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

Doctoral Thesis

The relationship between family expressed emotion (EE) and caregiver burden in stroke and acquired brain injury (ABI)

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Word Count Statement

Thesis Section	Main Text	Appendices	Total
Thesis Abstract	300	-	300
Literature Review	6,542	10,599	17,062
Empirical Paper	7,776	7,178	14,583
Critical Appraisal	3,310	767	4,077
Ethics Section & Appendices	8,371	4,830	13,201
Total	26,287	23,374	49,673

Thesis Abstract

Section one describes a narrative systematic literature review examining the relationship between expressed emotion (EE) and mental health in acquired brain injury (ABI) populations. Nine papers were identified through searching 5 electronic databases using MeSH terms for ABI and search terms for EE. Six of the nine studies reviewed found significant relationships between EE and some measure of psychological outcome. Studies gathered data from the ABI survivor, the caregiver or both. None of the nine were rated the highest score for quality. The results showed a lack of research in this area and evidence to support the relationship between EE and mental health in ABI but not consistently. Further higher quality and more focussed research is required. The review highlighted areas for improvement and directions of future research in this domain.

Section two describes a research study which aimed to identify whether high EE predicted high levels of burden in stroke caregivers and if stroke knowledge moderated this relationship. Significant positive correlations were identified between EE and measures of caregiver burden. Regression analyses found EE significantly explained the variance in measures of caregiver burden, Stroke knowledge was not found to be a significant moderating effect between EE and caregiver burden in this study. Services should consider the impact of EE and how to support caregivers in order to facilitate good outcomes for both the stroke survivor and their caregiver. Further exploration of stroke knowledge and development of appropriate measures is indicated.

Section three describes a critical appraisal of the thesis as a whole. This includes an overview of the main findings from the other papers and discussions of issues and limitations raised including terminology used, measures and the impact of culture. It also has reflections on the thesis journey as a whole and makes recommendations for further research.

Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology programme at the Division of Health Research at Lancaster University from September 2018 to August 2022. 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 any higher degree elsewhere.

Clare Rooney

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Finally, to my daughters Willow and Lily, thank you for being the most wonderful of distractions but also for being my reason and motivation to keep going. I love you.

Contents

Section 1: Literature Review

Family expressed emotion (EE) and mental health in people affected by brain injury and their caregivers: A systematic review

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Word count (exc. title page, abstract, appendices, figures and tables): 4816

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Abstract

Purpose: Due to the complexity of their needs, acquired brain injury (ABI) survivors may be reliant on others to provide lifelong care and support. Those who provide this care are generally informal caregivers who are a valuable social and economic resource. Expressed emotion (EE) is a construct measuring aspects of interpersonal relationships in families. It has been explored in psychiatric populations and more recently in physical health. High levels of EE are consistently associated with negative outcomes for both caregiver and survivor in other conditions. This review aimed to explore the relationships between EE and psychological well-being in ABI populations to ascertain if consistent associations are found here too. **Methods:** A narrative systematic literature review was conducted. Searches were completed using 5 electronic databases using MeSH terms for ABI and search terms for EE. Articles were screened and nine met the inclusion criteria. **Results:** Six of the studies found statistically significant relationships between EE, and psychological wellbeing in ABI populations. Where EE was higher there were negative psychological outcomes for the ABI survivor, caregiver or both. None of the studies were rated the highest score for quality. Difficulties were identified in drawing comparisons across types of ABI with variations in how ABI was defined and participant demographic differences. Additionally in some studies EE and psychological well-being were not the primary aims of the study, limiting conclusions that can be drawn. **Conclusions:** The results show some evidence to support the relationship between high EE and negative outcomes for both survivors and caregivers in ABI. Further higher quality and more focussed research is required to develop this area more fully.

Keywords: Acquired brain injury, expressed emotion, depression, anxiety, caregiver, correlates

Acquired brain injury (ABI) is generally defined as damage to the brain by events which happened after birth, rather than due to a genetic or congenital disorder. Injury may be through a trauma such as an accident or blow to the head, via a medical incident such as a stroke or sustained through infection or disease (Fryer et al., 2017; Ontario Brain Injury Association, 2011;).

Impacts of ABI are wide ranging, variable and difficult to predict. The outcomes can be grouped into the following three categories:

- Physical effects such as fatigue, impaired mobility, weakness/paralysis and speech problems;
- Cognitive effects such as memory problems, impaired reasoning, reducing problem solving ability and executive functioning difficulties;
- Emotional and behavioural effects such as personality changes, depression, anxiety and aggression (Turner-Stokes, 2003; Ponsford, 2013).

Different ABI types can have variable impacts depending on location, type and severity of injury incurred resulting in a heterogeneous patient group. Those with brain injuries are at higher risk of mental health conditions, self-harm and suicide than the general population (Simpson & Tate, 2007; Teasdale & Engberg, 2001; Bahraini et al., 2013; Rosenthal et al. 1998).

Due to complexity and heterogeneity of needs, survivors of ABI may depend on others to provide lifelong care and support (Holloway & Tasker, 2019; Masel & DeWitt, 2010). They may be reliant on health and welfare services and be unable to return to or maintain employment (Ponsford, 2013; Brooks et al. 1987). Gormley et al. (2019) found that nearly half of TBI survivors were in employment following their injury, however only a third were able to return to the same level of work they did prior to their injury. This results in a significant economic burden to both society and the individual (Humphreys et al., 2013; Hyder et al., 2007).

Informal caregivers are those that “take on responsibility for assisting another person without getting additional time or resources and are differentiated from formal caregivers who are trained and paid to provide care” (Hildebrand, 2016, p 313). The term informal caregiver, carer and caregiver are often used interchangeably, however within this review will be referred to as caregiver. Caregivers often provide the majority of long-term care, making them a valuable economic resource (Hickenbottom et al., 2002). Caring for an ABI survivor can present a number of challenges. Often caregivers receive no training and little support to manage and cope with their new role (Leith et al., 2004; Lezak, 1987). Previous research has shown the value and importance of the informal caregiver and the positive impact good family and social support can have for a survivor, including improved functional outcomes for the ABI survivor and reduced psychological impact for both survivor and caregiver (Bivona et al., 2020).

The burden of providing care can have multiple negative outcomes for the caregiver. Caregivers have been found to have poorer mental health and wellbeing as well as poorer physical health (Carnwath and Johnson, 1987; Schulz, Boerner, Shear, Zhang and Gitlin, 2006; Wade, Legh-Smith and Hewer, 1986) than the general population. They are frequently less economically active (Burton-Smith et al., 2009; Kitter and Sharman, 2014) adding to financial strain. Where the burden of care is higher and mental health of the caregiver is lower, this is associated with poorer outcomes for both the caregiver and the cared for individual (Burton-Smith et al., 2009; Holloway & Tasker, 2019). Caregivers of ABI survivors have been found to experience significant stress and strain in particular reference to the change in behaviours of their loved one and difficulties in managing this (Frosch et al., 1997; Nabors et al. 2002; Tramonti et al., 2019; Wells et al., 2005). Additionally, although there was variability in the rates, a review by Godwin et al. (2011) found increased rates of relationship/marital breakdown in TBI populations. Given the variability in type and severity of ABI it is difficulty to provide any certainty around recovery and timescales.

Expressed Emotion (EE) is a construct which was designed to measure key aspects of interpersonal relationships within families (Hooley & Parker, 2006). It encompasses measures of criticism, hostility, warmth, positive comments and ‘emotional over-involvement’. However, the negative aspects are mainly used to classify relatives as either high or low in EE, with criticism being considered the main measure (Wearden et al. 2000). Initial research into EE was in reference to relationships in households with a person with a diagnosis of schizophrenia (Brown & Rutter, 1966) and the impact of expressed emotion on recovery and relapse of those individuals experiencing schizophrenia and psychosis. Those who had caregivers scoring highly on the negative aspects of EE were significantly more likely to experience a relapse in their recovery (Butzlaff & Hooley, 1998). Hooley and Richters (1995) proposed there to be a complex circular relationship between EE and relapse, with patient behaviour impacting on relative EE which in turn may impact the outcomes and illness course.

The concept of EE has since been explored in a variety of other psychiatric conditions (Barrowclough & Hooley, 2003) and, more recently research has been conducted across physical health conditions (Wearden et al., 2000). In addition, the relevance of EE in the care of those with dementia has also been explored (Safavi et al., 2017). A consistent pattern of EE being associated with negative outcomes for both caregivers and those cared for has thus been found. Research in EE has found that those living with relatives rated high EE were more likely to experience low mood and depression and additionally the relatives themselves are more likely to suffer poor mental health outcomes where EE is rated as high in a family setting (Wearden et al. 2000).

High criticism in EE has previously been associated with relatives or caregivers believing that the symptoms are controllable and idiosyncratic to the cared for individual and believing they are responsible for their difficulties (Barrowclough & Hooley, 2003). Considering the range in type and severity of cognitive sequalae following ABI and the lack of training and support given to caregivers, it is likely that their understanding of the condition is likely to be poor, which may result in beliefs around patient 'controllability' of symptoms. A caregiver may understand in general terms that 'memory' may be impacted following ABI, however more complex constructs such as executive functioning may be more difficult for caregivers to understand, (Burgess & Simons, 2005; Goodwin et al., 2016) impacting on the caregiving style and survivor outcomes (Bivona et al., 2020). An example may be that where concentration is affected following ABI, recall may be variable depending on circumstance and the cared for individual could be perceived by the caregiver as 'not trying' when they recall one thing and not another. Post-stroke memory and behaviour changes have been found to be some of the most distressing symptoms for caregivers to manage (Clark et al., 2006) and similar cognitive difficulties are evident across ABI. Research has found that cognitive and behavioural symptoms play a larger role in the levels of caregiver distress over time (Marsh et al., 2002) and the caregiver burden is higher where the survivor has poorer neuropsychological functioning (Machamer et al., 2002).

As highlighted above, the support provided by informal caregivers is vital to optimal outcomes. It has been found that where family support fails or is unavailable the outcomes for ABI survivors are poor with increased risk of homelessness (Topolovec-Vranic, 2012), increased risk of substance misuse (Horner et al., 2005), further head injury and decline in mental health (O'Donnell et al., 2008). Brain injury rehabilitation services have been reported to be underdeveloped, poorly resourced and not always valued (Krug & Cieza, 2017), meaning effective formal support is not always available. Additionally, brain injury support is often time limited, whereas the effects may be life-long.

Survivors of acquired brain injury can present with complex needs and require high levels of support with difficult symptoms to understand and manage. It is important to consider how services can support ABI survivors and their families to facilitate positive relationships and outcomes for both.

The review aims to examine the research conducted into the relationship specifically between EE and acquired brain injury and how this may be associated with negative outcomes for those affected as well as their caregivers. Understanding these relationships may help to guide future support and legislation to improve the lives for both ABI survivors and their caregivers. It may also highlight gaps in the research in this area, where current research could be improved and what further research is needed to explore these concepts fully.

Methods

Search Strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) checklist was used to guide the structure of this review (Appendix 1-A). No published protocol exists for this review. A preliminary scoping search was completed to identify a suitable research question and ascertain the existing research in the area of stroke and expressed emotion. These initial searches helped to clarify the research question as well as identify and develop the search terms to be used. Initial scoping found very little on the specific combination of expressed emotion and stroke, so the decision was taken to widen ‘stroke’ and include other brain injuries. Following the initial scoping, consultation with a subject-specific librarian was completed to maximise the efficiency of the systematic searches.

Inclusion criteria

Any peer reviewed published article applying quantitative methods of data collection and analysis which explored the relationship between EE and the emotional wellbeing of the ABI survivor, their caregiver or both. Studies were required to be published in English due to restrictions on resources for translation. No date exclusions were set.

Exclusion criteria

Studies which focussed on dementia or other degenerative conditions were excluded. Recovery and improvement are not expected in degenerative conditions and the impact of expressed emotion on wellbeing may be very different (Wearden et al, 2000). Studies which did not include some measure of expressed emotion were excluded. Review articles were also excluded.

The databases used for this search were Academic Search Ultimate, CINAHL (Cumulative Index to Nursing & Allied Health), MEDLINE Complete, PsycINFO and PsycArticles. These databases were selected as they were relevant for health, neurology, psychology and medicine.

After some preliminary searches, the final full search process was completed on 16th June 2022. An initial search using the MeSH terms for "brain injury" was completed. This was intentionally broad, including traumatic brain injury (TBI), ABI, stroke, in order to include as many relevant papers as possible. MeSh terms were utilised to ensure all aspects of acquired brain injury were encompassed by the search. This was followed by an exploration of the term "expressed emotion". In relation to "expressed emotion" initially the term itself was searched and "EE" along with the category terms of "hostil*" "critic*" "emotional" and "warm". Due to large numbers being returned with these terms (>80,000) the category terms were removed searching just for "expressed emotion" and "EE" reducing the results to 4684.

Following the initial separate searches around ABI and EE the two searches were then combined to find all research where both were considered. Searching presented another concept with the acronym EE, ‘environmental enrichment’. In order to ensure relevant results were returned the search was adapted with ‘NOT Environmental Enrichment’

Duplicates were removed and titles were screened to exclude those articles which were not relevant. Following initial screening, abstracts were reviewed to ascertain if they met the inclusion/exclusion criteria. Finally, where enough detail was not available within the abstract to make a decision around suitability, the full text of the remaining articles were screened (See Appendix 1-C for list of articles and reasons for exclusion). In four of the studies, the collection of and analysis of data on EE and the psychological impact was an element of the study, rather than the main aim, but these studies were still included. Included papers’ reference lists were checked for further potentially relevant citations and additionally forward searching was completed using Google Scholar. Three further possible articles were found via this method.

Following the searching and screening process nine articles remained (see Figure 1 for PRISMA diagram) including one which was found through citation searching.

Insert Figure 1 here please

Data Extraction

Meta-analysis was not completed due to the heterogeneity of definition of ‘brain injury’ utilised across the studies. There was a mix of self-report and information taken from medical records. Detail on this was not clearly defined, with some simply stating “from medical records” others mentioned what information was gathered, such as Glasgow Coma Scale (GCS) or Post-Traumatic Amnesia (PTA) but not the detail of this or cut-off levels utilised. Where self-report was utilised, no clarity was given on what parameters needed to be met to be defined as brain injured.

Information ascertaining the methodological quality of the included studies was extracted. Information on the study design and setting/location as well as characteristics of the sample were also extracted. Additionally information was gathered on the measures used, and how ABI was defined and if measures of wellbeing/burden were completed with the ABI survivor, the caregiver or both. Data were also extracted regarding participant demographics including age, gender and relationship of the caregiver to the ABI survivor.

An amended version of the National Institute for Health and Care Excellence (NICE) quality appraisal checklist – quantitative studies reporting correlations and associations (2012; Appendix 1-B) was used to assess the quality of the articles included in the review. This tool was specifically developed for assessing correlational studies and is based on the appraisal step of the ‘Graphical appraisal tool for epidemiological studies (GATE)’ developed by Jackson et al. (2006). The tool enables reviewers to give ratings on both internal and external validity. The tool has 17 questions over four categories with five possible responses (See Table 2 for full list of questions and possible responses). The final section provides a summary of the scores of internal and external validity assessments.
The tool was not used to exclude articles from the review. The results of the quality appraisal were considered when looking at the findings of the included studies and to draw conclusions about their strength.

The initial two papers (25%) were quality appraised by two raters, blind to each other’s initial scores. Ratings were then discussed and discrepancies highlighted so that a consistent agreed approach could be adopted by the main rater for the rest of the papers.

Publication bias was not enumerated within this review as it was not possible to contact all the authors to ascertain if there were any additional unpublished data. Risk of bias is considered in the discussion.

Insert Table 1 here please

Results

The main characteristics of the studies reviewed can be found in Table 2. The date range of the studies was 1998-2018, with 8 of the 9 completed after 2006. Six of the studies were based in the UK with a further one based in the Republic of Ireland and two in Australia. All studies included a measure of expressed emotion and at least one measure of emotional wellbeing or mood completed with the ABI survivor, the caregiver or both.

The quality appraisal showed that all but one (Flanagan, 1998) of the studies reviewed scored the same overall score of + for external and + for internal validity indicating that information is either unclear or the study may not have addressed all sources of bias. Despite the similarity in overall score, there were differing strengths and weaknesses within the various sections of the checklist.

In five of the nine studies reviewed the reporting of power calculations or sufficient information to complete these were absent. Only one study (Weddel et al., 2006) was given the highest ranking for reliability and procedures of outcome measures, the rest were ranked as potentially not addressing all sources of bias in this regard. Flanagan (1998) scored the lowest on the quality appraisal, indicating that sources of biases remained within the study. It was lacking information about the population studied, confounding variables were not fully considered, no power calculations were completed and further outcomes were not assessed.

The majority of the studies were cross-sectional, single time point studies with only one study completing a 12 month follow up (Alway, et al., 2016) and two others collecting data at several time points, but not reporting the data of interest to this review from the additional time points in their studies (Weddell and Wood, 2016; 2018).

