search the databases for subject headings related to all my main search terms, to ensure that I included papers under those, and related topics. This did lead to lots of papers, which were not relevant, to appear in the search results, because of the wide scope of the search. It is believed that the search was sensitive enough. Evidence for this was found in the second phase of searching the literature – reference searching. This search identified another three papers, which met the pre-defined criteria. These papers were not found in the original search due to the particular naming of the population of people with brain injury as “neurocritical care patients” and “neuroscience-ICU” (Meyers et al., 2020b; Zale et al., 2018; Shaffer et al., 2016a). All of these studies came from one research hospital in the United States.

I decided, eventually, to include intervention studies in the review to strengthen the results. One of the main limitations of cross-sectional research is that it lacks directionality; that is, for many studies it is unclear if what the study is measuring causes the outcome, or if the outcome makes what the study is measuring possible. Including intervention studies (even though the only ones completed in ABI caregivers were interventions increasing resiliency skills and hardiness), helped to give some directionality, and show that increasing resiliency skills improved outcomes.

One of the limitations of the review was that I decided not to include papers written in languages other than English. All titles and abstracts from chosen databases had English translations, and two papers in the full paper screen were not in the English language. I read these papers through Google Translate’s camera function before excluding them. Although these papers did not appear to fit the inclusion criteria, it is acknowledged that words such as

‘resilience, resiliency, PTG and hardiness’ are less common in everyday language, which may be mistranslated more easily. These papers were not translated professionally due to funding constraints. It is also acknowledged, that there may be words in different languages that either explain these constructs more clearly, or there may be additional, different and more nuanced words that do not translate into the English language, which the original search would have missed.

Another possible limitation with the scope of the search was the decision not to include theses as these have not been through the peer review process. The search found four theses by doctoral students which met all of the other criteria. I tried to see if these had been published, as most were completed before 2019, but I could not find any that had. Another reason theses were not included was due to time constraints; theses are not all electronically stored, and it was beyond the scope of this review to hand-search theses and dissertations from individual universities to ensure all relevant work was captured.

2.2 Research Paper

2.2.1 Strengths

The empirical paper is one of the first, to my knowledge, exploring in-depth how working-aged partners of people with ABI (both men and women) understand the cognitive and emotional difficulties in their injured partner. This is important because it is this population that is evidenced to have the most unmet needs from services following ABI (Perry & Middleton, 2011; Nabors et al., 2002). Outside of military research, working-age partners are suspected to be one of the most difficult populations to represent in ABI research. This difficulty likely concerns the many external pressures and stressors, such as having younger families and full-time occupations on top of their ABI supporting roles (Turner et al., 2010). It is also a strength that the current research included the voices of male partners of females who had an ABI. Male voices as carers are also typically

underrepresented in the literature (Ghosh-Cannell et al., 2022) and further research may be beneficial, to highlight experiences of male partner caregivers in particular.

The empirical study used interpretative phenomenological analysis (IPA), which in itself, has abundant strengths as a methodology. The brain is a highly complicated organ. Brain injury, causing changes in cognitive and emotional function is still something that researchers, clinicians and scientists still do not fully understand. IPA has its epistemological roots in phenomenology. It is more towards the relativist pole, as opposed to that of the realist (Dempster & Hannah, 2015) and takes more of a ‘critical realist’ approach (Smith, 1994). There is an underlying assumption that a reality can be perceived, but different people view and understand this reality differently, depending on their lens of the world. Thus, this approach allows for idiographic accounts, which one would expect to see, when trying to understand experiences of people who are living day-to-day with something as unique as a brain injury.

Using this methodology, allows us to interpret the sense-making process of these nuanced cognitive and emotional difficulties through the eyes of people who are likely to know the person with ABI closest. Gaining a sense of how people make sense of their partner's difficulties, and how this impacts them, can help us to evidence what is needed to best support them. The use of Yardley's (2008) criteria for quality in qualitative research helped to ensure the quality and validity of the results here.

2.2.2 Recruitment and data collection

Finding participants who met the inclusion criteria was very difficult. The empirical project went through two amendments to the original approval due to the difficulty in finding people who met the original, and narrower criteria. Originally, I had hoped to seek partners of people with traumatic brain injury (TBI), as this was the most likely brain injury, which younger people (under the age of 40; National Institute for Health and Care Excellence

[NICE], 2019). I originally also sought partners of people who were between 20 and 40, however, only one person meeting this criterion came through all of the recruitment methods I employed. It was important to me to keep the focus of the research on younger uninjured-partners, as they are particularly under-represented in the ABI caregiver literature (Turner et al., 2010). I increased the age criteria in May 2021, to allow people who were older than 40, to talk about their experiences retrospectively. Following this, I extended the criteria to include partners of people with other types of brain injury in August 2021 and I increased the age again to include all people of working age in order to recruit more people into the study.

I decided to recruit through private neurorehabilitation professionals as a first point of call for several reasons. Firstly, for practical reasons. The COVID-19 pandemic started at the time of seeking ethical approval for this project and NHS ethics boards were only accepting projects related to COVID-19 for review at the end of 2020. It was because of this (as well as not knowing when other, non-COVID-19 projects would be reviewed) that I decided against seeking NHS ethical approval to recruit through neurorehabilitation hospitals. Secondly, anecdotally, third sector groups such as ABI charities had been primarily attended by older caregivers of people with ABI, and it seemed as though younger people steered clear of these support groups for this reason. Working-age participants in my thesis supported this. Finally, private neurorehabilitation professionals were likely to see many young people with ABI, as this younger population is one of the specific groups which traumatic brain injury (TBI) is more likely to affect, particularly young males (Majdan et al., 2016; Yates et al. 2006).

Despite this avenue of recruitment, teamed with online advertising and through third sector local support groups facilitated by UK brain injury charity, Headway, recruitment was slow. It is thought that online recruitment (primarily due to local COVID-19 restrictions) impacted this somewhat. Many of the neurorehabilitation professionals, however, reported

that they struggled to find people on their caseloads, who met all of the criteria. Most people seemed to be young adults without a partner, or whose partner had left, or people who had partners were over the age limit for the study. Some professionals reported that they did have uninjured-partners who met all of the criteria, but they were on caseloads because they were in an emotionally difficult place in the brain injury journey, and it was felt to be unethical to approach them to take part in research.

Another recruitment challenge was the time taken to complete interviews. Three people contacted via email to express interest in being involved with the study, however, declined to take part after learning that the data was collected using interview. All three reported that they were uncomfortable with being interviewed, but would have been happy to fill out a questionnaire. One hypothesis for younger people being unrepresented in the literature was that they might struggle for the time, considering other care-giving demands (perhaps young families) and needing to manage occupational roles on top of their caregiving roles. It is possible, that this was a reason it was so difficult to recruit younger partners in this work.

One of the challenges of recruiting through the third sector and online was ensuring that participants' partners met the inclusion criteria for having a moderate-severe brain injury. Severity classifications are primarily used for TBI and measures assessing these have many limitations (Hawryluk & Manley, 2015; Saatman et al., 2008). There are also different categorisations for stroke (Hage, 2011). The severity criteria was included to keep the sample as homogeneous as possible as it sought to find partners of people who needed help with day-to-day activities. When participants did not come through case-management, severity was operationalised by the type of help people with ABI needed day-to-day. This was addressed by asking questions, in the demographic part of the interview schedule, which were based

loosely around the most used classification systems (Mayo Classification system; Malek et al. 2007)

2.2.3 Participants

A few possible limitations of the present empirical study comes from the method of recruiting through the private sector, where four participants were identified. These individuals had sought and received help beyond that of the statutory services, and in fact, even people recruited via Twitter had accessed private services. Private services are relatively costly, and are typically inaccessible for people from low-income backgrounds, outside of insurance and litigation cases. Although IPA does not seek to generalise the experiences of people concerned in the study to a wider population, it is a particular aspect of the present participants worth noting. It may be that the sample of participants here represent, primarily, people who have received care over and above what the majority of people would receive from statutory services.

Several other important differences between participants are worth discussing. For example, some of the participants had small children, some had older children no longer at home, and one did not have any children. This difference may have influenced the way that some participants made sense of the cognitive and emotional difficulties in their partner, how they approached these difficulties, and perhaps how these difficulties affected the relationship. It was noted throughout the analysis however, that themes crossed all three of these groups. That is, each theme was contributed to by participants in all three groups. Another large difference between the participants was the type of brain injury their partner sustained. There were some differences between participants in terms of their sense-making based on the approximate areas of damage and in how injuries were sustained. These differences tended to not to be interpreted and discussed in the findings of the main research

paper due to the small scope of the project, however, this would be an interesting avenue for future research.

Some might argue that the number of participants in the empirical study is small. Due to the nature of IPA and the focus on depth of data rather than breadth, smaller samples are thought to be more appropriate because of the richness of results (Murray & Wilde, 2020). Including more participants, while perhaps capturing a greater breadth of experience, may have resulted in some of the richness of the current six participants being diluted. Smaller numbers of participants in the current study should not be viewed as a limitation. IPA does not seek to generalise findings to other partners of people who have had an ABI, but rather to explore in depth the views of a homogeneous sample. The plethora of quantitative research showing contradicting outcomes of this population, teamed with the complicated nature of ABI in, and of itself, is perhaps argument enough that any experiential findings in ABI are, by their nature, never fully generalizable. Indeed, this was an argument made by many of the participants here.

3 Clinical Implications

A clinical implication which I will take forward in my clinical work was born from participants' shock on being exposed to the cognitive and emotional changes in their partner once they left the structured environment of the hospital. This was omitted from the main paper due to it being discussed elsewhere in the literature (Turner et al., 2007; Turner et al., 2009; Young et al., 2014). This helped me to think about how we, as services in the UK, can sometimes set a false idea about what life will be like for informal caregivers once their loved ones leave the support of statutory services. In the empirical paper, Anna in particular talked about how she had not prepared herself for Adam's discharge, despite warnings of how difficult things might be from the rehabilitation team. Structure can be important for people who have had a brain injury, to help compensate for cognitive difficulties, however, we have

perhaps not thought thoroughly enough about the impact on informal caregivers. While considering how to create a realistic expectation about some of the possible difficulties for them post-discharge, it is also important to consider the positive effects of hope. The importance of hope is illustrated in the literature review here (hope accounted for significant variance in caregiver resilience, and acts as a mediator of the relationship between resilience and positive outcomes), and qualitative research including family caregivers of people with TBI (Keenan & Joseph, 2010; Nalder et al., 2012). This project has helped me to understand the importance of balancing realistic expectation, while also allowing for hope. This will be something I will take forward, if I should decide to continue in the field of neuropsychology.

In addition to the clinical implications of the empirical paper of this thesis, particularly the implication around online homogenous peer support groups, there is increasing evidence of greater support needed for caregivers of people with ABI following the COVID-19 pandemic. Although COVID-19 did not form a major theme in the current research, some participants talked about its impact on post ABI services (for those recently post-ABI) and support services. This is an emerging picture, beyond the participants here (Lester et al., 2021). A survey, run by Headway (2020), of 933 people with brain injury and 121 partners highlighted that 50% of respondents lost 'vital rehabilitation input' over lockdown. Additionally, 24% felt that lockdown affected their relationships in a negative way. Furthermore, 30% felt their relationship with family had been impacted and 37% of friendship relations. This is important in view of the findings of the literature review, where social support was found to be an important predictor of resilience in caregivers of people with ABI. Another important finding was that 70% of surveyed partners felt their stress levels had increased in lockdown. This more recent research further strengthens the case for better and more accessible peer, and professional support.

4 Personal Reflections

4.1 Empirical Paper

I chose this project because of my passion for clinical work in neuropsychology. I have a personal history with brain injury; a close family member had a moderate-severe TBI when I was in my teenage years and I became their primary caregiver. Because of this, I had an early awareness of some of the difficulties post-ABI and I identified with many of the experiences of the participants in the current study. I have also worked in the field of neurorehabilitation prior to embarking on the DClinPsy, both as an assistant psychologist and a support worker. It was during this work that my awareness of the impact of ABI on the family system increased. I was struck by difficulties partners and families were facing and how little they had been invited into sense-making processes.

I kept a reflective diary after each interview, which included my initial feelings and brief thoughts about each participant's experience. Some of this work helped me to bracket initial thoughts and feelings, when I came to the coding process. Keeping a reflective lens throughout helped me to see when I was being pulled to different participants' experiences. This was important because I noticed this might have influenced the individual themes I created and the quotes I chose, as well as why I was feeling guilt about not including some people as much as I would have liked (I often felt as though I could have written individual papers on the experiences of each of the uninjured-partners here as there was so much data and their experiences had important and unique elements which inevitably could not all be captured in the final themes). After coding the first interview and developing initial thematic threads, I found it useful to check this process with my research supervisors. Talking through each thread then framed the interpretive paragraphs, in line with this stage in Murray and Wilde's (2020) IPA process.

I noticed another difficulty during interviews. I found that I was switching between the clinical psychologist hat and the researcher hat. Some interviews were emotionally more difficult than others and I felt a pull to jump into my clinical role. This was more prominent when relational and emotional difficulties were disclosed and the difficulty people expressed with accessing appropriate services. Using supervision was helpful in managing this.

4.2 The Research Process

Prior to embarking on the thesis project, I felt a deep sense of dread and fear about conducting research. The doctoral thesis was felt to be a hurdle to overcome, before never again dipping my toes into the research-conducting pond in the future. I can say now that overall I have thoroughly enjoyed the vast majority of the project process, both the quantitative and the qualitative. I think the initial fear may have stemmed from the idea of research needing to be ‘new’ and ‘innovative’, finding out what is unknown, to then fill that knowledge gap. This was something that, at the beginning, seemed like a huge, unboundaried, almost void-like task. I have since learned, with the help of some stellar supervision, that there is actually a very logical, and systematic process by which research is conducted. I found that I felt comfort in this process, a comfort that has helped greatly in a job, which can otherwise be filled with uncertainty. I can now safely say that this project has given me the confidence and inclination to continue to contribute to the world of research going forwards.

5 Conclusion

Presented throughout these chapters are a quantitative, systematic literature review and a qualitative empirical paper. Both are centred around caregivers of people with have a brain injury. Strengths and limitations have been explored, as well as important clinical implications and future research suggested. It is felt that both papers improve the current knowledge around caregivers’ sense-making of cognitive and emotional difficulties after

ABI, and how caregiver RARCs can influence positive and not-so-positive outcomes following ABI. Through the conduction of this research, I have also learned valuable lessons to take with me into (hopefully) qualified life, and the pivotal and guiding role of research in clinical practice.

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Section Four: Ethics Proposal

Ethics proposal for the empirical study:

***How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following
Acquired Brain Injury***

Word count (excluding references, tables and appendices): 5213

Hayley Butler

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

May 2022



. Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

Guidance on completing this form is also available as a word document

Title of Project: How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury.

Name of applicant/researcher: Hayley Butler

ACP ID number (if applicable)*:

Funding source (if applicable)

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects. **Complete sections one, three and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:

E-mail: h.butler5@lancaster.ac.uk

Telephone: 07854192463

Address:

Division of Health and Medicine

HI One

Lancaster University
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LA1 4YW

3. Names and appointments of all members of the research team (including degree where applicable)

Hayley Butler, studying for DClinPsy
Dr Fiona Eccles, DPhil, DClinPsy
Dr Will Curvis, DClinPsy, MSc
Dr Alan Gray, DClinPsy, MA
Dr David Todd, DClinPsy, PgDip

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete FHMREC form UG-tPG, following the procedures set out on the [FHMREC website](#))

PG Diploma Masters by research PhD Thesis PhD Pall. Care
 PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD
 DClinPsy SRP [if SRP Service Evaluation, please also indicate here:] DClinPsy Thesis

4. Project supervisor(s), if different from applicant:

Dr Fiona Eccles, Research Supervisor
Dr Will Curvis, Research Supervisor
Dr David Todd, Field Supervisor
Dr Alan Gray, Field Supervisor

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Fiona Eccles, Lecturer, Lancaster University
Will Curvis, Clinical Tutor, Lancaster University
Alan Gray, Clinical Psychologist
David Todd, Clinical Psychologist

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date: _____ End date: _____

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

The data will be formed from Interviews with participants about these experiences. These interviews will be approximately one hour long. These interviews will be recorded onto a Dictaphone and then transcribed

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? N/A

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

This research aims to gain an understanding of people's experiences of having a partner with cognitive impairment caused by ABI. In particular we want to learn about the non-injured partner's understanding of such difficulties, how that influences their day-to-day life with their partner, if they had an opportunity to learn about the specifics of their partner's acquired cognitive deficits and if so, how this understanding aided their appraisal of their partners' behaviours or helped them to facilitate their partner's rehabilitation journey.