The search strategy was deliberately broad in order to include various types of brain injury in the review. Despite this, seven of the reviewed studies were focussed on traumatic brain injury (TBI), one on stroke (Rashid et al., 2012) and the final one looked at acquired brain injury, which included both TBI, CVA and other forms of ABI (tumour, encephalitis and hypoxia) (Fortune et al., 2016).

Most of the studies reported and characterised (to differing levels) the non-responders and only one study did not (Flanagan, 1998). Of the eight that did report on non-responders, four completed analyses with the data collected to ascertain if there was a significant difference between the participant group and the non-responders.

Insert Table 2 here please

Population/Participants

The range of participant numbers across the studies were between 28 and 87 participant pairs with the average number of participants pairs being 63.3. Seven of the studies had a sample size of between 60-90 participant pairs. The other two studies had 43 (Always et al., 2012) and 28 (Flanagan, 1998) participant pairs. Only four studies reported power analyses to indicate whether they were adequately powered. There was little cultural variation in the participants in the studies reviewed. Where reported, the participants were predominantly white.

The number of participant pairs across all of the studies combined was 573. In terms of the demographics of the full cohort of participants, 63.5% of the ABI survivors included in the studies were male. This is consistent with the research about the prevalence rates of TBI in terms of gender (Bruns & Hauser, 2003). 79.6% of the full cohort of caregivers recruited to the studies reviewed were female. This is again in-line with previous data that suggests that female relatives are more likely to be in informal caregiving roles (Erikkson et al., 2013). It is worth noting that two studies were completed with the same cohort of participants. Additionally for three participants, they were listed as ‘support workers’ and no gender information provided. These three were excluded in calculations on the gender split on caregivers.

Mean participant ages were gathered. In 8 of the 9 studies the mean ABI survivor age range was between 21.30 and 41.97 years. The mean age of the stroke survivors in Rashid et al. (2013) was older than the other studies at 67.35 years. Given the majority of studies focussed on TBI survivors, the younger age range is concordant with prevalence data in this area. The age of the caregiver was only reported in 5 of the 9 studies with a range of means from 44.54-65.67 years.

The relationship of caregivers to the ABI survivors was reported in all studies but in varying detail (Table 2). The majority were either parental or spousal and female. Rashid et al. (2013) focussed only on spousal caregivers with the remaining studies reporting a variety (See Appendix 1-D for tables of detailed participant demographics and frequencies).

Whether or not the ABI survivor and caregiver lived at the same address was not always clear from the information provided. Two studies (Rashid et al., 2012 and Flanagan, 1998) reported all participants lived at the same address with Rashid (2012) specifying that they should have lived together for at least one year prior to the stroke and a minimum of three months post stroke. Two studies included both those who lived together and those who did not (Alway et al., 2012 and Alway et al., 2016) and one of these provided some data on the split recruited with 65% living together (Alway et al., 2012). The remaining five studies either did not report on location or it was not explicit from the information provided whether they lived at the same address or not.

ABI Definition

How the brain injury was defined was split across the studies reviewed, with five studies using medical records to confirm presence of injury and the other four using self-report. Where self-report was utilised on three occasions specific details were requested to confirm presence and severity of injury, including details of Post- Traumatic Amnesia (PTA), Glasgow Coma Scale (GCS) or length of time unconscious, all of which are utilised as indication of brain injury severity (Sherer et al., 2008). It was not clear in the study by Fortune et al., (2016) what information was requested from participants in relation to defining the brain injury through self-report. Utilising self-report involves a lay person making a judgement about what constitutes a medical condition and may lead to inaccurate responses (Bailie et al., 2017). Previous research suggested a combination of self-report and review of medical records are collected in order to ensure accuracy of response regarding presence of TBI and that even when cued, not all instances of TBI are recalled (McKinley et al., 2016). Where medical records were utilised, two studies reported using information about PTA to define presence of injury and severity; the others mention medical records, but not specifically what information was used to define it. PTA and GCS would be less relevant in some of the populations discussed, including stroke. Additionally, presence or absence of a brain injury or severity category does not clearly map onto the long-term impact (Bramlett and Dietrich, 2015).

Measures

A mix of different measures were utilised across the studies reviewed, including self-report measures, semi-structured interviews, and formal cognitive analysis.

The measures of EE used across the studies varied. The most frequently used measure of EE was Family Questionnaire (FQ) (n=4) followed by Camberwell Family Interview (CFI) (n=3) and additionally one used Level of Expressed Emotion Scale (LEE) and one the Perceived Criticism Scale (PCS). The CFI is considered “the gold standard” in the assessment of EE (Hooley and Parker, 2006). The three studies which made use of the CFI were completed before 2010. All of the studies in this review completed after 2010 made use of shorter form assessments of EE; FQ, LEE and PCS. These shorter form assessments of EE have been reviewed and comparisons drawn between them and the CFI. The FQ was found to significantly correlate with the CFI on both initial and validation samples (Wiedemann et al., 2002). The PCS correlates reasonably well with CFI (Hooley & Parker, 2006) and was found to have good stability and validity (Renshaw, 2008). The LEE was also found to have good test-retest reliability and good internal consistency (Cole & Kazarian, 1988) although only two of its scales correlated with the critical comments (CC) scale of CFI (Van Humbeeck et al., 2002).

In terms of measures of psychological outcomes there was a variety utilised and all studies contained a measure of anxiety, depression or the two combined. The most frequently used measure of mood was the Hospital Anxiety and Depression Scale (HADS), utilised by four of the studies reviewed, with the General Health Questionnaire-28 (GHQ-28), State Trait Anxiety Inventory (STAI) and Zung Depression Rating Scale (ZDS) each used by two studies and the remaining a mix of other measures. The HADS is designed to assess elements of mood which are less likely to impacted by elements of physical health (Dawkins et al., 2006). It consists of two subscales, for anxiety and depression. Alway et al. (2012) split the

HADS into its subscales and conducted analyses with them separately. Fortune et al. (2016) and Weddell and Wood (2016; 2018) all utilised the total overall score.

Statistical Analyses

The choices of analysis utilised across the studies were appropriate for the study designs. As previously mentioned, the links between ABI, EE and emotional wellbeing were not always the primary aim of the studies included and as a result there were often options for further analysis that were not completed. Analyses were often cross-sectional and correlational in nature and therefore it was not possible to identify the direction of influence. All of the studies reviewed completed some correlational analyses with four completing further regression analyses. One study (Fortune et al., 2016) completed analysis on interventional effects. Weddell and Wood (2016; 2018) completed initial correlational analyses but the variables of interest were not included in the further analyses at later time points.

Findings – Associations between EE and Outcomes

Six of the nine studies reviewed found significant relationships between EE and some measure of psychological outcome (Alway et al., 2012; Alway et al., 2016; Flanagan, 1998; Rashid et al., 2012; Weddell, 2010; Weddell & Leggett, 2006). There was variance in whether the outcomes were related to the ABI survivor (n=8), the caregiver (n=5) or both (n=4).

Alway et al. (2012) referred to the critical comments (CC) element of EE as ‘family criticism’ within their paper. Within the research Alway et al. (2012) found that ABI survivor anxiety and depression was significantly positively associated with both ‘family criticism’ (the critical comments element of EE) and emotional over-involvement element of EE in the caregiving relationship ($p < .05$ in all associations). Additionally, family criticism and emotional over-involvement was also found to be significantly associated with caregiver anxiety and depression (*p* < .01 in all associations). The results indicated that high EE in the caregiving relationship was significantly associated with poorer psychological outcomes for both the ABI survivor and the caregiver.

Always et al. (2016) recruited ABI survivor and relative dyads and looked at both the criticism sensitivity of the survivor as well as a measure of EE with the relative at baseline and 12 months later. At baseline measurement ABI survivors with a family member scoring highly for EE were more likely to have a psychiatric diagnosis in this study ($X^2 = 5.68$, $p = 0.02$, phi = 0.31). Additionally, high criticism sensitivity was positively associated with increased probability of psychiatric diagnoses at follow up. ABI survivors were also more likely to be high in criticism sensitivity if their relative scored highly on measures of EE. The measure utilised for criticism sensitivity was the Perceived Criticism Measure, which is a short self-report measure, but could be argued may not capture the nuances of family life.

Flanagan (1998) found a significant difference between relatives rated either high or low for EE with measures of anxiety significantly higher in the high EE group (t(26) = 2,37, *p* < .05). No significant difference was found between the groups for depression, however this study was rated lower for methodological quality and was conducted with fewer participants.

Rashid et al (2012) looked specifically at stroke and was interested in the location of lesions in the study in relation to other variables. Additional analyses found a significant relationship between levels of EE in the caregiving relationship and post-stroke depression of the stroke survivors. The importance of perceptions was also explored with those with a left hand side lesion who perceived high EE in the caregiving relationship scoring significantly higher on measures of post-stroke depression (p = 0.005, f = 8.591, df = 1,56).

Weddell (2010) focussed on the critical comments element of EE and found a significant relationship between EE and ABI survivor depression and anger scores.

Additionally they found that depression increased over time where EE (critical comments) was rated highly in the relationship.

Weddell and Leggett (2006) were focussed on the factors related to judgements of personality change, however included a measure of EE as well as measures of anxiety and depression for the ABI survivor and a measure of mood for the relative. The results indicated that EE (critical comments aspect) significantly predicted judgements of personality change and also moderately correlated with the ABI survivor measures of depression and anxiety. As it was not the main focus, further exploration of the data in relation to these factors was not completed as the focus was on personality change.

The picture around the relationships between EE and psychological outcomes, for survivors and caregivers, was not clear given that the correlations were not always the primary aim in some of the studies reviewed. Where it was not one of the primary aims of the study, there was often less exploration and reporting around these data, making it more difficult to draw full conclusions, particularly in those studies where quality was found to be lower. There was also variation across the studies in terms of who completed which measures, with relatives/caregivers completing in some cases and ABI survivors in others, this lack of consistency again limits the conclusions that can be drawn.

Two of the studies utilised the same cohort of participants, both were adequately powered. Weddell and Wood, (2016) found EE in the caregiving relationship and emotional distress of the TBI survivor were positively correlated, but the strength of the relationships was not as expected with only some reaching statistical significance on one-tailed tests. The second study (Weddell and Wood, 2018) did not report again on the previous links between emotional distress and EE, but instead looked at the discrepancy between survivor and informant perspectives. The results highlighted that patients and informants held differing views on how they conceptualised patient personality change. The impact of patient insight post-injury could explain this variation. The results showed the importance of gathering both survivor and caregiver perspectives.

Both studies by Weddell and Wood (2016; 2018) considered a mix of medico-legal patients and NHS patients. Efforts were made to minimise possible impact of malingering by removing any patients who failed the Word Memory Test (Green et al., 1999) and Test of Memory Malingering (Tombaugh, 1996).

Fortune et al., (2016) was a study of the efficacy of a family intervention. Prior to the intervention, correlation analysis was completed including EE, caregiver strain and caregiver anxiety and depression. No significant correlational relationship was found between their measure of EE and the measures of distress or carer strain. Univariate analysis did not appear to have been completed or was not reported in the study. Fortune et al., (2016) provided narrative information as to why some participants did not complete all elements of the study, explaining that most reported travel and alternative care arrangements to be the main reasons. It is possible that where travel and alternative care are difficult to manage it may mean that participants with more severe difficulties were not captured within the study.

Discussion

The aims of the current review were to explore the relationships between EE in the caregiving relationship and psychological well-being in ABI populations to ascertain if consistent associations were found. Systematic searches of five electronic databases using MeSH terms for ABI and search terms for EE identified 117 records of which nine were eligible for inclusion into the study. Six of the nine studies reviewed found significant relationships between EE and some measure of psychological outcome (Alway et al., 2012; Alway et al., 2016; Flanagan, 1998; Rashid et al., 2012; Weddell, 2010; Weddell & Leggett, 2006). There was variance in whether the outcomes were related to the ABI survivor (*n*=8), the caregiver (*n*=5) or both (*n*=4).

One of the main issues highlighted within this review is the lack of research in ABI and EE in general but also specifically with stroke populations. As mentioned, almost all of the studies reviewed here were focused on TBI populations, with only one (Rashid et al., 2012) exploring stroke exclusively and another (Fortune et al., 2016) researching a mix of ABI types. Further research should explore the relationship in other forms of ABI such as stroke in order to build further understanding.

Whilst six of the studies reviewed found significant relationships between EE and some measure of psychological outcome, there was variation across the studies making it difficult to draw firm conclusions. There was more of a focus within the studies reviewed on the outcomes for the ABI survivor, with only five studies completing measures with the caregiver/relative and often fewer measures and analyses completed. The variance in whether the outcomes were related to the ABI survivor, caregiver or both limited the comparisons that can be drawn and further highlighting the lack of research in this area. There was more focus given to the impact of EE in the caregiving relationship on the psychological wellbeing of the ABI survivor than the caregiver in the studies reviewed here. Given the evidence on the impact of caregiver wellbeing on outcomes (Bivona et al., 2020), further research exploring the link between EE and caregiver outcomes is indicated. In the wider literature regarding EE in other conditions or mental health problems, EE of carers is associated consistently with their levels of distress or wellbeing (Safavi et al., 2017). Further research could explore the dyadic relationship and consider outcomes of the dyad as opposed to just the individual ABI survivor and caregiver. Cook and Kenny (2005) developed Actor Partner Interdependence Model (APIM) and statistical analyses which consider the impact of both parts of the dyad in relation to the outcomes.

There was a variety of measures utilised across the studies reviewed. Consistent use of measures would allow for easier comparison across research both in relation to measures of EE and psychological outcome measures. The HADS was the most frequently used in the papers reviewed here. The HADS is often used within medical and physical health populations and research in TBI populations has found it to be a reliable measure of emotional distress (Whelan-Goodinson et al., 2009). Despite frequent use, there is argument to interpret results with caution in ABI populations, particularly the depression subscale, as some symptoms may be related to the ABI sequalae as opposed to mood, such as “I feel as if I am slowed down” in relation to stroke survivors (Dawkins et al., 2006).

There has been research on the differing impact of ABI and the changing needs of the ABI survivor over time (Frosch et al., 1997) and given the differences, further research should consider gathering information regarding the time since ABI occurred. Additionally, the levels of intervention, support and rehabilitation which have been provided to ABI survivors and caregivers would also be useful to know.

Research by Migliorini et al. (2019) suggested that living circumstances may be a strong predictor variable of caregiver burden. There were lower levels of family burden where the brain injured survivor lived in shared supported accommodation. However, relatives adjusted better when the survivor lived in the family home (Migliorini et al., 2019). In the studies reviewed here, information about living situation was not always gathered and/or reported on, limiting what can be drawn from the results in relation to this.

Strengths and Limitations

This review explored an area of research which had not previously been reviewed. Evidence was found to support the links between EE and psychological wellbeing in ABI populations with six of the studies finding significant relationships. Only nine relevant studies were found for this review. Whilst this highlights the huge lack of research in this area it also limits the conclusions that can be drawn. Additionally, none of the studies had large participant numbers with the maximum being only 87 pairs. This indicates that a substantial level of caution should be used in the interpretation of these findings. However, they are consistent with other areas of physical and mental health examining the relationships between EE and outcomes for both carers and people affected by symptoms (Safavi et al., 2017).

Whilst the papers included were quality appraised blind by two raters, the inclusion and exclusion of the papers into the study was completed by the principal investigator only and would have benefitted from a second opinion to reduce the risk of bias.

Additionally, the variables of interest to this review were not always the main focus of the study and instead were part of wider analyses. This limits what can be extracted and discussed about the results.

Conclusion

There has not yet been a wealth of consistent high quality research into EE, ABI and emotional wellbeing. Whilst this review suggests some evidence of links, often the combination of these factors has been secondary to other aspects of the research in question. Further research with a focus on the EE and psychological outcomes along with consideration of other contributing factors would be beneficial in developing the concept within ABI populations.

Overall quality assessment showed that none of the studies reviewed met the highest requirements to be considered to have been designed or conducted in such a way as to have minimised the risk of bias. Most had not addressed all sources of bias or did not report the detail within the study. Further research into this area should seek to minimise bias where possible and be thorough in their reporting of processes in order increase the quality of studies produced in this area.

Clinicians should be aware of EE as a concept and also the relationship between high EE and psychological wellbeing of both the survivor and caregiver in ABI populations. Services should consider how they can support families and reduce the potential negative impact of high EE in terms of outcomes.

Overall, there is scope and justification for further high quality and more detailed and focussed research into the links between EE and emotional wellbeing in those affected by ABI and their caregivers in general. Considering the variation between types of brain injury, future research may benefit from focus on a specific type of brain injury such as stroke or areas of neuropsychological problems and the impact on caregivers both of which are not frequently represented within research.