It is hoped that this will give us an understanding of the wider benefits of teaching partner caregivers about cognitive problems in the early stages of adjustment and recovery following ABI, outside of the inpatient rehabilitation environment. It also hopes to highlight which neuropsychological impairments partners find most difficult to cope with and or/ understand, as well as techniques and skills which people have found helpful in maintaining their psychological wellness and relationships with partners who have suffered an ABI.

2. **Anticipated project dates (month and year only)**

Start date: 01/2021

End date: 05/2022

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Due to the qualitative design and use of interpretive phenomenological analysis [IPA]), I plan to use purposive sampling to recruit between 8-12 partners of people who have sustained a TBI, as is a typical size for an IPA study (Smith, Flowers & Larkin, 2009; Townshend & Norman, 2008; Shotton, Simpson & Smith, 2009) .

Inclusion criteria:

Participants must have:

1. A partner, living with them, who has sustained a moderate to severe ABI (see 'recruitment' section for details on how this is ascertained)

2. Been in a relationship with the person with an ABI prior to their injury

3. Been with their partner for at least 1 year before the interview to allow for relationship development. This is in line with other research in this area e.g. Crewe-Brown, Stipinovich & Zsilavec (2011).

4. Their partner's injury must have happened while they were of working age (below 67) in order to keep the sample homogenous.

5. The person with ABI must have neuropsychological/ cognitive impairment(s), which affects day-to-day functioning, caused by the ABI.

6. A base in the UK. Using an IPA approach, the sample needs to be as homogeneous as possible; people rehabilitating in different countries are likely to have vastly different experiences to those rehabilitating in the UK.

7. A level of spoken English sufficient for an hour-long, in-depth interview about experience due to the limitation of the primary researcher's skill in languages other than English and the lack of research funds to cover the costs of an interpreter.

Exclusion Criteria

1. Partners who have their own ABI / cognitive impairment
2. Partners of people who also have a degenerative brain injury/ disease as it is expected that the experience of living with a partner whose cognitive and behavioural sequelae will become gradually worse will be different.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

There will be a staged, purposive recruitment process in order to ensure that enough participants are recruited into the current study, stages are outlined below.

Independent Neurorehabilitation Organisations

The first stage will focus on recruitment from independent brain injury and neurorehabilitation organisations. Inclusion and exclusion criteria will be shared with neuropsychologists, clinical psychologists, psychological clinicians and head admin staff at the organisations. They will then screen the couples with which the clinicians/ organisations are currently working, and those they have worked with in the past, using these criteria, including severity of brain injury, which will have been already determined and part of their clinical information, and provide study packs, including the participant information sheet, consent form and principal investigator contact details (non-personal) to those who meet them. Participants can then choose to contact the researcher directly or give their consent to contact to the clinician or organisation, who will then pass the participant's details to the researcher via Microsoft Teams. On first contact with the participant, if they wish to proceed, verbal consent will be gained and an interview date will be arranged. This will be done by reading out the consent form and asking them to confirm that they understand each point on the form (see Appendix B on 'Research Protocol' for detailed view). The gaining of consent will be recorded separately and then stored securely on the university secure drive/or university approved cloud storage, e.g. OneDrive. I will make the participant aware that the interview will last approximately 60 minutes.

Charity Organisations

If not enough participants are gained using the above recruitment method and coronavirus restrictions allow, I will attend Brain Injury Charity meetings (online or in person, as Covid restrictions permit), where people with brain injuries and their carers seek support, network and socialise, in the North West, to hand out study packs to partners of people with ABI.

People who are interested in taking part will indicate this to me directly either in the meeting, or afterwards. I will then check to see if they meet the study criteria. Potential participants will be eligible to take part in the study if they identify that their partner has cognitive problems that have a functional impact on activities of daily life.

Should there be further restrictions due to COVID-19 which mean that these meetings cannot take place in person, I will ask to attend any online meetings and/or request that an advertisement (Appendix A in 'Research Protocol') be placed in their regular newsletter and on their social media

pages (Twitter and/ or Facebook) with my contact email address for interested parties. Should potential participants get in touch to express interest via email, I will gain their consent to be contacted via telephone at this time, in order to check that they meet the study criteria in the same way as the above and discuss the study with them.

Case management and Occupational Therapy Companies

At the same time, alongside recruitment from charity organisations, I will widen the scope of recruitment to case management and independent occupational therapy companies who specialise in brain injury rehabilitation. I will provide a copy of the inclusion and exclusion criteria to these organisations so that case managers and occupational therapists can screen their caseloads for couples who meet them. Partners can then express their interest to take part directly to the case managers, occupational therapists or case management/ Occupational Therapy organisation, who will gain consent for the principal investigator to contact them to arrange a suitable time and date for interview. I will also ask that case management companies, occupational therapy and independent brain injury rehabilitation organisations place a study advertisement in their regular newsletters and on their social media pages (Appendix A in 'Research Protocol'). This will invite potential participants to get in touch with me by email and I will then telephone the potential participant. On this telephone call, it will be ensured that the partner meets the inclusion criteria and does not meet the exclusion criteria. If the participant is unaware if their injured partner's injury was moderate or severe, this will be judged functionally, as above in the 'charity organisations' recruitment procedure.

Social Media – Twitter

Concurrently to the professional organisation recruitment, A professional twitter account will be set up in order to tweet the social media advertisement in appendix A. I will then request that professional/ charity organisations and other twitter users re-tweet the advertisement so that it reaches a wider audience. On first contact with the potential participant, I will check that they meet the study criteria in the same way as the above and discuss the study with them, before gaining their consent to participant as outlined above, and arrange an interview date with them

If people who are interested in taking part, but are not eligible because they do not meet the study criteria, they will be informed about the reasons why they are not eligible and the importance of having a homogeneous group of participants will be emphasised. I will also offer a copy of the results if they are interested. If I should get a bigger response than expected in a small time-frame, I will prioritise those in the younger age-bands, in order to keep the sample as homogenous as possible and because younger samples are underrepresented in the literature.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Design

The design of the proposed study is a qualitative one, using interpretive phenomenological analysis (IPA) as the research methodology. IPA is the most appropriate methodology for the research question because it is focussed on the in-depth of experiences of people who share a common life experience (Smith, Flowers & Larkin, 2009). Here all have a partner who has sustained a TBI, which has caused cognitive deficit that impacts on their day-to-day functioning.

The aim is to gain an in-depth understanding of how people make sense of their partner's brain injury, what is the understanding of the cognitive impact and how this affects their partner, and how they themselves cope with those impacts. It is understood that the epistemological underpinning of IPA is one of phenomenology: each person interprets their world to form their reality. In trying to

understand how partners of people with brain injury make sense of that injury, I am interpreting their interpretations (the double hermeneutic, Smith, 2004). Throughout the research, I will use audit trails and a reflective diary to ensure that I can bracket my own reflections so that I am keeping as close to the participant experience as possible.

Materials

I will be making use of semi-structured interview to look for similarities and differences in participants' accounts. I will be using an interview schedule to guide the interview and ensure that questions asked are primarily open, in order to promote deep and rich responses, (Ogden & Cornwell, 2010) in line with the IPA approach (Smith & Osborn, 2003).

I will be collecting some basic demographic data about the sample: age, gender and ethnicity of both partners occupation of participant, length in relationship, family situation (i.e. living with children and/ or parents), cause of injury and time since their partner's injury. I will also ask some questions based loosely on the Mayo classification system for traumatic brain injury (Malek et al. 2007), such as time spent unconscious, time in hospital, approximate length of post traumatic amnesia (the length of time partners noticed confusion and memory problems) to gain a sense of injury severity, I will also ask about the types of difficulties their partners have day-to-day, to gain a sense of the severity of other brain injuries as well as sources of current and past support (such as brain injury rehabilitation). This will be gathered at the start of the interview.

Data collection

Once an appropriate time has been agreed for interview, I will give the option of using telephone for interviews or use of Microsoft Teams internet software. Verbal consent will be gained to participate as well as consent to being recorded. Participants choosing to use MS Teams will be made aware that the safety of interviews over the internet cannot be guaranteed, however, MS Teams uses end-end encryption and is the best option freely and widely available It will be made clear to them that the primary researcher will be conducting interviews in a private space, and that they should also try to ensure a private space in which to be interviewed.

Participants will be interviewed using their chosen medium for approximately 60 minutes, using the interview schedule as a guide. All interviews, both phone and Teams will be recorded using a pickup device and a dictaphone.

I will transcribe the interviews verbatim. Transcriptions will be completed using the Lancaster university VPN and stored using password protect on OneDrive or the University secure drive (H Drive) – both encrypted, separate from the recordings.

Transcribed data will be viewable by myself and my research supervisors.

Proposed Analysis

Interviews will be re-listened to, read and re-read in order to become immersed in the data (Smith & Larkin 2014).

I then plan to code each transcript, identifying topics of importance, keeping to the participant's own words as much as is possible. I will then summarise these to develop emergent themes. I will then look at all the emergent themes across the transcript to see if there are any that recur or are similar, and use these to form subordinate themes. After I have coded all the transcripts this way, I will look across the transcripts to see if there are any superordinate themes that come out of the data, keeping a note of key quotations to evidence these themes. These will be cyclical processes.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Data Storage: Interviews.

Interviews will be recorded separately using a pickup device and Dictaphone for telephone interviews or using Microsoft Team's audio recording facilities for interviews conducted via Teams. After the interview is recorded, I will transfer it to the university's OneDrive and password protect it. This is accessed on a personal laptop through the university's virtual proxy network (VPN). Due to the dictaphone not being an encrypted device, transference to the above, secure location will be done as quickly as is possible. Until then, the dictaphone will be kept in a secure location. After transfer to OneDrive, the recordings will be deleted from the dictaphone. It is anticipated that the storage space for 12 audio recorded interviews will not exceed 10GB. Interview recordings will be kept until the DCLinPsy has been completed and fully examined, at which point, it is the responsibility of the main researcher to destroy these recordings.

Data Storage: Transcriptions and Consent Recordings

Transcripts and consent recordings will be kept securely on OneDrive, in separate files (also separate from the interview recordings) and with separate passwords until the DCLinPsy course is complete. They will then be securely transferred to Sarah Heard, the DCLinPsy research coordinator who will store them for 10 years or 10 years from publication, whichever is longer, under the direction of supervisor Fiona Eccles. They will then be destroyed.

Transcribed data will be viewable by myself and my research supervisors.

7. Will audio or video recording take place? no audio video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

All audio files will be stored only in OneDrive or the University secure drive (H Drive). The dictaphone used to record telephone interviews and consent is not encrypted however, I aim to move the audio files directly from the dictaphone to the University OneDrive or H drive as soon as a WiFi connection can be established; the dictaphone will be kept in a secure location until transfer to OneDrive is possible. Any audio recordings will then be immediately removed from the dictaphone. OneDrive has end-to-end encryption.

Interviews will be recorded separately to consent recordings and both of these will be stored separately in OneDrive with different passwords.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings of the interview will be kept until the end of my course, after the completion and grading of the thesis, when they will be deleted from OneDrive. I am responsible for the deletion of these.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

After the end of the DClinPsy course, transcripts and consent audio recordings will be securely transferred to Sarah Heard, the DClinPsy research coordinator who will store them for 10 years from the end of the course or 10 years from publication, whichever is longer, under the direction of supervisor Fiona Eccles. They will then be destroyed.

8b. Are there any restrictions on sharing your data ?

For the purposes of publication, due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request. Access will be granted on a case by case basis by the Faculty of Health and Medicine.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

At the start of the interview I will gain verbal consent over the telephone or Teams. I will do this by reading out the consent form and asking them to confirm that they understand each point on the form (see Appendix B on 'Research Protocol' for detailed view). The gaining of consent will be recorded separately and stored securely on the university OneDrive. Participants will have access to the consent form for information purposes in advanced of the interviews, so participants can see what they are agreeing to.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Confidentiality

I will be alert to any safeguarding issues that present during interviews. I will be informing participants that the standard safeguarding applies i.e. if anything they say in the interview makes the researcher concerned about their safety or that of somebody else, confidentiality may have to be breached and risks reported to the appropriate agencies such as support agencies, health services, or mental health organisations to reduce those risks. This is stated clearly in the information sheet and consent form.

Possibility of Participant Emotional Distress

Because the interviews are semi-structured and led by the interviewee in some respects, there may be scope for some of what comes out of it to be emotional or anxiety provoking for participants. I will remain vigilant of changes in facial/ emotional expression and tone of voice (telephone) and use active listening and therapeutic skill to manage the situation should this arise during interviews; the interview will be stopped, the participant given time and then they will be asked if they wish to stop their participation in the study, reschedule the interview, or continue after a break. Should

participants need further support, I will refer them to the organisations and recourses included in the participant information sheet (Appendix C in 'Research Protocol').

Also, because of the current situation with Covid-19, it is possible that those with caring responsibilities will be in the same building as the people they are sharing their experiences about. I Although unable to be able to ensure that the participants are in a private space, the researcher will advise this and be prepared to stop the interview at any point if the space becomes occupied by others. The interview may need to be held at two separate times to allow for flexibility in this.

Withdrawal of Data

Due to analyses of transcripts running concurrently to the conduction of interviews, the possibility of removing individual data will likely not be possible after a two-week period post-interview. Participants will be made aware of this time period before the interview while gaining consent, and afterwards (on the debrief sheet). Contact information and the procedure to follow in order to withdraw data is also detailed on the debrief sheet. The participant will contact the researcher or the research supervisor in order to have the data removed from the study in the 2-week timeframe. If contacted, I will ensure that all data are removed from OneDrive or dictaphone, depending on where the recording is in the process.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

I, the principal researcher have personal experience of living with someone who suffered a TBI. I will keep regular journals about how this experience may be guiding my interpretations. I will also reflect regularly how the interviews are affecting my emotions. Should I need further support, I will make the research supervisors aware and keep in contact with my personal tutor at Lancaster University.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits in taking part. The research will hopefully forward knowledge of partners' experiences after traumatic brain injury and may go on to help to inform future interventions for partners and couples following TBI. It may be a positive experience for participants to share their experiences freely with the researcher and feel heard. They may also gain benefit from reading the results of the study and gaining more insight into the experiences of others in a similar situation.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
N/A

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participants will be informed during the consent phase that there are limits to confidentiality: If I become concerned that harm may come to the participant or others during interviews, I will need to break confidentiality.

Because direct quotations will be used in the final thesis, it is impossible to guarantee confidentiality of participants completely. I will however ensure anonymity, by using pseudonyms from the start of the transcription phase. All identifiers such as hospitals, professional's names, locations, family member's names etc. will be redacted in the transcripts. Quotations from different transcripts will be used in the final report; people who have been interviewed will likely be able to identify their own quotes, but not the quotes of others.

I will be transcribing audio recorded interviews and only my research supervisors and I will have access to the audio recordings and full transcripts.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

I have had an Expert by Experience, i.e, partner of someone who had had a TBI read over my study pack documents (consent form, information sheet, debrief sheet and interview schedule) to confirm that were appropriate for this cohort. Amendments were made to ensure this due to their feedback

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

My thesis

Results of the research may be submitted for publication in an academic/ professional journal. Participants will be sent a copy of the findings, if they wish these. Findings may be presented at appropriate conferences, special interest groups and study days. Findings will be presented at the DClInPsy thesis presentation day.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

SECTION FOUR: signatureApplicant electronic signature: Date

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable): Date application discussed

Submission Guidance

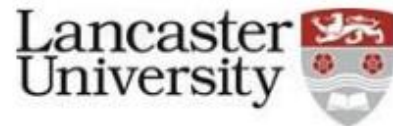
1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
 - i. **FHMREC application form.**
Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.
 - ii. **Supporting materials.**
Collate the following materials for your study, if relevant, into a single word document:
 - a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
 - b. Advertising materials (posters, e-mails)
 - c. Letters/emails of invitation to participate
 - d. Participant information sheets
 - e. Consent forms
 - f. Questionnaires, surveys, demographic sheets
 - g. Interview schedules, interview question guides, focus group scripts
 - h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
 - i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to [Becky Case by the committee deadline date](#). Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
 - ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has not been completed, and is not required]**. Those involving:
 - a. existing documents/data only;
 - b. the evaluation of an existing project with no direct contact with human participants;

c. service evaluations.