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Figure 1: *Flow diagram showing the process of identifying articles (PRISMA, 2009)*

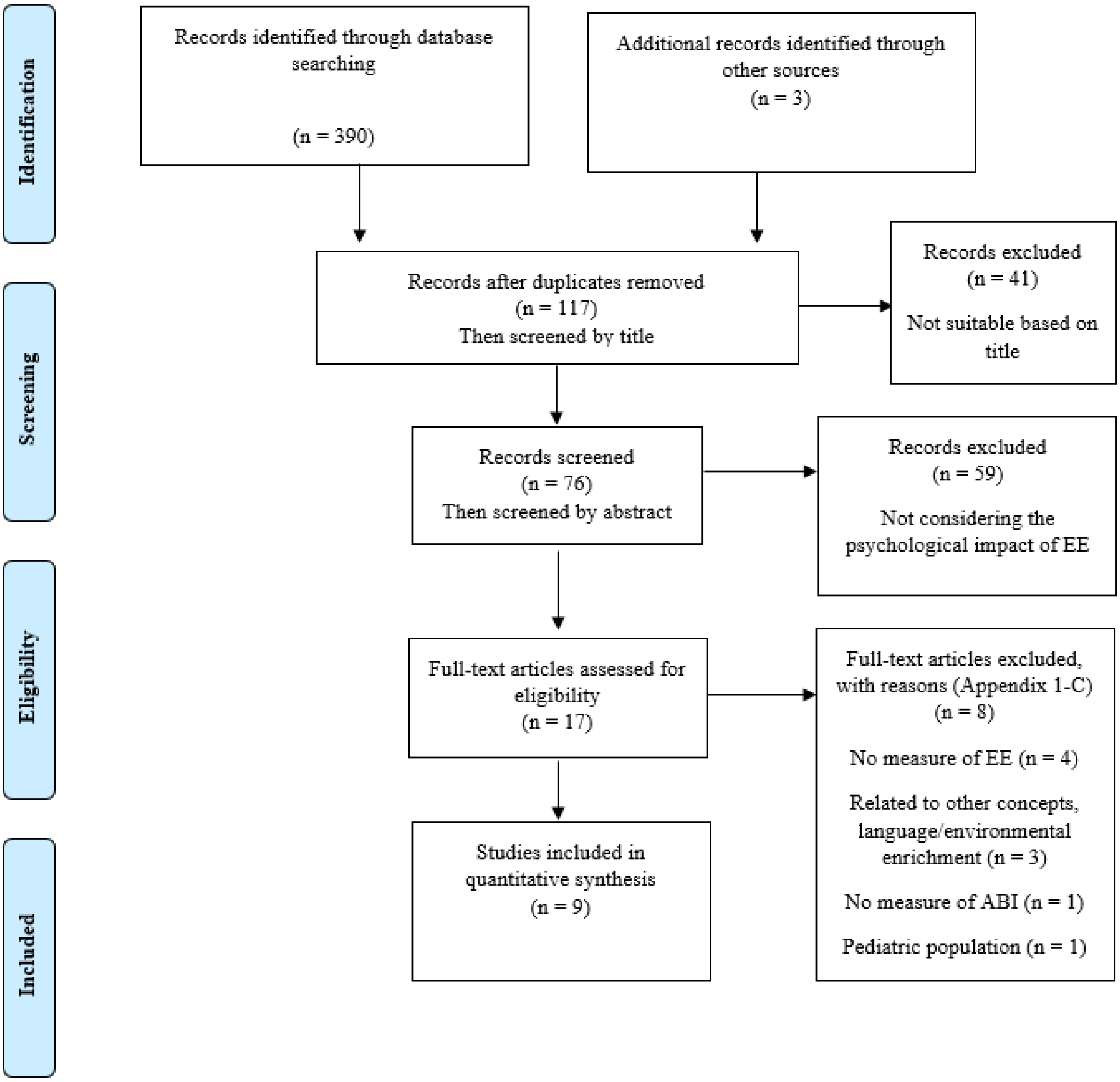


Figure 1. PRISMA Flow Diagram for articles identified through database searching

Table 1: *Quality assessment ratings (NICE, 2018)*

Study	1.1	1.2	1.3	2.1	2.2	2.3.	2.4	2.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.6	Total Internal Validity	Total External Validity
	Source population or source area well described	Eligible population or area representative of the source population	Selected participants or areas represent eligible population	Selection of exposure and control bias minimised	Selection of explanatory variables based on a sound theoretical basis	Contamination acceptably low	How well were likely confounding factors identified and controlled	Setting applicable to the UK?	Outcome measures and procedures reliable	Outcome measurements complete	All important outcomes assessed	Similar follow-up time in exposure and comparison groups	Follow-up time meaningful	Study sufficiently powered to detect an intervention effect	Multiple explanatory variables considered in the analyses	Analytical methods appropriate	Association given or calculable, association meaningful	Are the study results internally valid (i.e. unbiased)?	Are the findings generalisable to the source population (i.e. externally valid)?
Alway et al. 2016	+	+	+	NA	+ +	NA	+	+	+	+ +	+	NA	NA	NR	+	+	+	+	+
Alway et al. 2018	+	+	+	NA	+	NA	+	+	+	+ +	+	+ +	+ +	NR	+	+	-	+	+
Flanagan, 1998	-	NR	NR	NA	+	NA	-	NR	+	+	-	NA	NA	NR	+	+	-	-	-
Fortune et al. 2016	+	+	-	NR	+	NR	+	+ +	+	+	+	+ +	+	+ +	+	+	+	+	+
Rashid et al. 2013	+	+	+	NA	+	NA	+	+ +	+	+	+	NA	NA	+ +	+	+	+	+	+
Weddell et al. 2006	+	+	+	NA	+	NA	+	+ +	+ +	+	+	NA	NA	NR	+	+ +	+	+	+
Weddell, 2010	+	+	+	NA	+	NA	+	+ +	+	+ +	+	NA	NA	NR	+	+	+	+	+
Weddell & Wood, 2016	+	-	-	NA	+	NA	+	+ +	+	+	+	NA	NA	+ +	+	+	+	+	+
Weddell & Wood, 2018	+	-	-	NA	+	NA	+	+ +	+	+	+ +	NA	NA	+ +	+	+	+	+	+

Questions: The NICE quality appraisal checklist – quantitative studies reporting correlations and associations (p. 200 - 205; 2018)

Section 1: Population
1.1 - Is the source population or source area well described?
1.2 - Is the eligible population or area representative of the source population?
1.3 - Do the selected participants or areas represent the eligible population or area?

Section 2: Method of selection of exposure (or comparison) group
2.1 - Selection of exposure (and comparison) group. How was selection bias minimised?
2.2 - Was the selection of explanatory variables based on a sound theoretical basis?
2.3 - Was the contamination acceptably low?
2.4 - How well were likely confounding factors identified and controlled?
2.5 - Is the setting applicable to the UK?

Section 3: Outcomes
3.1 - Were the outcome measures and procedures reliable?
3.2 - Were the outcome measurements complete?
3.3 - Were all important outcomes assessed?
3.4 - Was there a similar follow-up time in exposure and comparison groups?
3.5 - Was follow-up time meaningful?

Section 4: Analyses
4.1 - Was the study sufficiently powered to detect an intervention effect (if one exists)?
4.2 - Were multiple explanatory variables considered in the analyses?
4.3 - Were the analytical methods appropriate?
4.6 - Was the precision of association given or calculable? Is association meaningful?

Section 5: Summary
5.1 - Are the study results internally valid (i.e. unbiased)? – Total Internal Validity
5.2 - Are the findings generalisable to the source population (i.e. externally valid)? – Total External Validity

Scale

++ indicates that for that particular aspect of study design, the study has been designed or conducted in such a way to minimise the risk of bias.
+ indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.
- should be reserved for those aspects of the study design in which significant sources of bias may persist.
NR not reported should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered.
NA not applicable should be reserved for those study design aspects that are not applicable given the study design under review.

Table 2:

Characteristics of studies reviewed

Study	Quality Rating	Design	Setting and Location	Sample Characteristics	Outcome measures	Types of measures utilised	Brain injury characteristics	Impact on relative or caregiver?	Findings and Comments
Alway, McKay, Ponsford and Schönberger, (2012)	+ +	Cross Sectional Study	Inpatient rehabilitation service at Epworth Hospital, Melbourne, Australia.	43 participant pairs, patients with TBI (34 males, 9 females) and relatives (5 males 38 females)	Patients; HADS – Anxiety and Depression. Relatives; FQ – levels of EE. IPQ-R-PC – attributions of patient's symptom controllability and HADS	Self-report measures	TBI of varying severity as defined by PTA duration records from hospital	Relatives also completed HADS	Significant association between higher levels of family criticism with patient anxiety and depression. Emotional over-involvement (EOI) also associated with higher patient anxiety and depression. Further association found between relatives patient directed criticism and relatives anxiety and depression
Alway, Ponsford and McKay, (2016)	+ +	Cohort Study – Baseline and 12 month follow up	Inpatient rehabilitation service at Epworth Hospital, Melbourne, Australia.	60 participant pairs, patients with TBI (49 males, 11 females) and relatives (10 males, 50 females)	Patients; SCID-I, PCM and demographics. Relatives; FQ and demographics	Semi-structured interviews	TBI of varying severity as defined by PTA duration records from hospital	Not Assessed	High criticism sensitivity at baseline associated with increased probability of a psychiatric diagnosis at follow up. High EE relatives were associated with psychiatric diagnosis in TBI survivor at baseline, but not predictive of outcome at follow up.

Flanagan, (1998)	- -	Retrospective Cross Sectional Study	UK based. No detail on recruitment methods or specific location.	Care-givers - 28 participants; (25 female, 3 male) 16 self-defined as family carers, 12 as sole carers.	Relatives; Leeds Scale for Self-Assessment of Anxiety and Depression at start and 12 months. CFI and demographics Patients; None	Semi-structured interviews and self-report measures	TBI was defined as between 1 and 180 days unconscious	Relatives completed Leeds Scale at initial and 12 months	12 high EE and 16 low EE. Anxiety significantly higher in high EE group. Sole carers significantly higher levels of EE than those who identified as family carers. Multiple regression revealed carer status most predictive of EE. No measures completed with TBI patient.
Fortune, Rogan and Richards, (2016)	+ +		Neurorehabilitation services, advocacy groups and support networks for carers of people with ABI in the Republic of Ireland.	113 participants at initial enrolment, 76 completed group program, 61 at 3 month follow up. 82% female participants. 47% parent, 44% spouse/partner, 5% son or daughter and 4% siblings	Relatives; FIM/FAM, CSI, PCS, HADS Patients; PCS	Self-report measures	Self-reported, categorised and defined by study participants	CSI and HADS	Focus of the study was on the efficacy of a family intervention. However, initial analysis included regression with EE, caregiver strain and caregiver anxiety and depression. There was no significant interaction between the measure of EE and carer strain or distress. No measures completed with the ABI patients
Rashid, Clarke and Rogish, (2012)	+ +	Cross Sectional Study	Community stroke teams from three NHS hospitals in East Riding,	60 participant pairs, 30 left lesion and 30 right lesion and	Patients; EADL scale, assessing independence	Self-report measures	Ischaemic or haemorrhagic stroke confirmed by	Not Assessed	Interaction between lesion laterality, spousal EE and post-stroke depression (PSD) was not directly supported. Importance of

			Yorkshire, England.	their partner/spousal carer. (43 male stroke survivors and 17 female)	and abilities. PSDRS, measure of mood and LEE, measure of EE. Partner/spousal carer; LEE, measure of EE.		medical records. Excluded if bilateral stroke, severe lang difficulties or risk of dying		perceived EE in relation to PSD was significant; LHS who perceived high EE showed significantly higher levels of PSD. Additionally, relationships were found between level of EE and PSD and also lesion laterality and PSD.
Weddell, (2010)	+ +	Cross Sectional Study	Acute neurosurgical unit, Swansea, Wales, UK	78 white participant pairs. TBI patients comprised 63 males and 15 females. Relatives comprised 41 mothers, 2 fathers, 24 wives and 11 husbands (65 female, 13 male)	Patients; ZDS as a measure of depression, STAI as a measure of anxiety STAXI measuring anger expression. ATR measuring anger towards relative. Cognitive tests, WAIS-R and WMS subtests. B-SIT for smell identification. Plus, demographics and BI data. Relatives; CFI	Mix of self-report measures, semi-structured interview and cognitive testing was utilised.	Admissions for a severe TBI to an acute neurosurgical unit. TBI of varying severity utilising medical records to confirm	Relatives completed GHQ-28 as a measure of mood	Study focussed on the ‘critical comments’ element of EE during the CFI. Patient outcomes and emotional reactions were significantly associated with CC from their relatives after controlling for social class and TBI severity. Study also found that depression increased over time where there was high CC in the relationship.

					measuring EE, ATR and GHQ-28 for mood.				
Weddell and Leggett, (2006)	+ +	Cross Sectional Study	Acute neurosurgical unit, Swansea, Wales, UK	87 participant pairs. 72 severe TBI and 15 mild TBI (71 male and 15 female). Relatives comprised 45 mothers, 4 fathers, 25 wives, 12 husbands and 1 brother.	Patients; PTA duration, Cognitive tests, WAIS-R and WMS subtests. UPSIT as a measure of olfaction. STAI and ZDS for mood and ATR. Relatives CFI measuring EE and GHQ-28	Mix of self-report measures, semi-structured interview and cognitive testing was utilised.	Admissions for a severe TBI to an acute neurosurgical unit. TBI of varying severity utilising medical records to confirm	Relatives completed GHQ-28 as a measure of mood	Study investigated relative's judgements of personality change (PC) following TBI. The study found a relationship between patient mood measures and CC element of EE. Also that social-emotional factors were predictive of PC judgements in both participant and relatives.
Weddell and Wood, (2016)	+ +	Cross Sectional Study	Recruited from two groups; 1. medico-legal claimants referred by their solicitor, patients referred to sub-regional neuropsychology dept. Wales, UK	71 participant pairs recruited. (63 with severe TBI and 8 with moderately severe TBI). Informants comprised 9 fathers, 18 mothers, 29 female and 7 male partners, 3 daughters, 1 son,	Patient; Cognitive tests - WAIS-III, WMS-III, verbal fluency and BADS zoo map. B-SIT and SIT for olfaction. DEX questionnaire and BIS-11 for executive and social function.	Mix of self-report measures, semi-structured interview and cognitive testing was utilised.	Moderately severe or severe TBI as assessed by self-report of GCS and PTA	Not assessed	Self-reported PC was not correlated with high expressed emotion of relatives. Although relationships were found between EE and emotional distress of the patient, these were not found to be significant in this study.

				1 sister and 3 support workers	HADS, BDI-FS, STAXI-II and self-reported PC as measures of emotional adjustment. Informants; FQ as measure of EE, specifically CC element.				
Weddell and Wood, (2018) †	+ +	Case Control Design	Recruited from two groups; 1. medico-legal claimants referred by their solicitor, patients referred to sub-regional neuropsychology dept. Wales, UK	71 participant pairs recruited. (63 with severe TBI and 8 with moderately severe TBI). Informants comprised 9 fathers, 18 mothers, 29 female and 7 male partners, 3 daughters, 1 son, 1 sister and 3 support workers	Patient; Cognitive tests - WAIS-III, WMS-III, verbal fluency and BADS zoo map. B-SIT and SIT for olfaction. DEX questionnaire and BIS-11 for executive and social function. HADS, BDI-FS, STAXI-II and self-reported PC as measures of emotional adjustment.	Mix of self-report measures, semi-structured interview and cognitive testing was utilised.	Moderately severe or severe TBI as assessed by self-report of GCS and PTA	Not Assessed	Same cohort as Weddell and Wood (2016) but with a shifted focus in comparing participant and informant perspectives. There were links between EE, participant emotional distress and both patient and informant perceived PC. However, the links were influenced on whether it was from patient or informant perspective. The relationship between EE and emotional distress was not discussed.

Informants; FQ as measure of EE, both CC and EOI. Ratings of PC were utilised from previous paper.

┼The data included in the Weddell and Wood (2018) study is from the same cohort of participants as the Weddell and Wood (2016) study. However there were different measures completed and therefore the studies have been reported separately.