3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

Letter of Ethical Approval

Applicant: Hayley Butler
Supervisor: Fiona Eccles; Will Curvis
Department: DHR
FHMREC Reference: FHMREC21012

28 September 2021

Re: FHMREC21012

"How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Traumatic Acquired Brain Injury."

Dear Hayley,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "T. Morley".

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

Appendix A: Research Proposal

How People Make Sense of their Partner's Cognitive and Emotional Difficulties
Following Acquired Brain Injury.

Primary researcher: Hayley Butler, Trainee Clinical Psychologist, Lancaster
University

| Name | Job role | Organisation/Address | Supervisory role e.g. indicate whether theoretical, methodological, clinical expertise |
|--------------|---------------------|-----------------------------|---|
| Will Curvis | Research Supervisor | Lancaster University | Clinical Expertise/ Theoretical/ Methodological |
| Fiona Eccles | Research Supervisor | Lancaster University | Theoretical/ Methodological |
| David Todd | Field Supervisor | Reconnect Psychology | Clinical/Theoretical Expertise |
| Alan Gray | Field Supervisor | Headwise | Clinical/Theoretical Expertise |

Introduction

Brain Injury is a leading cause of death and disability in people under 40 years old (Majdan et al. 2016; National Institute for Health and Care Excellence [NICE], 2019), with the majority of cases caused by stroke, road traffic accidents and assaults (Lawrence et al. 2016). Each injury is unique with wide ranging difficulties, including neurobehavioural sequelae, cognitive, language and physical impairments (Lezak, Howieson & Loring, 2004). The UK Acquired Brain Injury Forum, (2019) worked out that the cost of support and care related to acquired brain injury (ABI), including traumatic brain injury (TBI) in the UK is approximately ten percent of National Health Service's (NHS) yearly budget per annum.

It is known that family members (predominantly partners and parents) typically become formal or informal primary caregivers of people with ABI (Headway 2018). This usually means a change in role for the family member; caregivers' responsibilities vary from help with personal care to transportation, memory aides and becoming their family member's rehabilitation assistants, which can sometimes mean giving up occupational roles (Turner et al. 2007). Caregivers can experience high levels of psychological distress (Kreutzer, Marwitz & Kepler, 1992); It is thought that the lesser-known sequelae of the ABI such as difficulties in emotional control (irritability and anger), personality and mood changes create the biggest strain on family relationships (Brooks, Campsie, Symington, Beattie & McKinlay, 1986), with reduced deficit awareness also being a source of tension among affected couples (Yeates, Henwood, Gracey & Evans, 2007).

Indeed couples may experience difficulties, which are particular to them and different from parent carers (Yeates, Murray, Creamer & Mahadevan, 2013; Anderson et al. 2009). A review of studies looking at the divorce rate and separation after one partner has had a brain injury found a range of 15-78% (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011), where those with more severe injuries being more likely to be divorced or separated (Kreutzer,

Sima, Marwitz & Lukow, 2016), and both older age and length in relationship prior to the injury found to be protective factors (Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007). Six years is the average time after the injury that couples separate after brain injury (Wood & Yurdakul, 1997; Tate et al., 1989).

Looking at marriage stability and relationship distress rather than divorce rates in the earlier stages after brain injury (80% of the sample were less than 3 years post-injury), Kreutzer, Sima, Marwitz and Lukow (2016) found that out of 42 partners of people who had sustained a brain injury, 29% rated their relationships as unstable and 50% felt that their relationship was in distress. The authors concluded that more research is needed to explore the experiences of those who felt their marriage was stable, but in distress. A recent Headway survey in the UK (2018) found that as many as 38% of romantic relationships broke down after one partner sustained a brain injury; this is thought to be because of a lack of understanding of the injury and social isolation of the carer. Protective factors were found to be having a good understanding and taking an active role in the rehabilitation process

Attributions theory can be helpful in understanding relational distress after TBI. Quantitative research in brain injury found that a carer's belief in their ability to control their family member's neurobehavioural problems, was associated with lower stress levels and negative attributions of challenging behaviour (a belief that the person with the injury had control over this behaviour) was associated with higher caregiver depression (Riley, 2007). This is consistent with research looking at caregivers for people with dementia; carers who have a personal sense of mastery or the perceived sense of control one has over events (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) and positive belief about their ability to care for their partners, who present with challenging behaviours associated with Alzheimer's disease, was associated with positive outcomes for both parties (Brent et al. 2006). This

indicates that appraisal of cognitive and neurobehavioural difficulties may play an important role in caregiver outcomes and perception of relational satisfaction, adjustment and stability

In order to take an active role in rehabilitation, gain a sense of mastery and engage in a process of relational and emotional adjustment and change, individuals must first have an understanding of the underlying problems in order to master skills and strategies, using the cyclical process above, to overcome these in an effective way. It is well documented that information about brain injury sequelae is one of the most unmet needs for caregivers (Manscow & Arntzen, 2018), with many unaware of the cognitive sequelae until after discharge home from hospital (Perry & Middleton, 2011).

Research looking at carer education interventions have shown variable results. Those that are active in nature and catered to the individual are more successful and tend to yield better neuropsychological rehabilitation outcomes for patients with brain injuries, because caregivers were able to take a more active role in rehabilitation (Forster et al. 2012; Zhang, Zhang, & Sun, 2019). A recent systematic review highlighted the potential benefits of family involvement in the brain injury rehabilitation process for both caregivers and patients with brain injury (Fisher, Lennon, Bellon & Lawn, 2015), with further research showing the important role of spouses in re-integration to the community and rehabilitation progress (Godwin, Kreutzer & Arango-Lasprilla, 2011).

Informational needs of this population are intermittently met. Given the significant strains and burdens placed on caregivers, and the particular needs of couples, it is important to gain an insight about partners' perceptions, understanding, and beliefs about cognitive and behavioural sequelae after ABI; where and how this understanding was acquired, the usefulness of this information and the effect of this understanding, or lack thereof on relationships. Doing this will give us a sense of the best way to meet these needs in the

partner carer population. The research question for this study therefore is: How do people make sense of their partner's cognitive and emotional difficulties following ABI?

Method

Design

The design of the proposed study is a qualitative one, using interpretive phenomenological analysis (IPA) as the research methodology. IPA is the most appropriate methodology for the research question because it is focussed on the in-depth of experiences of people who share a common life experience (Smith, Flowers & Larkin, 2009). Here all have a partner who has sustained an ABI, which has caused cognitive deficit that impacts on their day-to-day functioning.

The aim is to gain an in-depth understanding of how people make sense of their partner's brain injury, what is the understanding of the cognitive impact and how this affects their partner, and how they themselves cope with those impacts. It is understood that the epistemological underpinning of IPA is one of phenomenology: each person interprets their world to form their reality. In trying to understand how partners of people with brain injury make sense of that injury, I am interpreting their interpretations (the double hermeneutic, Smith, 2004). Throughout the research, I will use audit trails and a reflective diary to ensure that I can bracket my own reflections so that I am keeping as close to the participant experience as possible.

David Todd and Alan Gray, both psychologists in the field of brain injury rehabilitation and an expert by experience (partner of someone who has a traumatic brain injury) have fed back on the social media advertisement (Appendix A), consent form (Appendix B), information sheet (Appendix C), debrief sheet (Appendix D) and interview schedule (Appendix E) for their appropriateness for their intended use.

Participants

Due to the qualitative design and use of interpretive phenomenological analysis [IPA]), I plan to use purposive sampling to recruit between 8-12 partners of people who have sustained an ABI, as is a typical size for an IPA study (Smith, Flowers & Larkin, 2009; Townshend & Norman, 2008; Shotton, Simpson & Smith, 2009) .

Inclusion criteria:

Participants must have:

1. A partner, living with them, who has sustained a moderate to severe ABI (see 'recruitment' section for details on how this is ascertained)
2. Been in a relationship with the person with an ABI prior to their injury
3. Been with their partner for at least 1 year before the interview to allow for relationship development. This is in line with other research in this area e.g. Crewe-Brown, Stipinovich & Zsilavec (2011).
4. Their partner's injury must have happened while they were of working age (below 67) in order to keep the sample homogenous.
5. The person with ABI must have neuropsychological/ cognitive impairment(s), which affects day-to-day functioning, caused by the ABI
6. A base in the UK. Using an IPA approach, the sample needs to be as homogeneous as possible; people rehabilitating in different countries are likely to have vastly different experiences to those rehabilitating in the UK.
7. A level of spoken English sufficient for an hour-long, in-depth interview about experience due to the limitation of the primary researcher's skill in languages other than English and the lack of research funds to cover the costs of an interpreter.

Exclusion Criteria

1. Partners who have their own ABI / cognitive impairment

2. Partners of people who also have a degenerative brain injury/ disease as it is expected that the experience of living with a partner whose cognitive and behavioural sequelae will become gradually worse will be different

Materials

I will be making use of semi-structured interview to look for similarities and differences in participants' accounts. I will be using an interview schedule to guide the interview and ensure that questions asked are primarily open, in order to promote deep and rich responses, (Ogden & Cornwell, 2010) in line with the IPA approach (Smith & Osborn, 2003).

I will be collecting some basic demographic data about the sample: age, gender and ethnicity of both partners occupation of participant, length in relationship, family situation (i.e. living with children and/ or parents), cause of injury and time since their partner's injury. I will also ask some questions based loosely on the Mayo classification system for traumatic brain injury (Malek et al. 2007), such as time spent unconscious, time in hospital, approximate length of post traumatic amnesia (the length of time partners noticed confusion and memory problems) to gain a sense of injury severity. I will also ask about the types of difficulties their partners have day-to-day, to gain a sense of the severity of other brain injuries as well as sources of current and past support (such as brain injury rehabilitation). This will be gathered at the start of the interview.

Procedure: Recruitment

Independent Neurorehabilitation Organisations

There will be a staged, purposive recruitment process in order to ensure that enough participants are recruited into the current study, stages are outlined below.

The first stage will focus on recruitment from independent brain injury and neurorehabilitation organisations. Inclusion and exclusion criteria will be shared with neuropsychologists, clinical psychologists, psychological clinicians and head admin staff at the organisations. They will then screen the couples with which the clinicians/ organisations are currently working, and those they have worked with in the past, using these criteria, including severity of brain injury, which will have been already determined and part of their clinical information, and provide study packs, including the participant information sheet, consent form and principal investigator contact details (non-personal) to those who meet them. Participants can then choose to contact the researcher directly or give their consent to contact to the clinician or organisation, who will then pass the participant's details to the researcher via Microsoft Teams. On first contact with the participant, if they wish to proceed, verbal consent will be gained and an interview date will be arranged. This will be done by reading out the consent form and asking them to confirm that they understand each point on the form (see Appendix B for detailed view). The gaining of consent will be recorded separately and then stored securely on the university secure drive/or university approved cloud storage, e.g. OneDrive. I will make the participant aware that the interview will last approximately 60 minutes.

Charity Organisations

If not enough participants are gained using the above recruitment method and coronavirus restrictions allow, I will attend Brain Injury Charity meetings (both in person where restrictions allow and online), where people with brain injuries and their carers seek support, network and socialise, in the North West, publicise the study and to hand out study packs to partners of people with ABI.

People who are interested in taking part will indicate this to me directly either in the meeting, or afterwards. I will then check to see if they meet the study criteria. Potential

participants will be eligible to take part in the study if they identify that their partner has cognitive problems that have a functional impact on activities of daily life.

Should there be further restrictions due to COVID-19 which mean that these meetings cannot take place in person, I will ask to attend any online meetings and/or request that an advertisement (Appendix A) be placed in their regular newsletter and on their social media pages (Twitter and/ or Facebook) with my contact email address for interested parties.

Should potential participants get in touch to express interest via email, I will gain their consent to be contacted via telephone at this time, in order to check that they meet the study criteria in the same way as the above and discuss the study with them.

Case management and Occupational Therapy Companies

At the same time, alongside recruitment from charity organisations, I will widen the scope of recruitment to case management and independent occupational therapy companies who specialise in brain injury rehabilitation. I will provide a copy of the inclusion and exclusion criteria to these organisations so that case managers and occupational therapists can screen their caseloads for couples who meet them. Partners can then express their interest to take part directly to the case managers, occupational therapists or case management/ occupational therapy organisation, who will gain consent for the principal investigator to contact them to arrange a suitable time and date for interview. I will also ask that case management companies, occupational therapy and independent brain injury rehabilitation organisations place a study advertisement in their regular newsletters and on their social media pages (Appendix A). This will invite potential participants to get in touch with me by email and I will then telephone the potential participant. On this telephone call, it will be ensured that the partner meets the inclusion criteria and does not meet the exclusion criteria. If the participant is unaware if their injured partner's injury was moderate or severe, this will be judged functionally, as above in the 'charity organisations' recruitment procedure.

Social Media – Twitter

Concurrently to the professional organisation recruitment, A professional twitter account will be set up in order to tweet the social media advertisement in appendix A. I will then request that professional/ charity organisations and other twitter users re-tweet the advertisement so that it reaches a wider audience. On first contact with the potential participant, I will check that they meet the study criteria in the same way as the above and discuss the study with them, before gaining their consent to participant as outlined above, and arrange an interview date with them.

If people who are interested in taking part, but are not eligible because they do not meet the study criteria, they will be informed about the reasons why they are not eligible and the importance of having a homogeneous group of participants will be emphasised. I will also offer a copy of the results if they are interested. If I should get a bigger response than expected in a small time-frame, I will prioritise those in the younger age-bands, in order to keep the sample as homogenous as possible, and because younger samples are underrepresented in the literature.

Procedure: Data collection

Once an appropriate time has been agreed for interview, I will give the option of using telephone for interviews or use of Microsoft Teams internet software. Verbal consent will be gained to participate as well as consent to being recorded. Participants choosing to use MS Teams will be made aware that the safety of interviews over the internet cannot be guaranteed, however, MS Teams uses end-end encryption and is the best option freely and widely available It will be made clear to them that the primary researcher will be conducting interviews in a private space, and that they should also try to ensure a private space in which to be interviewed.

Participants will be interviewed using their chosen medium for approximately 60 minutes, using the interview schedule as a guide. All interviews, both phone and Teams will be recorded using a pickup device and a dictaphone.

As soon as is possible, interviews will be moved directly from the dictaphone to the university OneDrive via a personal laptop (interviews will not be saved onto the personal laptop). Following upload to OneDrive, the interview will be deleted from the dictaphone.

I will transcribe the interviews verbatim. Transcriptions will be done using my own, personal laptop and will be stored and encrypted on One Drive, separate from the recordings.

Transcribed data will be viewable by myself and my research supervisors.

Proposed Analysis

Interviews will be re-listened to, and read and re-read in order to become immersed in the data (Smith & Larkin 2014).

I then plan to code each transcript, identifying topics of importance, keeping to the participant's own words as much as is possible. I will then summarise these to develop emergent themes. I will then look at all the emergent themes across the transcript to see if there are any that recur or are similar, and use these to form subordinate themes. After I have coded all the transcripts this way, I will look across the transcripts to see if there are any superordinate themes that come out of the data, keeping a note of key quotations to evidence these themes. These will be cyclical processes.

Practical Considerations

Due to the COVID-19 epidemic, in order to minimise risk, interviews will be conducted via telephone or Microsoft Teams video software depending on participant's preference. I will be following the available government and NHS pandemic guidance throughout this project. Because of this, participants will likely have to have use of a

telephone or a computer for Microsoft Teams interviews. I have considered that there may be a number of people unable to access a computer, therefore, telephone interviews are also offered. I will use a pickup devices which are capable of recording these telephone interviews.