Note: **TBI** = Traumatic Brain Injury; **HADS** = Hospital Anxiety and Depression Scale; **FQ** = The Family Questionnaire; **EE** = Expressed Emotion; **IPQ-R-PC** = The Illness Perceptions Questionnaire – Revised – Personality Change; **PTA** = Post Traumatic Amnesia; **EOI** = Emotional Over-Involvement; **CC** = Critical Comments; **SCID-I** = The Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders (DSM-IV); **PCM** = Perceived Criticism Measure; **CFI** = Camberwell Family Interview; **FIM/FAM** = The Functional Independence Measure/The Functional Assessment Measure; **CSI** = Caregiver Strain Index; **PCS** = Perceived Criticism Scale; **ABI** = Acquired brain Injury; **EADL** = Extended Activities of Daily Living Scale; **PSDRS** = Post Stroke Depression Scale; **LEE** = Level of Expressed Emotion Scale; **PSD** = Post-Stroke Depression; **ZDS** = Zung Depression Rating Scale; **STAI** = State Trait Anxiety Inventory; **STAXI** = State Trait Anger Expression Inventory; **ATR** = Anger Toward Relative Questionnaire (Created for study Weddell, 2010); **WAIS-R** = Wechsler Adult Intelligence Scale- Revised; **WAIS-III** = Wechsler Adult Intelligence Scale – Third Edition; **WMS** = Wechsler Memory Scale; **WMS-III** = Wechsler Memory Scale – Third Edition; **B-SIT** = Brief Smell Identification Test; **SIT** = Smell Identification Test; **BI** = Brain Injury; **GHQ-28** = General Health Questionnaire -28; **UPSIT** = University of Pennsylvania Smell Identification Test; **PC** = Personality Change; **BADS** = Behavioural Assessment of the Dysexecutive Syndrome; **DEX** = The Dysexecutive Questionnaire; **BIS-11** = Barratt Impulsiveness Scale; **BDI-FS** = Beck Depression Inventory – Fast Screen; **STAXI-II** = The State-Trait Anger Expression Inventory-2; **GCS** = Glasgow Coma Scale

Appendix 1-A:

PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
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.	

Section and Topic	Item #	Checklist item	Location where item is reported
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).	
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 estimate 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	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	

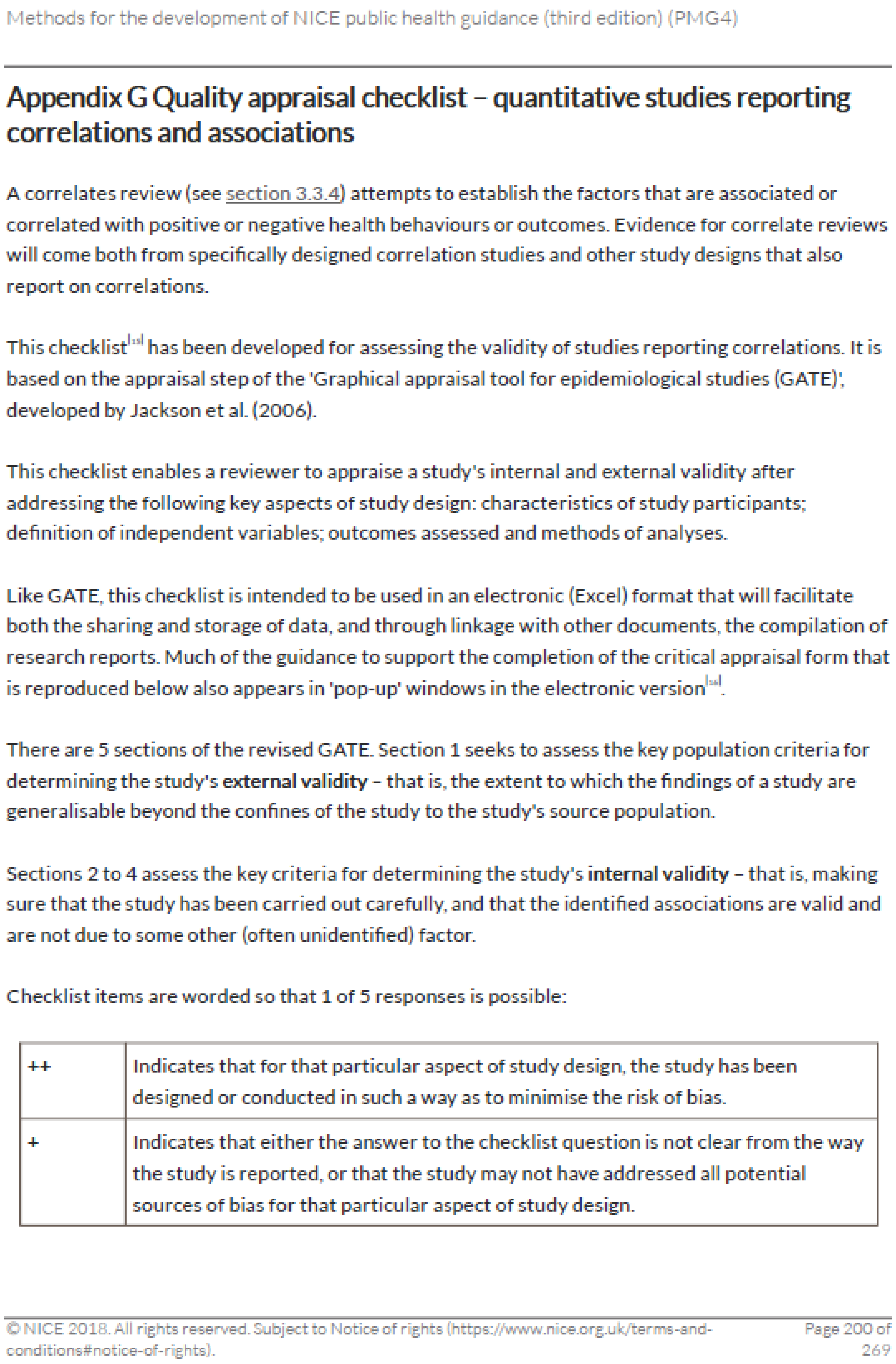
Section and Topic	Item #	Checklist item	Location where item is reported
evidence			
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	
	23b	Discuss any limitations of the evidence included in the review.	
	23c	Discuss any limitations of the 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 found: 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

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

Appendix 1-B:

NICE Quality Appraisal Checklist



Appendix G Quality appraisal checklist – quantitative studies reporting correlations and associations

A correlates review (see section 3.3.4) attempts to establish the factors that are associated or correlated with positive or negative health behaviours or outcomes. Evidence for correlate reviews will come both from specifically designed correlation studies and other study designs that also report on correlations.

This checklist[15] has been developed for assessing the validity of studies reporting correlations. It is based on the appraisal step of the 'Graphical appraisal tool for epidemiological studies (GATE)', developed by Jackson et al. (2006).

This checklist enables a reviewer to appraise a study's internal and external validity after addressing the following key aspects of study design: characteristics of study participants; definition of independent variables; outcomes assessed and methods of analyses.

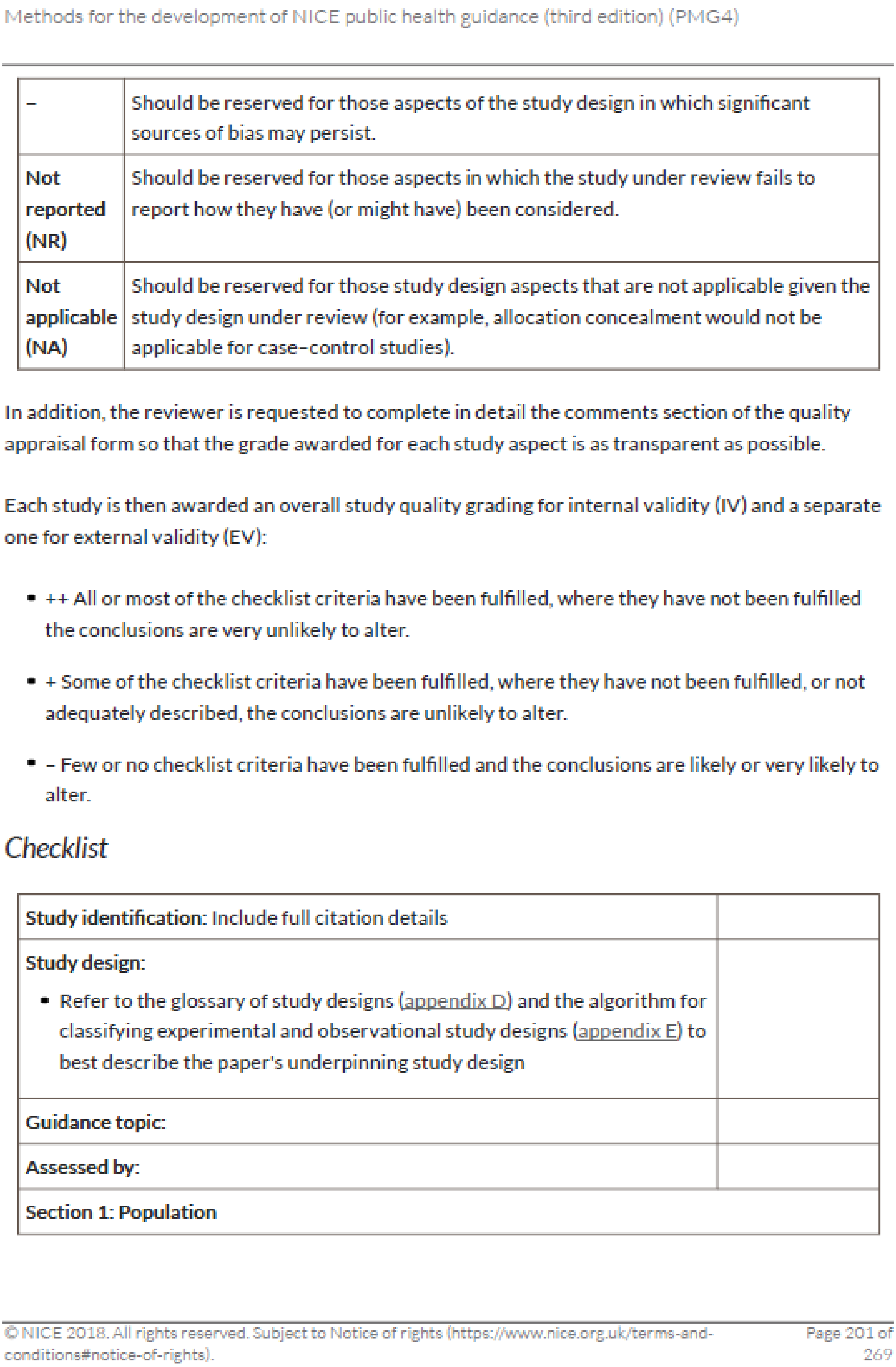
Like GATE, this checklist is intended to be used in an electronic (Excel) format that will facilitate both the sharing and storage of data, and through linkage with other documents, the compilation of research reports. Much of the guidance to support the completion of the critical appraisal form that is reproduced below also appears in 'pop-up' windows in the electronic version[16].

There are 5 sections of the revised GATE. Section 1 seeks to assess the key population criteria for determining the study's **external validity** – that is, the extent to which the findings of a study are generalisable beyond the confines of the study to the study's source population.

Sections 2 to 4 assess the key criteria for determining the study's **internal validity** – that is, making sure that the study has been carried out carefully, and that the identified associations are valid and are not due to some other (often unidentified) factor.

Checklist items are worded so that 1 of 5 responses is possible:

++	Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias.
+	Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.



–	Should be reserved for those aspects of the study design in which significant sources of bias may persist.
Not reported (NR)	Should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered.
Not applicable (NA)	Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case–control studies).

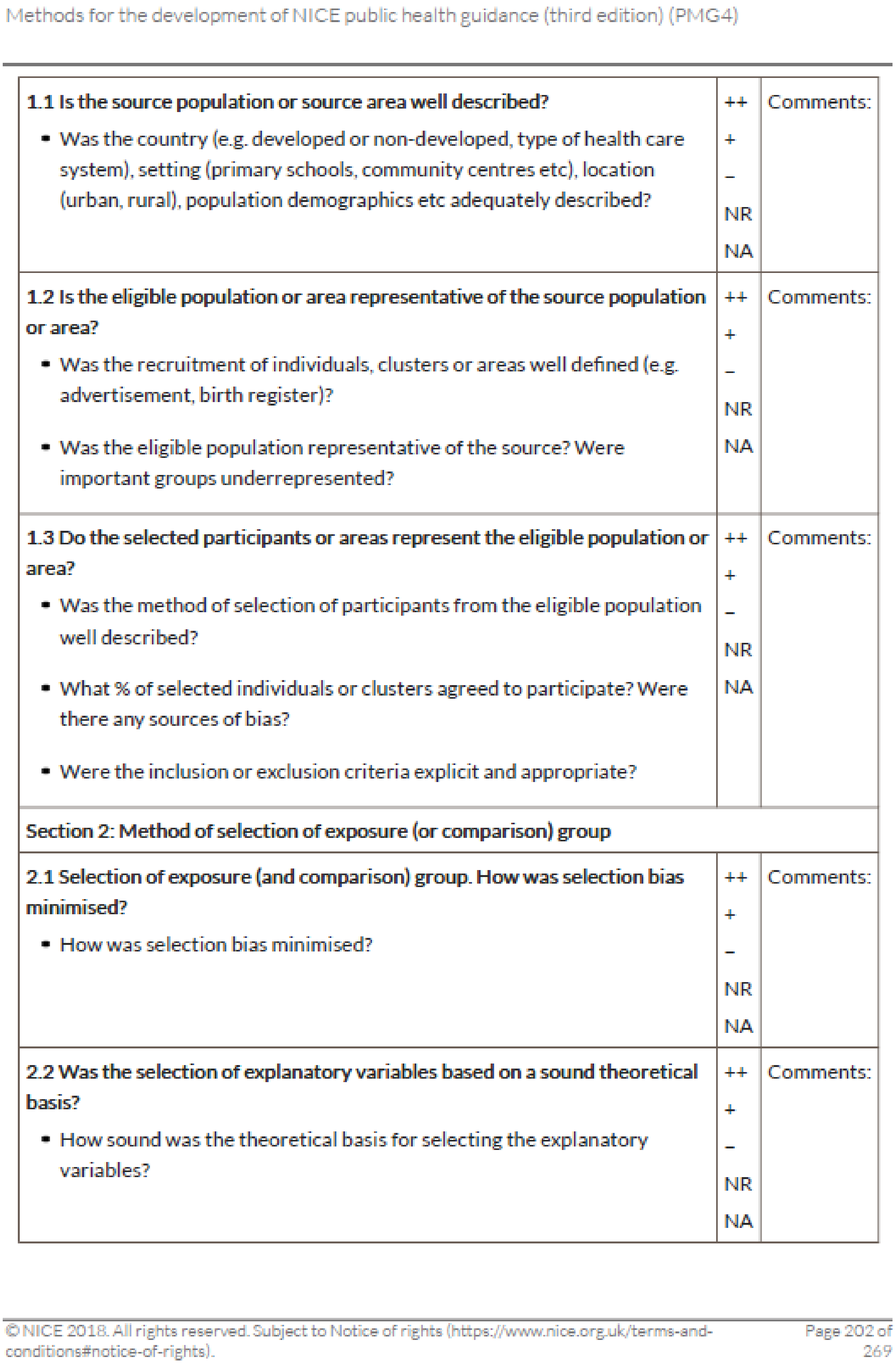
In addition, the reviewer is requested to complete in detail the comments section of the quality appraisal form so that the grade awarded for each study aspect is as transparent as possible.

Each study is then awarded an overall study quality grading for internal validity (IV) and a separate one for external validity (EV):

- ++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.
- + Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
- – Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

Checklist

Study identification: Include full citation details	
Study design: - Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design	
Guidance topic:	
Assessed by:	
Section 1: Population	



Methods for the development of NICE public health guidance (third edition) (PMG4)

1.1 Is the source population or source area well described? - Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described?	++ + − NR NA	Comments:
1.2 Is the eligible population or area representative of the source population or area? - Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? - Was the eligible population representative of the source? Were important groups underrepresented?	++ + − NR NA	Comments:
1.3 Do the selected participants or areas represent the eligible population or area? - Was the method of selection of participants from the eligible population well described? - What % of selected individuals or clusters agreed to participate? Were there any sources of bias? - Were the inclusion or exclusion criteria explicit and appropriate?	++ + − NR NA	Comments:
Section 2: Method of selection of exposure (or comparison) group		
2.1 Selection of exposure (and comparison) group. How was selection bias minimised? - How was selection bias minimised?	++ + − NR NA	Comments:
2.2 Was the selection of explanatory variables based on a sound theoretical basis? - How sound was the theoretical basis for selecting the explanatory variables?	++ + − NR NA	Comments:

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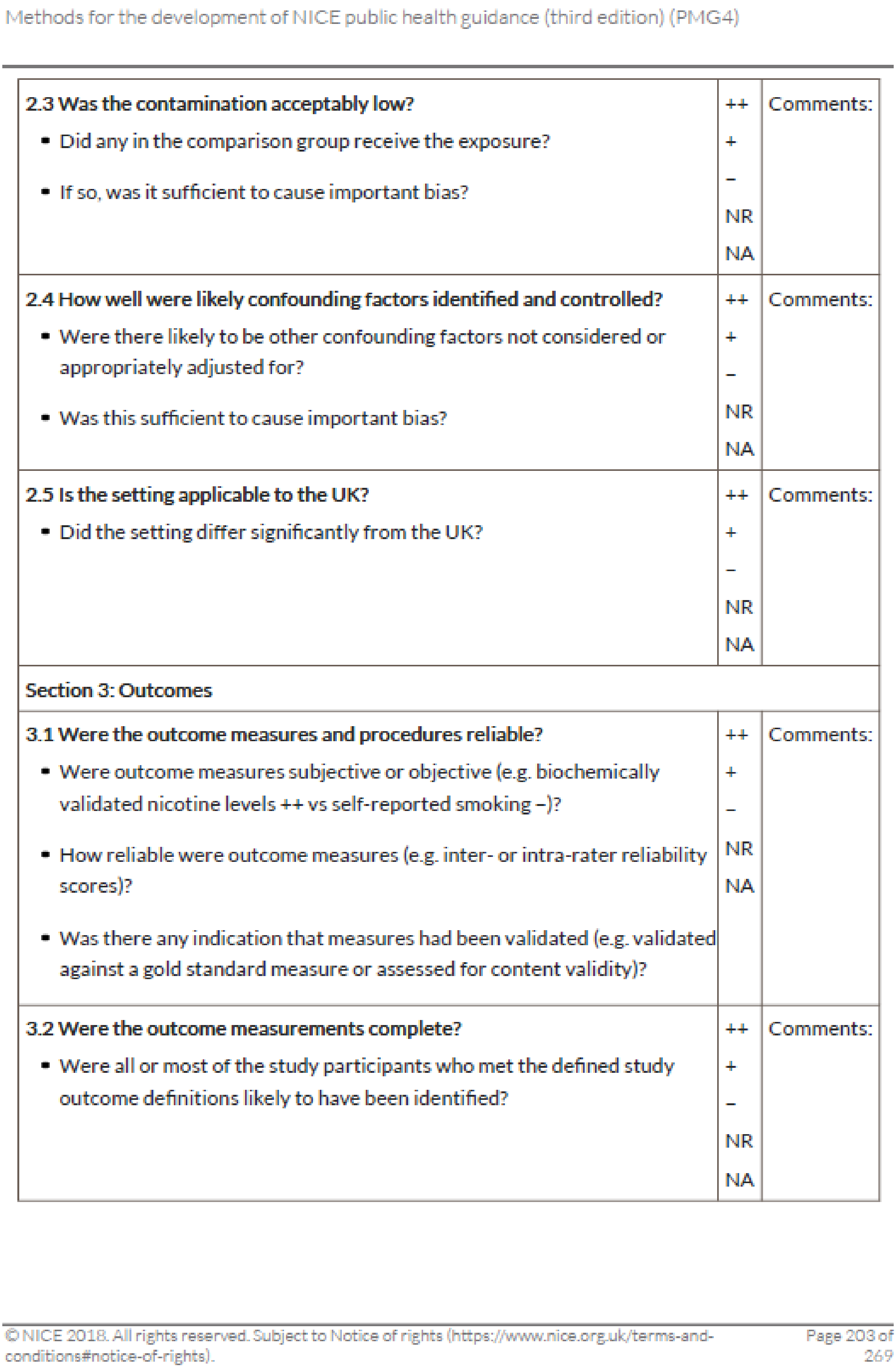

Methods for the development of NICE public health guidance (third edition) (PMG4)

2.3 Was the contamination acceptably low? - Did any in the comparison group receive the exposure? - If so, was it sufficient to cause important bias?	++ + – NR NA	Comments:
2.4 How well were likely confounding factors identified and controlled? - Were there likely to be other confounding factors not considered or appropriately adjusted for? - Was this sufficient to cause important bias?	++ + – NR NA	Comments:
2.5 Is the setting applicable to the UK? - Did the setting differ significantly from the UK?	++ + – NR NA	Comments:
Section 3: Outcomes		
3.1 Were the outcome measures and procedures reliable? - Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking –)? - How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)? - Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?	++ + – NR NA	Comments:
3.2 Were the outcome measurements complete? - Were all or most of the study participants who met the defined study outcome definitions likely to have been identified?	++ + – NR NA	Comments:

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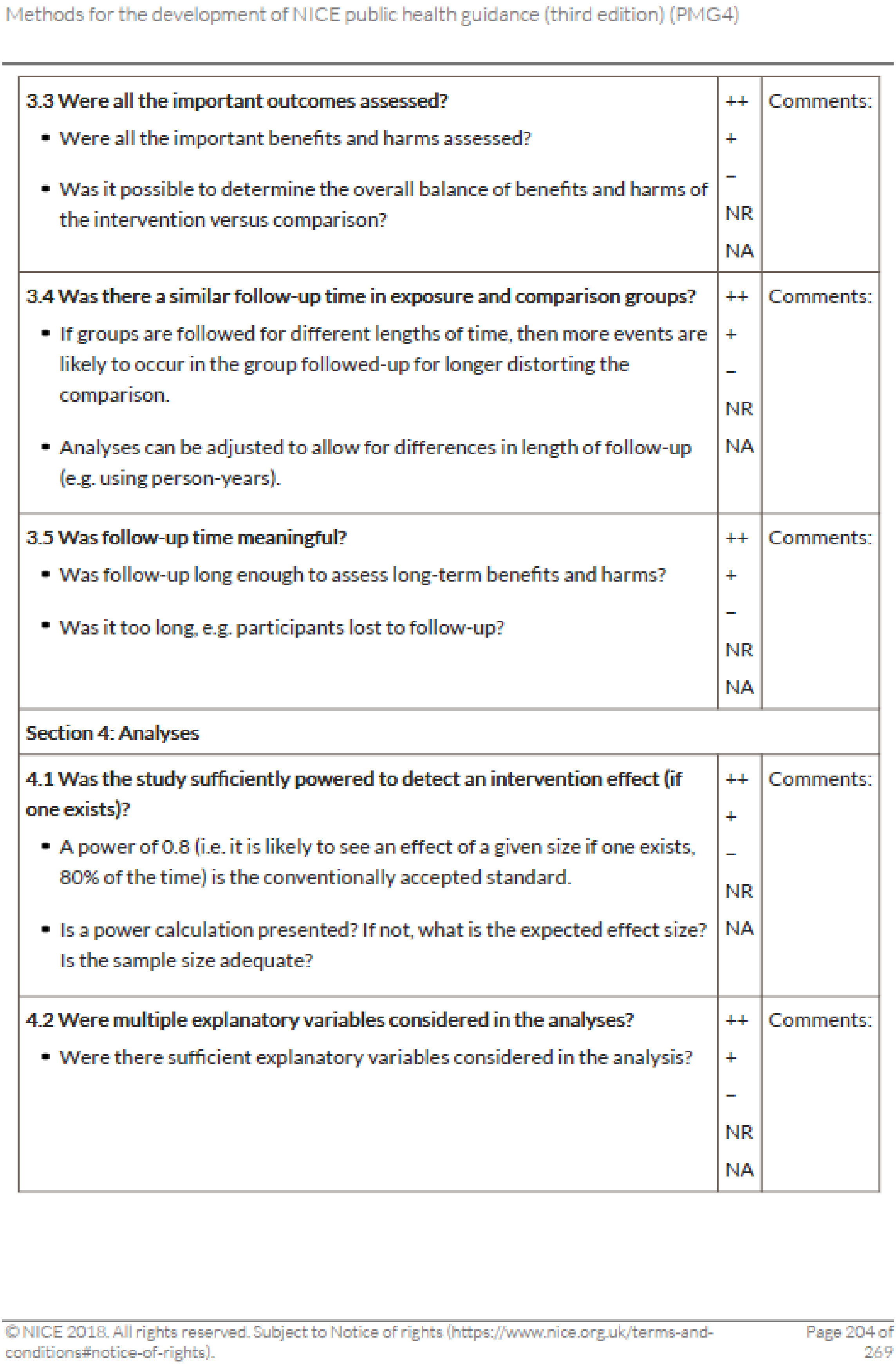
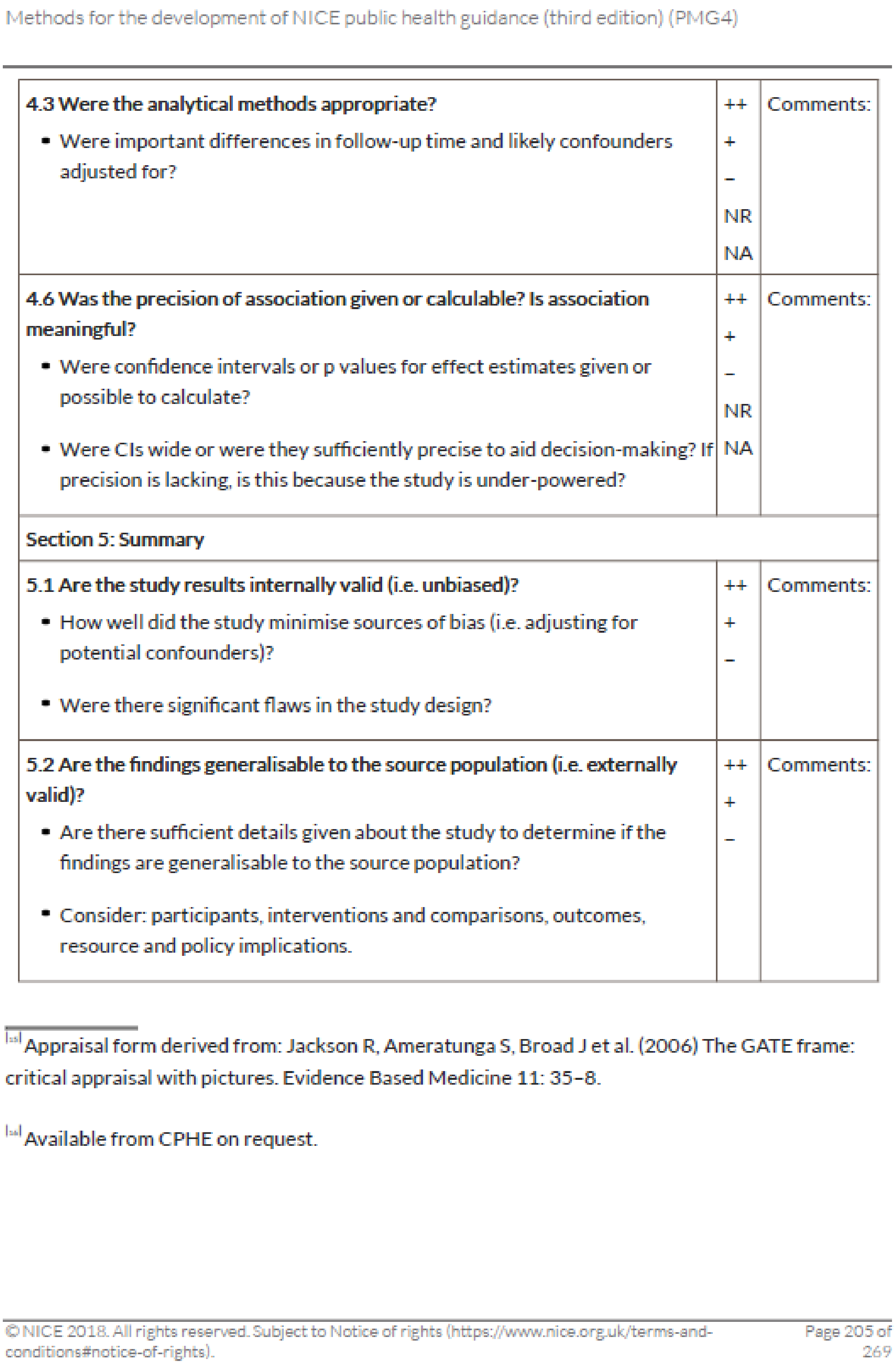


Methods for the development of NICE public health guidance (third edition) (PMG4)

3.3 Were all the important outcomes assessed? ▪ Were all the important benefits and harms assessed? ▪ Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?	++ + − NR NA	Comments:
3.4 Was there a similar follow-up time in exposure and comparison groups? ▪ If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison. ▪ Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).	++ + − NR NA	Comments:
3.5 Was follow-up time meaningful? ▪ Was follow-up long enough to assess long-term benefits and harms? ▪ Was it too long, e.g. participants lost to follow-up?	++ + − NR NA	Comments:
Section 4: Analyses		
4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)? ▪ A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard. ▪ Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?	++ + − NR NA	Comments:
4.2 Were multiple explanatory variables considered in the analyses? ▪ Were there sufficient explanatory variables considered in the analysis?	++ + − NR NA	Comments:



4.3 Were the analytical methods appropriate? - Were important differences in follow-up time and likely confounders adjusted for?	++ + − NR NA	Comments:
4.6 Was the precision of association given or calculable? Is association meaningful? - Were confidence intervals or p values for effect estimates given or possible to calculate? - Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?	++ + − NR NA	Comments:
Section 5: Summary		
5.1 Are the study results internally valid (i.e. unbiased)? - How well did the study minimise sources of bias (i.e. adjusting for potential confounders)? - Were there significant flaws in the study design?	++ + −	Comments:
5.2 Are the findings generalisable to the source population (i.e. externally valid)? - Are there sufficient details given about the study to determine if the findings are generalisable to the source population? - Consider: participants, interventions and comparisons, outcomes, resource and policy implications.	++ + −	Comments:

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[55] Appraisal form derived from: Jackson R, Ameratunga S, Broad J et al. (2006) The GATE frame: critical appraisal with pictures. Evidence Based Medicine 11: 35–8.

[56] Available from CPHE on request.

Appendix 1-C:

Articles Excluded with Reasons

Study	Reason for Exclusion
Dams-O'Connor, K., Spielman, L., Singh, A., Gordon, W. A., Lingsma, H. F., Maas, A. I., ... & Vassar, M. J. (2013). The impact of previous traumatic brain injury on health and functioning: a TRACK-TBI study. *Journal of neurotrauma*, *30*(24), 2014-2020.	No measures of EE or family criticism completed
Dennis, M., Purvis, K., Barnes, M. A., Wilkinson, M., & Winner, E. (2001). Understanding of literal truth, ironic criticism, and deceptive praise following childhood head injury. *Brain and language*, *78*(1), 1-16.	Looking at language understanding rather than the impact of criticism
Dimoska, A., McDonald, S., Pell, M. C., Tate, R. L., & James, C. M. (2010). Recognizing vocal expressions of emotion in patients with social skills deficits following traumatic brain injury. *Journal of the International Neuropsychological Society: JINS*, *16*(2), 369.	Looking at understanding of emotion in language
Dou, Z. L., Man, D. W. K., Tam, S. F., & Hui-Chan, C. W. Y. (2004). Community-based cognitive rehabilitation services for persons with traumatic brain injuries in China. *International Journal of Rehabilitation Research*, *27*(1), 81-84.	Related to enriched environment, not expressed emotion
Karver, C. L., Wade, S. L., Cassedy, A., Taylor, H. G., Stancin, T., Yeates, K. O., & Walz, N. C. (2012). Age at injury and long-term behavior problems after traumatic brain injury in young children. *Rehabilitation psychology*, *57*(3), 256.	Excluded as not looking as expressed emotion or family criticism or over-involvement, also related to child head injury.
Martindale, S. L., Epstein, E. L., Taber, K. H., Brancu, M., Beckham, J. C., Calhoun, P. S., ... & Rowland, J. A. (2018). Behavioral and health outcomes associated with deployment and nondeployment acquisition of traumatic brain injury in Iraq and Afghanistan Veterans. *Archives of physical medicine and rehabilitation*, *99*(12), 2485-2495.	Doesn't consider family influence in outcomes
Stanhope, N., Goldstein, L. H., & Kuipers, E. (2003). Expressed emotion in the relatives of people with epileptic or nonepileptic seizures. *Epilepsia*, *44*(8), 1094-1102.	Whilst epileptic seizures can result in ABI, there was no measure of brain

	injury within the study and focus was comparison between epileptic and non-epileptic seizures.
Yue, J. K., Vassar, M. J., Lingsma, H. F., Cooper, S. R., Okonkwo, D. O., Valadka, A. B., ... & Sinha, T. K. (2013). Transforming research and clinical knowledge in traumatic brain injury pilot: multicenter implementation of the common data elements for traumatic brain injury. *Journal of neurotrauma*, *30*(22), 1831-1844.	No measures of EE or family criticism

Appendix 1-D:

Tables of Participant Demographics

	Gender					Measures			ABI Definition		Total Participants
	ABI		Caregiver		Other	ABI	Caregiver	Both	Medical Records	Self-Report	
Study	Male	Female	Male	Female							
1	34	9	5	38		1	1	1	1	0	43
2	49	11	10	50		1	0	0	1	0	60
3	N/A	N/A	3	25		0	1	0	0	1	28
4	N/R	N/R	13	62		1	1	1	0	1	75
5	43	17	16	44		1	0	0	1	0	60
6	63	15	13	65		1	1	1	1	0	78
7	71	16	17	70		1	1	1	1	0	87
8	52	19	17	51	3	1	0	0	0	1	71
9	52	19	17	51	3	1	0	0	0	1	71
Totals	364	106	111	456	6	8	5	4	5	4	573