Study packs, including the consent form (appendix B) and participant information sheet (appendix C), and contact details of the investigator will be photocopied at the university, as will debrief sheets (appendix D), if these cannot be sent via email.

Ethical Concerns: Confidentiality

I will be alert to any safeguarding issues that present during interviews. I will be informing participants that the standard safeguarding applies: i.e. if anything they say in the interview makes the researcher concerned about their safety or that of somebody else, confidentiality may have to be breached and risks reported to the appropriate agencies such as support agencies, health services, or mental health organisations to reduce those risks. This is stated clearly in the information sheet and consent form.

Because direct quotations will be used in the final thesis, it is impossible to guarantee confidentiality of participants completely, but all steps will be taken as far as possible to ensure anonymity by using pseudonyms from the start of the transcription phase. All identifiers such as hospitals, professional's names, locations, family member's names etc. will be redacted in the transcripts. Quotations from different transcripts will be used in the final report; people who have been interviewed will likely be able to identify their own quotes, but not the quotes of others.

Possibility of Participant Emotional Distress

Because the interviews are semi-structured and led by the interviewee in some respects, there may be scope for some of what comes out of it to be emotional or anxiety provoking for participants. I will remain vigilant of changes in facial/ emotional expression

and tone of voice (telephone) and use active listening and therapeutic skill to manage the situation should this arise during interviews; the interview will be stopped, the participant given time and then they will be asked if they wish to stop their participation in the study, reschedule the interview, or continue after a break. Should participants need further support, I will refer them to the organisations and recourses included in the participant information sheet (Appendix C).

Also, because of the current situation with Covid-19, it is possible that those with caring responsibilities will be in the same building as the people they are sharing their experiences about. Although unable to be able to ensure that the participants are in a private space, the researcher will advise this and be prepared to stop the interview at any point if the space becomes occupied by others. The interview may need to be held at two separate times to allow for flexibility in this.

Data Storage

Because interviews are required to be transcribed for the data analysis, consideration also needs to be given as to how this personal data is stored. Consent and Interviews will be recorded separately using a pickup device and Dictaphone. After the interview is recorded, I will transfer both files to the university's OneDrive, accessed on a personal laptop through the university's virtual proxy network (VPN). Due to the dictaphone not being an encrypted device, transference to the above, secure location will be done as quickly as is possible. Until then, the dictaphone will be kept in a secure location. After transfer to OneDrive, the recordings will be deleted from the dictaphone. The audio recordings of interviews will be kept in the university storage drive until after the viva voce examination and then destroyed. .

Transcripts will be kept securely on OneDrive and consent audio recordings kept separately on One Drive, with separate passwords until the DClinPsy course is complete. They will then be securely transferred to Sarah Heard, the DClinPsy research coordinator

who will store them for 10 years or 10 years from publication, whichever is longer, under the direction of supervisor Fiona Eccles. They will then be destroyed.

For the purposes of publication, due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request. Access will be granted on a case by case basis by the Faculty of Health and Medicine.

Researcher Safety

The principal researcher has personal experience of living with someone who suffered a TBI. She will keep regular journals about how this experience may be guiding her interpretations. She will also reflect regularly how the interviews are affecting her emotions. Should she need further support, she will make the research supervisors aware and keep in contact with her personal tutor at Lancaster University.

Withdrawal of Data

Due to analyses of transcripts running concurrently to the conduction of interviews, the possibility of removing an individual's data will likely not be possible after a two-week period post-interview. Participants will be made aware of this time period before the interview while gaining consent, and afterwards (on the debrief sheet). Contact information and the procedure to follow in order to withdraw data is also detailed on the debrief sheet. The participant will contact the researcher or the research supervisor in order to have the data removed from the study in the 2-week timeframe. If contacted, I will ensure that all data are removed from OneDrive or dictaphone, depending on where the recording is in the process.

Timescale

November 2020: submitting ethics

December 2021 - February 2021: Ethics approval period

February – December 2021: Begin data collection, transcribe and analyse as I go.

Draft introduction, methods, results and discussion for current research.

End of March 2022: Drafts completed – Submit thesis.

April- August 2022 – Viva

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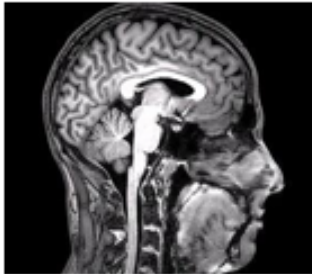
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Appendix AA: Study Advertisement

Are you living with a partner who has had a brain injury or stroke? Do they require support with their day-to-day activities like cooking, remembering appointments and planning?



If so, I am conducting some research for my doctoral degree at Lancaster University and would like to hear about your experience!

I am Hayley Butler and I have a keen interest in the area of acquired brain injury (ABI) and how this might affect families, particularly couples.

Project title: How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury.

- To be eligible to participate, you must;
- Be of working age (below 67)
- Be in a relationship with someone who had a brain injury, which might include stroke traumatic brain injury, infection, hypoxia etc. during their working age, and as a result needs help with daily activities (this might include regular reminders, setting alarms, support with cooking, cleaning, transport [because of worry about getting lost, timekeeping or becoming distracted easily], motivation to get going, managing risk, shopping or planning activities/ holidays/ budgets etc.
- Have been with your partner since before their injury.

I will send out an information pack and hope to ask you some questions about your experience and your understanding of your partner's difficulties over the internet-based video conferencing software: Microsoft Teams or via phone. This talk will last for around 1 hour.

If you are interested in taking part or have any questions, please don't hesitate to contact me:

H.butler5@lancaster.ac.uk or tel: 07852 516 400

Research Supervised by Fiona Eccles and Will Curvis

Appendix AB: Consent Form**Consent Form**

This form is being provided for information. These questions will be asked before the start of the research interview and consent will be verbally recorded separately from the interview.

Study Title: How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury.

We are asking if you would like to take part in a research project aiming to explore your experience of living with a partner who has had an acquired brain injury, which causes them difficulties in their day to day lives.

Before you consent to participating in the study I ask that you listen while I read out the participant consent form and indicate verbally if you agree to each of the below statements; this will be recorded and stored on a secure university drive. If you have any questions or queries indicating your consent, please do not hesitate to ask.

| | Indicate if verbal consent given |
|---|----------------------------------|
| 1. Do you confirm that you have read the information sheet and fully understand what is expected of you within this study? | <input type="checkbox"/> |
| 2. Do you confirm that you have had the opportunity to ask any questions and to have them answered? | <input type="checkbox"/> |
| 3. Do you understand that your interview will be audio recorded and then made into an anonymised written transcript? | <input type="checkbox"/> |
| 4. Do you understand that audio recordings will be kept until the research project has been examined? | <input type="checkbox"/> |
| 5. Do you understand that your participation is voluntary and that you are free to withdraw at any time without giving any reason, without your medical care or legal rights being affected? | <input type="checkbox"/> |
| 6. Do you understand that once your data have been anonymised and incorporated into themes it will not be possible for you to extract such data. It is anticipated that withdrawal of data will not be possible after two weeks of interview. | <input type="checkbox"/> |
| 7. Do you understand that the information from your interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project. | <input type="checkbox"/> |
| 8. Do you consent to information and quotations from your interview being used in reports, conferences and training events? | <input type="checkbox"/> |
| 9. Do you understand that the researcher will discuss data with their supervisor as needed? | <input type="checkbox"/> |
| 10. Do you understand that any information you give will remain confidential and anonymous unless it is thought that there is a risk of harm to you or others, in which case the principal investigator will need to share this information with their research supervisor? | <input type="checkbox"/> |
| 11. Do you consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished? | <input type="checkbox"/> |
| 12. Do you consent to take part in the above study? | <input type="checkbox"/> |

Name of Participant _____ Date _____ (Participant to confirm name for the tape; principal investigator will confirm the date)

Name of Researcher _____ Signature _____ Date _____

Appendix AC: Participant Information Sheet**Participant Information Sheet**

How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage:
www.lancaster.ac.uk/research/data-protection

My name is Hayley Butler and I am conducting this research as a student on the DClinPsy programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore what it is like living with a partner who has had an acquired brain injury (ABI) and has cognitive impairments, which affect their day-to-day lives as a result of that injury. We hope to explore what partners have found helpful in coping with these difficulties post-injury.