	Relationship - Percentage													
	Parental			Spousal			Sibling			Child			Other	
Study	Father	Mother	Both	Male	Female	Both	Male	Female	Both	Male	Female	Both		Notes
1	-	-	37.2	-	-	39.6	-	-	6.9	-	-	9.3	6.9	Aunt/SIL
2	-	-	50.0	-	-	45.0	-	-	1.7	-	-	3.3	-	
3	3.6	60.0	63.6	7.0	21.0	28.0	-	7.0	7.0	-	-	-	-	
4	-	-	47.0	-	-	44.0	-	-	4.0	-	-	5.0	-	
5	-	-	-	-	-	100.0	-	-	-	-	-	-	-	Spousal Only
6	2.6	52.6	55.2	14.1	30.1	44.2	-	-	-	-	-	-	-	

7	4.6	51.7	56.3	13.8	28.7	42.5	1.1	-	1.1	-	-	-	-	
8	12.7	25.3	38.0	9.9	40.8	50.7	-	1.4	1.4	1.4	4.2	5.6	4.2	Support Workers
9	12.7	25.3	38.0	9.9	40.8	50.7	-	1.4	1.4	1.4	4.2	5.6	4.2	Support Workers

	Age – Mean (SD)				
Study	ABI Survivor		Caregiver		Notes
1	37.21 (18.37)	Age at injury	47.67 (12.87)	Age at recruitment	
2	33.8 (15.40)	Age at injury	50.42 (11.26)	Age at recruitment	
3	29.82 (10.16)		44.54 (9.75)		
4	41.97 (14.64)	Intervention Group	52.08 (10.32)	Intervention Group	
5	67.35 (11.11)		65.67 (10.84)		NB. Stroke Study
6	29.70 (10.30)		N/R		
7	Range of ages: 21.3-38.8		N/R		Data split based on PC judgements
8	39.8 - NHS	33.8 - Medicolegal	N/R		
9	39.8 - NHS	33.8 - Medicolegal	N/R		
Overall Mean	39.93		52.07		Excluding Study 7

Study Numbers: 1 = Alway, McKay, Ponsford and Schönberger, (2012); 2 = Alway, Ponsford and McKay, (2016); 3 = Flanagan, (1998); 4 = Fortune, Rogan and Richards, (2016); 5 = Rashid, Clarke and Rogish, (2012); 6 = Weddell, (2010); 7 = Weddell and Leggett, (2006); 8 = Weddell and Wood, (2016); 9 = Weddell and Wood, (2018)

PC = Personality Change Appendix; **SIL =** Sister-in-law

Appendix 1-E:

Author Guidelines for Target Journal

Journal of
Neuropsychology

the british
psychological society

JNP AUTHOR GUIDELINES

Sections

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

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Section 2: Empirical Paper

Moderation analysis of the impact of stroke knowledge on expressed emotion and caregiver burden

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Abstract

Objectives: This study aimed to identify whether high levels of Expressed Emotion (EE) in the caregiving relationship predicted burden in stroke caregivers. EE is a measure of the family environment and quality of family relationships, looking at the extent to which family members express critical or “emotionally overinvolved” attitudes towards an unwell family member. EE has been explored in psychiatric and physical health populations including some research in other acquired brain injuries. There has also been research into the relationship between EE and the wellbeing of the stroke survivor, but EE has not been investigated as a predictor of burden in the caregivers of stroke survivors. It was hypothesised that there would be significant relationships between EE and caregiver burden and EE would explain the variance in caregiver burden above demographic variables. Additionally, that stroke knowledge would moderate the relationship between EE and caregiver burden.

Design: A cross sectional, correlational design was utilised to explore the relationship between expressed emotion, stroke knowledge and measures of caregiver burden.

Method: Caregivers of stroke survivors were recruited through social media and a local *Stroke Association* branch. Seventy-three participants completed the questionnaires around EE, caregiver burden, stroke knowledge and demographics. The resulting data were analysed using correlation, hierarchical regression and moderation analyses.

Results: Significant positive correlations were identified between EE and both measures of caregiver burden. Regression analyses found EE significantly explained the variance in both measures of caregiver burden, once variance due to demographic and stroke knowledge variables were accounted for, suggesting that those who score highly on measures of EE are more likely to experience burden and distress themselves. Stroke knowledge was not found to have a significant moderating effect between EE and caregiver burden in this study. Significantly higher EE scores were found for those living at the same address as the stroke survivor support previous research that living together to be more challenging for the caregiving relationship. Further correlations around age indicated that younger participants were significantly more knowledgeable and more distressed.

Conclusion: Services should consider how to support caregivers in order to facilitate good outcomes for both the stroke survivor and the wellbeing of their caregiver. Further exploration of stroke knowledge and appropriate measures is indicated. Limitations of the study are discussed with implications for further research.

Keywords: Stroke, expressed emotion, caregiver, burden, knowledge

Introduction

A stroke is a life-threatening event and happens when the blood supply in part of the brain is cut off. In the UK approximately 100,000 people per year have a stroke and this number is increasing (Royal College of Physicians Sentinel Stroke National Audit Programme; SSNAP, 2017). There are varying estimates of the number of people living with the after effects of stroke in the UK, with one estimate (Adamson, 2004) suggesting that there are over 300,000 such people. More recently, however, National Institute for Heath and Care Excellence (NICE) reported that there are over 1.2 million stroke survivors currently living in the UK and over two thirds of those are left with ongoing disability (NICE, 2019). Stroke can leave individuals with a range of difficulties including cognitive, physical, emotional and language deficits (Rigby et al., 2009). Whilst some people make a good recovery, many stroke survivors are left needing either formal or informal care support. Many are supported by informal caregivers such as spouses, adult offspring or other relatives.

Informal caregivers are those that “take on responsibility for assisting another person without getting additional time or resources and are differentiated from formal caregivers who are trained and paid to provide care” (Hildebrand, 2016, p.313). The informal caregiving role usually falls to the spouse or child of the person needing care or other close family members (Greenwood et al., 2008). As such, they are often in the role involuntarily and without formal training (Adelman, 2014). The term informal caregiver is often used interchangeably with carer and caregiver, within this study, the term ‘caregiver’ will be utilised from this point onwards. Caregivers are important both socially and economically. Cost savings in the USA were calculated as over 6 billion dollars saved through utilisation of informal carers across conditions (Hickenbottom et al. 2002). In the UK, the caregivers of people affected by stroke save an estimated £15.8 billion per year for services (Patel et al., 2020); enabling stroke survivors to return to living in the community (Patel et al. 2018).

However, there is a huge cost to individual caregivers, with the burden of care giving being linked with higher incidence of depression, anxiety (Carnwath & Johnson, 1987; Schulz et al., 2006; Wade et al., 1986) and poor life satisfaction as well as increased mortality (Schulz & Beach, 1999). The psychological impact can begin from as little as one-month post-stroke and continue for many years (Jones et al., 2000). Furthermore, stroke recovery is at its best when family are healthy and supportive of the stroke survivor (Glass et al., 1993).

The caregiving role has been found to have a negative impact on caregiver psychological health (Camak, 2015). Caregivers in stroke have poorer psychological health than the general population with this influenced by severity of survivor disability, quality of relationship and extent of cognitive/behavioural difficulties (Clark et al. 2004; Low et al., 1999). Informal carers' ability to cope was positively influenced by greater numbers of support strategies in place and higher levels of information/education about the condition (Evans et al., 1988; Kalra et al. 2004; McCullagh et al., 2005). Better patient mental health and cognitive function were associated with better carer mental health (Tooth et al. 2005). Recent NHS policy includes recommendations for caregivers to be provided with training and information relevant to their role, including elements such as moving and handling, but also regarding management plans, stroke information and the care pathway. However, there is little within the policy on how this should be achieved, when and by whom. Additionally there is little mention about the psychological impact for caregivers with the examples provided being around the physical aspects of caregiving (NHS, 2022).

One construct that has been considered in relation to the role of caregiving is Expressed Emotion (EE). This is a measure of the family environment and quality of family relationships. Specifically, EE looks at the extent to which family members express critical, hostile or "emotionally overinvolved" attitudes towards an unwell family member. Measures of EE tend to focus on critical comments (CC) or emotional over-involvement (EOI). Much of the early research in the 1970s to 1990s focussed on the impact of EE in psychiatric conditions and found that high levels of EE in the caregiving relationship are associated with higher risk of relapse in those conditions (E Sa et al., 2016). More recently research has found that EE also has an impact in physical health conditions including chronic illness (Rosland et al., 2011) and traumatic brain injury (Weddell, 2010). In addition, having high EE in the caregiving relationship is associated with increased incidence of post stroke depression for the stroke survivor (Rashid et al., 2013). A review by Barrowclough and Hooley (2003) found relatives that were found to be highly critical on EE measures were more likely to hold their relatives responsible for their difficulties across disorders. Additionally, in a review of the influence of EE in dementia it was found that relatives rated as high EE were more likely to attribute the problems as being personal and controllable by the patient (Safavi et al., 2017). Additionally, research has shown that sometimes caregivers may not recognise symptoms as being related to stroke outcomes (Clark et al., 2006). Given that research shows EE in the caregiving relationship can have a negative impact on outcomes for stroke survivors, it is important to consider how this impact can be reduced.

In other physical health conditions, family members who are rated low EE hold rational understanding and recognition of behaviours as symptoms of illness whereas those with high EE are often more anxious and fearful about the illness and have an increased desire for control (Barrowclough & Hooley, 2003). Barrowclough and Hooley (2003) found carers' beliefs and attributions were a mediating factor in controlling behaviour and the resulting risk of relapse. They argued for the development of interventions to help relatives recognise that the unwell person in not purposefully engaging in the behaviours and instead for the relatives to be more flexible in their approach. It is yet to be identified whether the same effect is found in stroke. That is, if caregivers have a better understanding of the impact of stroke, could this reduce EE and in turn, mitigate the impact of high EE on carer burden and improve stroke survivor outcomes? Whilst EE can be discussed as a characteristic of the relative in question, it is most appropriate to consider it a measure of the relationship between the patient and the relative (Hooley & Parker, 2006). Solomon et al. (2010) provided some evidence of EE being a bi-directional relationship meaning that whilst the previously discussed research has shown negative impacts for the unwell family member, there may also be negative impacts for the caregiver.

Where caregivers are in poorer psychological health and under increased burden, outcomes for both the caregiver and the cared for individual are poorer (Cheng et al., 2014; Camak, 2015). Providing extensive care for a loved one who may be experiencing physical, cognitive, communication and behavioural changes can be extremely difficult for family and loved ones. Increased stress could result in challenges providing optimal care.

The present study aims to discover if knowledge of stroke moderates the relationship between expressed emotion and caregiver burden in stroke. Assessing levels of stroke knowledge alongside EE and carer burden would enable exploration of these links. If relationships are found, it would suggest that improving caregiver knowledge could reduce the negative attributions associated with high EE.

Given the importance of informal caregivers and the role they play, it should be a priority for services to identify ways to work towards reducing the impact of caregiver burden. If stroke knowledge is a moderating factor in reducing caregiver burden, then it would justify the implementation of further support and education for carers and potentially the development of a family intervention model in stroke rehabilitation and care.

Research Question

Does caregiver knowledge of stroke moderate the impact of expressed emotion in caregiver burden?

The following hypotheses were considered;

- High levels of caregiver EE would be associated with higher levels of subjective caregiver burden above demographic and clinical variables
- High levels of caregiver EE would also be associated with higher levels of caregiver anxiety and depression above demographic and clinical variables
- Where there is a significant relationship between caregiver EE and caregiver burden, stroke knowledge will moderate this relationship

Method

Design

This research aimed to investigate whether there is an association between expressed emotion and caregiver burden in stroke. It also aimed to explore whether caregiver knowledge of stroke moderates the relationship between expressed emotion and caregiver burden. Adopting a cross-sectional survey design assessing levels of existing knowledge alongside a measure of EE and measures of carer burden enabled the exploration of these links and whether functional knowledge is a moderating factor for high EE in carers of stroke survivors.

Participants

Study participants were eligible to take part if they self-identified as informal caregivers of a stroke survivor, they were over the age of 18 and able to understand and complete an online or paper survey written in English. Participants were able to have assistance with completing the survey if required.

Inclusion criteria:

- Self-identification as an informal caregiver of a stroke survivor
- Over the age of 18

Exclusion criteria:

- Not having English language abilities to a level to understand the information sheet, consent and questionnaires. This would be assumed based on ability to read and understand the instructions on the advert and information sheet.
- Carers of stroke survivors with another primary neurological diagnosis other than stroke

Opportunistic sampling was utilised for the study with participants volunteering to take part after seeing an advertisement for the study, either online through social media, through advertising in the local Stroke Association branch or word of mouth. Study eligibility was based on participant self-report and demographic details were collected as part of the survey.

An a priori analysis was calculated using G*power (Faul et al., 2009), using a multiple regression analysis with 7/8/9 predictors, a power of 80% and a conservative effect size of 0.25. This led to a required sample size of 65/69/72, respectively. The effect size of 0.25 was selected as the minimum effect size which would be clinically relevant and therefore all effect sizes stronger than this would be adequately powered (α was set at 0.05).

Measures

The measures chosen assessed levels of stroke knowledge (Stroke Care information Test (SCIT); Evans et al., 1985), levels of EE (The Family Questionnaire (FQ); Wiedemann et al., 2002) levels of caregiver burden (Caregiver Burden Scale (CBS), Visser-Meily et al., 2004) and also a measure of caregiver psychological distress (The Depression, Anxiety and Stress Scale (DASS-21); Lovibond & Lovibond, 1995).

Stroke Knowledge

Stroke Care Information Test (SCIT) – A measure designed to assess family members' knowledge about stroke in the areas of physical loss, cognitive and perceptual disorders, language impairment, and sexuality. The test was found to have good reliability and validity (Evans et al., 1985). It contains 36 multiple choice questions with 1-point per correct answer resulting in a score range of 0-36 with higher scores indicating greater knowledge.

Expressed Emotion

The Family Questionnaire (FQ) – This is a self-report measure from the relative/caregiver perspective. Whilst the Camberwell Family Interview (CFI) is seen as the gold standard in assessment of expressed emotion, the FQ has been found to have good associations with CFI (convergent validity), however it has yet to be validated in relation to its ability to predict relapse (Wiedemann et al., 2002). It has good test-retest reliability with r=0.84 for critical comments (CC) scale and r=0.91 for emotional over-involvement (EOI) scale. It is short and easier to score and administer than the CFI. The FQ contains 20 questions, 10 for each subscale of CC and EOI with Likert-Scale responses of ‘never/very rarely’, ‘rarely’, ‘often’ and ‘very often’. Scores range from 1 to 4 for each item and the authors gave a cut-off point at 23 for high CC and 27 for high EOI.

Caregiver Burden

Caregiver Burden Scale (CBS) assesses the impact of caregiving on the individual. It asks about elements of subjective burden and can be divided into five categories: General Strain, Isolation, Disappointment, Emotional involvement and Environment. The CBS was found to have good construct validity and adequate internal consistency for all subscales (Cronbach’s α = 0.70–0.87), except for the Environment (α = 0.53). There was also good test-retest stability for all subscales (Cohen’s kappa = 0.89–1), again except for the Environment subscale (kappa = 0.53). (Elmståhl et al., 1996; Visser-Meily et al., 2004; Jaracz, 2022). It is brief to administer and score. The scale contains 22 items and is scored from 1 to 4 on a

Likert-Scale (not at all, seldom, sometimes, often). Scores can range from 22 up to 88 with higher score being indicative of higher burden.

The Depression, Anxiety and Stress Scale (DASS-21). The DASS-21 is a measure of distress across three subscales of depression, anxiety and stress (Lovibond & Lovibond, 1995). It provides a measure of the psychological impact of caregiving on the individual. It contains 21 items rated on a Likert-Scale (never, sometimes, often and almost always) scored from 0-3 with a max score on each subscale of 21 with higher scores indicative of higher distress. The DASS-21 provides some objective measures of mood alongside other measures of their subjective view of the burden. The measure has been used in other research looking at caregiver burden. The DASS-21 is an internally reliable measure with Cronbach's coefficient alphas of 0.94 and 0.88 reported for the depression subscale, 0.87 and 0.82 for the anxiety subscale and 0.91 and 0.90 for the stress subscale (Antony et al., 1998; Henry & Crawford, 2005).

Combined Burden Score. The scores from the CBS and DASS-21 were also added together to create a novel combined burden score. By combining the two it enabled exploration of the elements of burden as a whole.

Demographics

To control for potential confounders demographic predictors were also collected for inclusion in the analysis (age, gender, relationship to stroke survivor, employment status, living status) as well as the length of time they have been providing care to the stroke survivor and if there were any formal care arrangements (Appendix 4-F). The demographic variables were chosen to provide a picture of who was providing care in this population as well as a sense of the level of care being provided. In line with the gender hierarchy of care, caregivers are disproportionately female (Sharma et al., 2016) and spousal. Age of caregivers is important to consider in terms of the differing experiences of caring across the lifespan.

Age, gender and relationship to stroke survivor felt appropriate to check that the population within this study was representative. Living status and length of time providing care give indications of the level of care provided and are risk factors for increased burden (Migliorini et al., 2019 and Adelman, 2014) which may be confounding variables in analyses.

Procedure

Ethical approval was given by the principal investigator's host institution (See Section 4 for details). Due to limited timescales the study was not able to be reviewed in depth by any service user groups or stroke caregivers. However, the study was discussed with staff at the local Stroke Association group. They provided feedback and agreed to support with advertisement and recruitment where possible. They reported finding the topic of interest and felt it would be of interest and use to Stroke Survivors and their families.

Recruitment was completed via three different methods. First, study questionnaires were converted to online questionnaire packs using Qualtrics software. The link for this was shared on social media, including Facebook and Twitter, particularly on Stroke pages. The study was advertised on pages of organisations which support stroke survivors as well as informal groups for stroke support and particularly groups for caregivers. The Liverpool Stroke Recovery Partnership and local Stroke Association branch shared the link on their social media pages approximately every two weeks for three months. It was additionally shared on the host institution social media pages.

Second, physical copies of the questionnaire packs were located in local Stroke Association buildings and The Liverpool Stroke Recovery Partnership agreed to promote the research to those who visited as well as being promoted by case workers in the community. To maintain anonymity, participants were provided with pre-paid envelopes in order to post their responses back to the research team.

Third, some participants were recruited through word of mouth, with interested people sharing information about the study with those who met the criteria and might be interested in taking part as well as through word of mouth from other participants.

Participants accessed the study via the link in the online advert or by requesting a physical questionnaire pack. Physical copies of the questionnaire packs included a pre-paid envelope for participants to be able to return their questionnaire anonymously.

The questionnaire packs took approximately 20-30 mins to complete so that the task would be readily achievable for participants. Where the survey was completed online it was possible for the participants to download and keep both the participant information sheet and debrief sheet. In the paper copies participants were encouraged to keep these elements of the pack for future reference. In order to proceed with the online survey participants first had to complete the online consent form. Physical copies of this were included in the paper questionnaire packs.

The information sheet and debrief sheet made clear that once the survey had begun then the information provided would be anonymous meaning that no personal identifiable information would be held. As a result, it would not be possible to withdraw participant data after the survey had begun. See Appendix 4-B and 4-E for copies of the information and debrief sheets. The data collected for this study were stored securely and only the researchers conducting this study had access to these data.

Data Analysis

Data analysis was completed using IBM SPSS Version 27 (2020). Participants who did not complete the measures were removed. There were no missing data due to previously applied restrictions not allowing progression to the next question until each section was complete.

Outliers were checked for using boxplots and scores were checked for errors. All data were checked for normality. All data met the George and Mallery (2016) requirement of +/- 2 with some, but not all, also reaching the more conservative +/- 1 required in Kolmogorov-Smirnov test.

Following the tests for normality Pearson's correlational analysis was completed to initially explore the relationships between the variables. Independent samples t-tests were also completed to explore the differences between groups on outcome measures and binary variables such as 'living at the same address'.

After exploration of the correlational analysis a hierarchical block regression was completed. Predictors were entered based on theoretical grounds in a stepwise manner. Three regression models were completed for the three outcome variables of caregiver burden (CBS) and caregiver mental health (DASS-21) and the combined score of the two, (Combined Burden). The Durbin-Watson statistic was checked and was within the limits of +1 to +3 determining that the error assumptions were acceptable.

Variance inflation factors (VIF) values were consistently below 2 meeting the recommendation of being less than 10 and additionally falling below the more conservative less than 4 (O'Brien, 2007) showing that multicollinearity was not a concern. Assumptions of linearity and homoscedasticity were met and the data were normally distributed.

Finally, moderation analysis was conducted utilising Hayes Process tool on SPSS (Hayes, 2013) looking at whether stroke knowledge moderated the relationship between EE and Caregiver Burden measures (analysed with both CBS and DASS-21 as outcomes).

Results

Participants

A total of 73 participants were recruited. 131 participants opened the online survey but only 68 of these reached its completion. Due to the anonymous online nature of the study, it was not possible to ascertain the reasons for withdrawal or incompletion. A further 5 participants completed the paper copies of the survey and returned them. One of the questions on the stroke knowledge outcome measure was incomplete on one paper copy, however the participant had written a note next to the question with sufficient information to extrapolate a response so this participant was still included.

Please see Table 1 for the demographic characteristics of the participants. Most of the participants were female (*n* = 60, 82.2%) and were mainly either the spouse (*n* = 45, 61.6%) or child (*n*= 22, 30.1%) of a stroke survivor. The majority lived at the same address as the stroke survivor (*n* = 54, 74.0%) and did not receive any care support from health or social services (*n* = 54, 74.0%). Most were in some form of employment or education (*n* = 46, 63.0%). There was a spread across the age ranges, but almost half fell within 40-49 and 50-59 year old categories (*n* = 36, 49.3%). The mean time providing care was 41.8 months (*SD* = 45.7) with a range of 198 months.

Data about participant location was not formally collected, although Qualtrics did provide some information indicating there were participants from both the USA and UK. Qualtrics only provided this information for some participants, so it was not possible to ascertain the exact quantities from each location.

Means, standard deviation and Cronbach's alpha scores for the measures used are shown in Table 2. For all the measures, except the SCIT, Cronbach's Alpha ranged between 0.84 and 0.94 indicating good to excellent ratings of internal consistency. The SCIT had a Cronbach's Alpha of 0.57 which whilst indicating lower internal consistency, the measure explores different elements of stroke knowledge, e.g. physical/perceptual/language which may explain this relatively low score.

Correlation analysis

Pearson's correlational analysis (Table 3) showed several significant relationships between the variables explored. There was a significant positive correlation between the FQ (measure of EE) and the total scores on all measures of caregiver burden; CBS and DASS-21 and combined score. (CBS: *r*=.768, *p*<.001 and DASS-21: *r*=.461, *p*<.001; Combined: *r*=.721, *p*<.001). Where the FQ (EE) was broken down into its two individual categories of emotional over-involvement (EOI) and critical comments (CC) the significant positive correlations between CBS, DASS-21 and the combined score were maintained (FQ-CC with CBS *r*=.602, *p*<.001. FQ-CC with DASS-21 *r*=.289, *p*=.013. FQ-EOI with CBS *r*=.711, *p*<.001 and FQ-EOI with DASS-21 *r*=.518, *p*<.001). Additionally, age was negatively correlated with FQ subscale of EOI, SCIT Total Score and DASS-21. (*r*=-.259, *p*=.027, *r*=-.259, *p*=.027 and *r*=-.311, *p*=.007 respectively), indicating that younger participants were significantly more 'emotionally over-involved', scored higher on knowledge tests and rated themselves higher on the measure of psychological distress. The DASS-21 and CBS were also found to be positively correlated with each other (*r*=.462, *p*<.001).

Further exploration using an independent samples t-test for the binary variable of living at the same address, were completed. The FQ Total t=2.170, *p*=.033 (two tailed) *p*=.017 (one tailed) with CI=[0.471-11.195] indicating that those living at the same address scored significantly higher on the measure of EE.

Insert Table 1 here please

Insert Table 2 here please

Insert Table 3 here please

Regression analysis

This was completed in four blocks, the initial containing demographic variables including, age, gender, relationship to stroke survivor and employment status. Followed by the second block containing number of months care had been provided for and whether the caregiver lived at the same address. The third block included the SCIT total score and the final fourth block contained the FQ total score. The analysis was completed three times with DASS-21 or CBS or the combined burden score as the dependant variable. See tables 4 to 6 for the results of this analysis.

For the CBS, Block 1 (demographic variables) captured 6% of the variance, followed sequentially by 8% and 11%, for Block 2 and Block 3, none of which reached significance ($p > .05$). The addition of FQ total score at Block 4 resulted in a significant model ($F(1,64) = 13.86$, $p<.001$, $R^2=.63$) which accounted for 63% of the variance in CBS. It is noteworthy that R^2 change indicated that the addition of the FQ total score in block 4 captured an additional 51.8% of the variance in CBS. In this final model, FQ total score ($\beta = .80$, $p<.001$) was the only significant variable.

For the DASS-21, Block 1 of the hierarchical regression was significant ($F(4,68) = 2.76$, $p=.035$, $R^2=.140$), with age being the only significant predictor ($\beta = -.37$, $p=.005$). Blocks 2 and 3 were not significant; however, with the addition of the FQ total score, Block 4 resulted in significant model ($F(1,64) = 4.55$, $p<.001$, $R^2=.36$). R^2 change indicated that the addition of FQ total score accounted for an additional 17.9% of the variance compared to block three. In this final model, age ($\beta = -.35$, $p=.003$) and FQ total score ($\beta = .47$, $p<.001$) were the only significant variables.

For the combined burden score, Block 1 (demographics) captured 11% of the variance, with none of the individual variables reaching significance. The addition of Block 2 and Block 3 resulted in non-significant models ($p > .05$) capturing 13% and 17% respectively. However, once FQ total was added as Block 4, a significant amount of the variance in combined burden was captured by the model, (F (1,64)=13.31, p<.001, R^2=.62). R^2 change indicated that the addition of the FQ total score in Block 4 accounted for an additional 44.9% of the variance in Combined Burden. In this final model, age (β = -.25, p=.007) and FQ total score (β = .74, p<.001) were the only significant variables.

Insert Table 4 here please

Insert Table 5 here please

Insert Table 6 here please

Moderation analysis

Moderation analysis was completed using the Hayes PROCESS tool within SPSS 27 (Hayes, 2013). In the case of both outcome measures of caregiver burden; DASS-21 and CBS and the combined score of the two, the model itself was found to be significant. Despite this, there was not a significant interaction between the SCIT and FQ on the dependant variables, so the SCIT did not moderate the relationship between EE and Caregiver Burden (CBS, *p*=.82; DASS-21, *p*=.32; Combined Burden, *p*=.50).

Discussion

The present study investigated the relationships between expressed emotion, stroke knowledge and caregiver burden in the caregivers of stroke survivors. In stroke populations there has been previous research regarding the impact of EE on the stroke survivor (Rashid et al., 2013), however to the best of our current knowledge there has not been research into EE and caregiver burden within stroke populations.

Correlational analyses found that EE (as measured by FQ) was found to be significantly positively associated with both measures of caregiver burden (CBS and DASS-21). Additionally, independent t-tests found that living in the same address as the stroke survivor resulted in significantly higher scores on measures of EE than living elsewhere. This is consistent with Adelman's (2014) findings that residence with the care recipient was a risk factor for caregiver burden. The individual categories of EE (emotional over-involvement and critical comments) were also found to be significantly positively correlated with both measures of caregiver burden.

Hierarchical regression found that EE significantly explained the variance in both DASS-21 and CBS. The analyses showed that the overall models explained 63%, 36% and 62.1% of the variance in scores on the CBS, DASS-21 and combined burden respectively. The addition of EE at the final step reached significance for all outcome measures and accounted for an additional 51.8%, 17.9% and 44.9% on the CBS, DASS-21 and combined burden respectively. Therefore, EE was a significant predictor of negative outcomes in terms of caregiver burden. Demographic variables increased the effect size but not to a significant degree. An initial small correlation was observed in relation to living together and EE, but this was not a significant predictor in the model. Stroke knowledge explained some of the variance in DASS-21, CBS and combined burden but this was not significant. The first step in the DASS-21 model reached statistical significance and contained, age, gender, relationship status and employment. Age was found to be a significant predictor and it is possible this is linked with earlier correlational analyses finding younger participants scoring significantly higher on DASS-21 and warrants further investigation in the future. These findings suggest that in addition to EE having a negative impact for the stroke survivor (Rashid et al., 2013) there is a significant relationship between EE and caregiver burden in stroke. The results are consistent with research conducted in psychiatric conditions (Carra et al. 2012; Nuralita et al. 2019) as well as other physical health conditions (Wearden et al., 2000) including brain injury populations (Weddell, 2010). The results of both the correlation and hierarchical regression suggest that those who score higher in terms of their expressed emotion, that is to say are rated as more critical and emotionally over-involved are more likely to experience higher levels of burden and distress themselves. Following from previous research, this would indicate that where EE is high, there is likely to be higher caregiver burden which research suggests can also have poorer outcomes for the stroke survivor (McCullagh, 2005).

There was no significant interaction found within the moderation analyses completed with either measure of caregiver burden, suggesting that stroke knowledge (SCIT) did not moderate the relationship between expressed emotion and burden. The results would indicate that there is not sufficient evidence within the dataset to conclude that there is a moderating effect within the participants recruited. Further exploration of the sensitivity of the SCIT as a measure of stroke knowledge should be explored, particularly in relation to cognitive and emotional symptoms and functional knowledge of stroke (Barrowclough et al., 1987). Functional knowledge of stroke should be considered in conjunction with attributional knowledge. Additionally, the context of the study in relation to Covid-19 and the possible impact should be explored further. Whilst moderation analyses have not to the author's knowledge, been completed before in these specific populations, there has been research suggesting family psychoeducation and support can reduce the psychosocial impact on caregivers as well as less healthcare input for the stroke survivor (Cheng et al., 2014).

Ratings of EE were significantly higher for those living at the same address as the stroke survivor. The association between living with the stroke survivor and higher ratings of EE is consistent with previous findings. Providing intermittent care activities is likely to impact on the caregiving relationship and the psychological wellbeing of the caregiver less than those providing care in their own home on a 24-hour basis.

Additional correlations were found within the analysis in relation to age of participants. There was a negative correlation between stroke knowledge and the age of the caregiver, indicating that younger caregivers had higher knowledge of stroke. Correlational analysis showed a negative relationship between age of participant and levels of EOI. There was also a negative relationship between age and scores on DASS-21. Younger participants scored higher on these aspects suggesting that younger participants found the role of caregiver more psychologically distressing as well as showing higher levels of emotional over-involvement towards the stroke survivor. It is possible that younger caregivers hold less expectation of being a caregiver and therefore may have difficulty in adapting to the role as well as the potential role reversal of a parent-child relationship causing distress (McCarthy et al., 2020; Pinquart & Sörensen, 2011).

Strengths and Limitations

The participant sample recruited for the study was 86% female and the majority of caregivers were spousal (61%) or children (30%) of the stroke survivor. These numbers are comparable to previous research into informal caregivers in stroke populations (Greenwood et al., 2008).

The data for age of participants were found to be normally distributed and meet the required assumptions for analysis. However, when compared with the prevalence rates of stroke in a 2018 government report (Public Health England (PHE), 2018), there was a marked difference in the rates according to age. The majority of caregivers in this study are spousal (60.3%) which is similar to existing research about the demographics of informal caregivers (Greenwood et al., 2008). The *expectation* would be that the distribution of ages would be similar for caregivers and stroke survivors if most are spousal. In this study however, the majority of caregivers fell below age 60 (79.5%) and conversely the 2016 prevalence rates showed that 76.8% of stroke survivors were over the age of 60 (See Appendix 2-A for comparison). There is limited data on the age of caregivers of stroke survivors which is concordant with the general lack of literature in both stroke and caregivers.

Correlational analysis found a negative correlation between stroke knowledge and the age of the caregiver, suggesting that younger caregivers had higher knowledge of stroke. As discussed, exploration of the demographics showed that the age of participants in this study were younger than what would be expected based on national data statistics (Public Health England (PHE), 2018). (Appendix 2-A). A more representative sample, in terms of age, may show different results in terms of stroke knowledge. If we were to assume, as presented in this research, that older participants have a lower level of stroke knowledge, then a sample which was more representative, would contain more people with lower stroke knowledge scores and therefore may influence the outcomes and analysis.

Participants were mainly recruited through social media advertising and completed online questionnaires. Previous research has found that social media recruitment can result in a significantly younger cohort of participants in contrast with more traditional recruitment methods (Frandsen et al., 2016). In order to mitigate this and gain a more representative sample the hope had been for more traditional recruitment methods in combination with social media advertising. The local Stroke Association branch agreed to advertise in branch and for local team members to take the packs on visits however no copies were returned via pre-paid envelope or via the Stroke Association team during the initial recruitment phase. The Covid-19 pandemic began during the initial recruitment phase and as a result all face-to-face contact was stopped, and the team were no longer able to provide support to the study due to the shift in focus.

Further exploration is needed to ascertain the reasons for the lack of engagement through the face-to-face recruitment with Stroke Association. There may have been difficulty with the team explaining the study, or with the logistics of returning it. Solving this during recruitment was hampered by the Covid-19 pandemic and the impact of this. Attendance at a carers support group to advertise the study had been planned, but unfortunately the group did not run during the recruitment phase.

Given that the majority of participants were recruited via social media, this may explain the younger than expected age range found within the sample (Frandsen et al., 2016). Comfort and use of social media and computer skills may mean that a younger generation of caregivers would find this method of recruitment more engaging, quicker and easier to complete. Alternative methods of recruitment might support a sample more representative of stroke caregivers.