Why have I been approached?

You have been approached because the study requires information from people who are partners of people who have suffered an ABI in their working lives and have difficulties that affect them in their daily lives as a consequence of this

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. You can disregard this pack if you do not wish to take part and this will not affect the care or support you are receiving in any way.

What will I be asked to do if I decide to take part?

If you decide you would like to take part, you can either inform your clinician directly or contact the primary researcher, Hayley Butler, via email at h.butler5@lancaster.ac.uk or via telephone on 07852516400 in order to arrange an interview. This interview will last for approximately one hour and will take place via telephone or via video call through Microsoft Teams software (you will need a valid email address and working internet connection in order to receive a Microsoft Teams invitation)

If there is lots of interest in the study (too much for the scope of this research), partners of people who suffered their ABI at younger ages will be prioritised because this group is largely underrepresented in the literature. Please do get in contact and ask if you are not sure about this.

Will my data be Identifiable?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data.

- Audio recordings of interviews will be securely stored and password protected on OneDrive (that is no-one other than the researcher will be able to access them). The computer's operating system is also password protected.
- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Supporting documents (Transcripts and consent audio recordings) will be kept securely and separately on OneDrive (an encrypted, online storage area) until the DClinPsy course is complete. They will then be securely transferred to Sarah Heard, the DClinPsy research coordinator who will store them for 10 years from completion of the thesis project or 10 years from publication, whichever is longer, under the direction of supervisor Fiona Eccles. They will then be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The primary researcher will transcribe each interview and analyse them individually. Themes emerging from interviews will form the results of the study, which will be summarised and reported in a research thesis for the DClinPsy qualification and may be submitted for publication in an academic or professional journal. It is also possible that the results may be discussed at relevant and appropriate conferences.

A summary report will be available to all participants if they should wish to receive this. You will be asked at the end of your interview if you would like to receive a copy of this, in which case, your personal details will be kept until this becomes available.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the support services and look through the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. The research will hopefully forward knowledge of partner's experiences after traumatic brain injury and may go on to help to inform future interventions for partners and couples following TBI. You will also be offered a summary report of the final results.

Can I withdraw from the study at any time?

You can withdraw from the study at any point up until 2 weeks after your interview. After this point, transcripts will have had identifiable information separated and parts will have been incorporated into general themes with information from other transcripts. At this point, it will not be possible to separate your data from others'.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher: Hayley Butler on h.butler5@lancaster.ac.uk or telephone number 07852 516 400

If, after reading this information sheet, you are interested in taking part, please indicate your desire to do so to your clinician, who will pass your contact details on to the primary researcher. Alternatively, you may contact the researcher directly using the contact details above.

The researcher's supervisor names and contact details are recorded below:

Dr Fiona Eccles

Email: f.eccles@lancaster.ac.uk

Telephone: 01524 592 807

Dr Will Curvis:

Email: w.curvis@lancaster.ac.uk

Dr David Todd

Reconnect Psychology

Email: Dave@reconnectpsych.co.uk

Dr Alan Gray

Headwise

Email: agray@headwise.org.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study, please contact the researcher in the first instance. If you do not feel comfortable bringing your concern to the researcher directly, you can contact:

Ian Smith Tel: 07507 857 069

Email: i.smith@lancaster.ac.uk

Division of Health and Medicine

HI One

Lancaster University
Lancaster
LA1 4YW

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

- Your local GP
- Headway:
 - Website: <https://www.headway.org.uk/>
 - Telephone: 0808 800 2244.
- Samaritans:
 - Website: <https://www.samaritans.org/>
 - Tel: 116 123
 - Email: Jo@samaritans.org

Appendix AD: Debrief Sheet



Debrief Sheet

How People Make Sense of their Partner's Cognitive and Emotional Difficulties Following Acquired Brain Injury.

What are we looking to explore?

Thank you for taking the time to partake in this study and for your involvement in the project. The study aims to gather the experiences of people who are living with a partner who has suffered an acquired brain injury (ABI), with a particular focus on how difficulties resulting from that injury have impacted on the relationship and also as an exploration of what is most difficult to cope with and what has helped with coping. We hope to gain more of an understanding of how you understand the injury and how it has affected your partner. Results from previous studies have shown that relationships can come under strain after an ABI, and that difficulties relating to the ABI can cause psychological difficulties in caregiving partners in particular. It is the hope that this research will contribute to the current knowledge and information about successful coping mechanisms can be explored and used in future caregiver interventions.

What will happen with the results?

The results will be written up into a DClInPsy thesis and assessed and examined by an internal and external board of markers. After an embargo period of five years, it will be freely available for the public to view if they so wish in the thesis archives. The research may also be published in an academic journal. Results will be anonymised as far as possible, but there may be some identifying information in the form of direct quotations from this interview (where names and other directly identifying information will be removed and replaced with pseudonyms).

If you have opted in to receiving the summary report of the findings of the current research, this will be distributed to you on its completion. Feel free to share this as you wish. If you have not yet opted into receiving this, but would like to, please contact the principal investigator, Hayley on: h.butler5@lancaster.ac.uk

What will happen with my data?

Data in the form of interviews will be transcribed and kept in a secure database with the university for 10 years. Data in the form of recordings will be kept on the University

OneDrive until the thesis is examined and completed, at which time, the principle investigator will delete all recordings from this drive.

If you wish for your data to be withdrawn and permanently deleted from this research, you will have to do so within two weeks of this interview. If you choose to do this, you can contact the primary researcher on the above email address or phone number: 07852 516 400. You will not be prompted for a reason for your withdrawal and this will in no way affect any care that you are receiving.

Sources of support

Although every care has been taken when designing the interview schedule, in rare instances, some topics may evoke strong emotional responses. Should this have been the case here today, please see the following list of some support agencies and resources which you may find helpful.

- Contact your GP, who will be familiar with the appropriate support services in your local area if you and/ or your partner are finding things difficult
- Headway the Brain Injury Association. This is a national charity that specialises in supporting people with acquired brain injury and their families and carers. Their website: <https://www.headway.org.uk/> contains vast amounts of information about brain injury and its effects. There are also links to resources and support in local areas as well as online support. Tel: 0808 800 2244.
- Samaritans offer a 24 hour, 365 days a year telephone service for people who are struggling with their mental health: Website: <https://www.samaritans.org/> , telephone number: 116 123 (24 hours). Email: jo@samaritans.org

If you have any concerns or questions regarding any aspect of this research process, please contact me using the below email address.

Please keep a copy of this sheet for your information and records.

Many thanks again for your time and participation,

Hayley Butler

Trainee Clinical Psychologist

Appendix AE: Topic Guide

The following is a guide which examples of the types of questions to be asked; exact questions and prompts will be guided by the responses of the participants.

Topics:

1. Demographics:

- Age/ gender of both partners
- How long have you been together?
- Family layout (children/ parents living in the home)
- Occupation

2. General exploration of the injury

- When was the injury
- How did it occur?
- Was there a period of unconsciousness? If so, how long?
- How long was your partner in hospital?
- Was there a period of confusion and memory loss after the injury? If so, approximately how long?
- Sources of support (parents, carers, MDT, neurorehabilitation) – past and present

3. General experience to having partner with brain injury

Question: Can you tell me about what your experience has been like, having a partner who has had a brain injury?

Prompts: Positive experiences, Challenges, effects on the relationship

4. Understanding of the neuropsychological changes

Question: What is your understanding about x behaviours or x challenges or x positive changes? Or how do you make sense of these?

5. Knowledge/ understanding source

Question: Where or how did you come to this understanding?

Prompts: did it come from the rehab team/ hospital/ neuropsychologist/ websites?

6. Timeline/ change

Question: Has your experience changed over time?

Prompts: Was the experience different in the beginning?? Was it easier/ harder in the beginning/ further down the line?

7. How has your experience been affected by the care you've received and/ or rehabilitation and/ or professional involvement?

8. Coping

Question: Talk to me about what helps you to cope with some of the aforementioned challenges/ what do you think might be helpful to your coping?