It was noted that 131 people opened the online survey, but only 68 of those completed it. Due to the anonymous nature of the survey it was not possible to explore the reasons for withdrawal or not engaging with the study. Whilst the questionnaires were kept short to facilitate engagement, 20-30 minutes is still a significant period of time to spend. It is possible that those caregivers that have spare time to complete research may find their role less distressing and easier to manage. Those who are struggling with the role may not have felt they had time to complete the questionnaires. Future research should consider further exploration into what might limit caregivers taking part or completing research. Additionally, the author was contacted regarding a potential participant, who explained they had not felt able to share the study with their relative who was caring for a stroke survivor due to it feeling ‘too raw’ currently and did not want to cause the family distress or undue pressure to complete it. This raised the issue of the potential distress evoked through participation in the research.

It is important to consider the impact the Covid-19 pandemic may have had on this research given the time span of completion (See Critical Appraisal for a full timeline of recruitment). The study participants were split into two groups, 45 participants were recruited between Sept 2019 and March 2020, prior to the start of the Covid-19 pandemic, and a further 28 recruited approximately a year later, during the pandemic from April 2021 until its conclusion. This may have resulted in two heterogeneous groups being recruited to the study, with variable experience of stroke care, both in hospital and the community. During the pandemic, hospital visiting was extremely limited, there was reduced community working and increased pressure on services. It is possible this would have impacted on the services and support available to stroke survivors and caregivers in this time. Douiri et al. (2021) found that admissions for strokes fell during Covid-19 suggesting that there may be a group of untreated stroke survivors. Additionally, Ozkan et al. (2022) found that compared with 2019, stroke survivors reported poorer outcome across the domains investigated including both physical and psychological aspects of health. There was insufficient participant numbers to make comparisons between the two time points in the study.

It was not possible to measure any pre-existing mood, stress or depression of the participants prior to their becoming a caregiver. It was accepted that the lack of this information may have influenced the results as existing mental health maybe be the reasons for higher scores on measures such as the DASS-21 as opposed to simply the caregiving role.

Using both the DASS-21 and CBS in the research hopefully mitigated this issue as it provided a specific measure of burden alongside the measure of mood. It did not feel appropriate to exclude participants on the basis of their mental health as the research would then not generalise as well to people with mental health conditions and they may struggle more with the caregiving role. Additionally it was not possible to measure EE prior to the stroke and therefore the lack of data on the quality of the relationship before is a limitation and a possible confounding variable.

The moderation analysis showed that stroke knowledge did not moderate the relationship between EE and either measure of caregiver burden. The use of the SCIT as a measure of stroke knowledge may have had an impact on the study results, particularly the moderation analysis. On initial exploration, the SCIT was comparable to other current measures of stroke knowledge. The study results raised questions about what the measure really focussed on and whether it explored areas of stroke that caregivers find more difficult to cope and manage. The research referenced with regards to the reliability of the SCIT was completed in 1985 (Evans et al., 1985). The nuances and understanding of psychological and neuropsychological sequalae post-stroke are much improved compared to when the measure was written. On review of the measure post-data collection, there was a focus in the questions on the physicality of stroke as well as the signs and symptoms, there was less focus on the neuropsychological impact of stroke and the knowledge and understanding of these elements. One example of this relates to the understanding of psychological reactions following stroke. Item 1 requires the respondent to comment on the potential causes of post-stroke depression. The ‘correct’ answer is given as ‘brain damage’, which is a reductive perspective that is perhaps not in keeping with research into loss, adjustment, family relationships and change, as well as the consequences of disability. Neuropsychological aspects are also not as straightforward as other elements and can be multifactorial in nature, such as the interaction between fatigue, cognition and mood. More detail could have been considered around emotional expression, disinhibition and assessment of participant recognition of symptoms. Considering EE and the role of attributions (Barrowclough & Hooley, 2003) it was also noted that questions which explored knowledge pertaining to accurate attributions were limited in the measure. Barrowclough et al (1987) emphasise the role of *functional knowledge* rather than family members merely knowing things. For example, some symptoms are hard to understand as a process of a health condition (eg anergia) than others (eg hemiplegia). The complexities of executive functioning and other neuropsychological aspects are likely to be more difficult for people to understand without specialist knowledge and therefore less likely to be attributed to changes due to the stroke and more open to interpretation that they are controllable by the stroke survivor. Thus, for certain symptoms, it is not just understanding that they occur that matters, but whether the person affected is genuinely not able to control those difficulties. This functional knowledge underlies the attributions that lead to expressed emotion behaviours (Barrowclough et al., 1987). Given that the measure was found to be comparable to others, further exploration of other existing measures and the type of stroke knowledge they assess would be beneficial with the potential to develop new measures in the future. Finally, as with correlational analyses direction of relationship cannot be determined only presence of a relationship. In relation to moderation analysis performed in this study, it may be that moderation happens in another direction, so burden’s relationship with EE might be moderated by stroke knowledge.

Further exploration could be considered in terms of the direct relationship between stroke knowledge and EE in order to rule out the influence within a moderation. This is because it could be argued that those with the greatest burden and/or EE would be more driven to seek out information. However, no such relationship was found within this study, but a different measure of stroke knowledge may provide further information to explore this fully.

A review of the work around psychoeducation and EE in schizophrenia specifically found that the literature suggests that family intervention and psychoeducation reduce levels of EE, decrease relapse rates, improve treatment outcomes and improve family relationships (Amaresha & Venkatasubramanian, 2012). Further exploration around stroke knowledge and EE would be beneficial in supporting the NHS policy recommendations about training and education for caregivers (NHS, 2022) in providing more detail on what information caregivers need. With clear information about the elements of stroke caregiving which are the most difficult for caregivers and the associated attributions, education can be better targeted and more useful.

Qualtrics provided some information about the location of participants, but this was not formally collected and not available for all participants. Future research may consider collecting this data as it is important to consider the differing health and social care systems available to participants. The information that was collected showed some participants at least were from both the USA and UK. The USA and UK have very different healthcare systems in the National Health Service (NHS) in the UK and privatised and insurance-based healthcare in the USA. It is not known what the difference in systems may have had on the outcome of this study.

Finally, using self-definition as an “informal caregiver” was chosen to facilitate engagement in the study as opposed to providing a specific definition. Allowing this may have resulted in a very heterogenous group of caregivers with differing types and levels of care provided.

Conclusion

The results added further evidence to the links between expressed emotion and caregiver burden in stroke. Given existing research on the impact of caregiver burden on outcomes for stroke survivors it is important to consider how services can support caregivers in order to facilitate good outcomes for both the stroke survivor and the wellbeing of their caregiver. The study has presented a number of areas for improvement should the research be repeated, key themes would be around the methods of recruitment in order to gain a more representative sample and also further consideration about an appropriate measure for stroke knowledge. The potential for the development of a new measure of functional stroke knowledge with more of a focus on the neuropsychological aspects is indicated. It is clear that the role of knowledge and EE will bear further investigation with respect to enhancing the support provided to carers of those affected by strokes. Additionally further exploration would support recent NHS policy recommendations into caregiver support and help to provide some direction in the implementation of these.

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Table 1:

Demographic information of participants

Variable		**Sample**
Age		
	18-29	12 (16.4)
	30-39	10 (13.7)
	40-49	18 (24.7)
	50-59	18 (24.7)
	60-69	9 (12.3)
	70-79	4 (5.5)
	80-89	2 (2.7)
Gender		
	Male (%)	13 (17.8)
	Female (%)	60 (82.2)
Relationship		
	Spouse	44 (60.3)
	Child	22 (30.1)
	Parent	3 (4.1)
	Sibling	1 (1.4)
	Other	3 (4.1)
Living at the same address		

	Yes (%)	54 (74.0%)
	No (%)	18 (24.7)
	Other (%)	1 (1.4)
Employment Status		
	Employed, full time	30 (41.1)
	Employed, part time	10 (13.7)
	Self-employed	4 (5.5)
	Unemployed	6 (8.2)
	Retired	12 (16.4)
	Unable to work	7 (9.6)
	Other	4 (5.5)
Formal Care Support		
	Yes	54 (74.0)
	No	19 (26.0)
How Long Provided Care (Months)		
	Mean (SD)	41.81 (45.72)

Table 2:

Descriptive statistics for all study measures

Measure	Mean	Standard Deviation	Cronbach's Alpha
DASS-21 Total	23.3562	13.59878	0.943
DASS-21 Total Stress	10.0411	4.98731	0.853
DASS-21 Total Anxiety	5.1507	4.53588	0.844
DASS-21 Total Depression	8.1644	5.45439	0.911
The FQ Total	53.8356	10.21439	0.930
The FQ Total CC	23.7808	6.78079	0.866
The FQ Total EOI	30.0548	5.29908	0.872
The CBS Total	61.4795	13.91253	0.888
Combined Burden Total	84.8356	23.52541	0.939
SCIT Total Score	20.9589	3.98064	0.574

DASS-21 = Depression, Anxiety and Stress Scale; **FQ =** The Family Questionnaire; **CC =** Critical Comments; **EOI =** Emotional Over-Involvement; **CBS =** Caregiver Burden Scale; **SCIT =** Stroke Care Information Test.

Table 3:

Pearson's Correlation Matrix of Measures and Demographics

	FQ Total	FQ-CC	FQ-EOI	SCIT	CBS	DASS-21	Combined Burden	Months of Care	Age	Gender	Relationship	Address	Employment
FQ Total	-												
FQ-CC	.882**	-											
FQ-EOI	.798**	.421**	-										
SCIT	-.178	-.208	-.076	-									
CBS	.768**	.602**	.711**	-.111	-								
DASS-21	.461**	.289*	.518**	-.095	.462**	-							
Combined Burden	.721**	.523**	.720**	-.121	.859**	.851**	-						
Months of Care	-.059	-.077	-.015	.055	-.032	.062	.017	-					
Age	-.126	.013	-.259*	-.259*	-.195	-.311**	-.295*	.066	-				
Gender	.127	.059	.168	.222	.164	.084	.145	-.014	-.397**	-			
Relationship	-.021	-.026	-.008	-.003	.136	.089	.131	-.001	-.120	.006	-		
Address	-.297*	-.302**	-.187	.101	-.076	-.032	-.064	.084	-.113	.118	.402**	-	
Employment	-.094	-.169	.036	-.022	-.058	.115	.032	.094	.232*	-.113	-.097	-.170	-

Note. **DASS-21 =** Depression, Anxiety and Stress Scale; **FQ =** The Family Questionnaire; **FQ-CC =** Family Questionnaire Critical Comments; **FQ-EOI =** Family Questionnaire Emotional Over-Involvement; **CBS =** Caregiver Burden Scale; **SCIT =** Stroke Care Information Test.

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 4: *Summary of hierarchical multiple regression analysis model for CBS*

	Beta	**R^2**	**Adjusted R^2**	**R^2 Change**	**F**	**P**
Step 1		.061	.005	.061	1.096	.365
Age	-.14					
Gender	.11					
Employment	-.00					
Relationship	.12					
Step 2		.089	.006	.029	1.078	.385
Age	-.14					
Gender	.13					
Employment	-.03					
Relationship	.19					
Length of time as caregiver	-.00					
Living at same address	-.19					
Step 3		.116	.021	.027	1.220	.305
Age	-.17					
Gender	.15					
Employment	-.02					
Relationship	.18					
Length of time as caregiver	.01					
Living at same address	-.17					
SCIT – Total Score	-.17					
Step 4		.634	.588	.518	13.856	.000
Age	-.08					
Gender	.03					
Employment	.07					
Relationship	.10					
Length of time as caregiver	.00					
Living at same address	.12					
SCIT – Total Score	-.01					
FQ – Total Score	.80***					

Note. *$p < .05$; **$p < .01$; ***$p < .001$

Table 5: *Summary of hierarchical multiple regression analysis model for DASS-21*

	Beta	**R^2**	**Adjusted R^2**	**R^2 Change**	**F**	**P**
Step 1		.140	.089	.140	2.757	.035
Age	-.37**					
Gender	-.04					
Employment	.20					
Relationship	.07					
Step 2		.150	.072	.010	1.936	.088
Age	-.37					
Gender	-.03					
Employment	.19					
Relationship	.10					
Length of time as caregiver	.08					
Living at same address	-.08					
Step 3		.183	.095	.034	2.086	.058
Age	-.41**					
Gender	-.01					
Employment	.19					
Relationship	.08					
Length of time as caregiver	.09					
Living at same address	-.07					
SCIT – Total Score	-.19					
Step 4		.362	.283	.179	4.546	.000
Age	-.35**					
Gender	-.08					
Employment	.24					
Relationship	.04					
Length of time as caregiver	.09					
Living at same address	.11					
SCIT – Total Score	-.10					
FQ – Total Score	.470***					

Note. *$p < .05$; **$p < .01$; ***$p < .001$

Table 6: *Summary of hierarchical multiple regression analysis model for Combined Burden*

	Beta	R^2	Adjusted R^2	R^2 Change	F	P
Step 1		.110	.058	.110	2.103	.090
Age	-.29*					
Gender	.04					
Employment	.12					
Relationship	.11					
Step 2		.131	.052	.021	1.660	.145
Age	-.29*					
Gender	.06					
Employment	.09					
Relationship	.17					
Length of time as caregiver	.04					
Living at same address	-.16					
Step 3		.172	.083	.041	1.934	.078
Age	-.34*					
Gender	.09					
Employment	.10					
Relationship	.16					
Length of time as caregiver	.06					
Living at same address	-.14					
SCIT – Total Score	-.21					
Step 4		.621	.574	.449	13.131	<.001
Age	-.25**					
Gender	-.03					
Employment	.18					
Relationship	.08					
Length of time as caregiver	.05					
Living at same address	.13					
SCIT – Total Score	-.06					
FQ – Total Score	.74***					

Note. *$p < .05$; **$p < .01$; ***$p < .001$

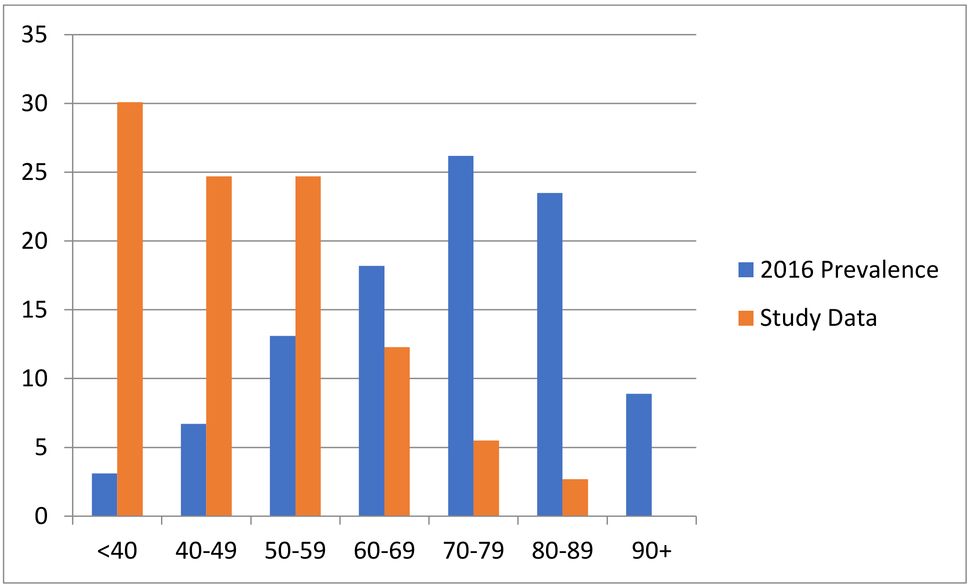
Appendix 2-A:

Comparison of 2016 Stroke Prevalence data for age with age of study participants (PHE, 2016)

Table of data

Age	2016 Stroke Prevalence %	Study Data %
<40	3.1	30.1
40-49	6.7	24.7
50-59	13.1	24.7
60-69	18.2	12.3
70-79	26.2	5.5
80-89	23.5	2.7
90+	8.9	0

Chart of data



Appendix 2-B:

Author Guidelines for target journal

British Journal of Health Psychology
the british psychological society

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Section 3: Critical Appraisal

Family expressed emotion (EE), caregiver burden and the impact of stroke knowledge

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The critical appraisal provides an opportunity to discuss and reflect on the whole thesis. I will begin with an overview of the findings from both the empirical paper and systematic literature review. I will discuss brain injury and think about the similarities and differences across causes of Acquired Brain Injury (ABI). I will similarly consider the concept of Expressed Emotion (EE), including its use within physical health and the research into cultural differences. I will discuss issues with the decisions made with regards to the recruitment process and difficulties that arose. I will also consider the measures chosen and demographic variables collected considering where improvements could be made. Additionally, I will consider some personal reflections about my thesis journey, the reasons for choosing the topic area and what I learned. Finally, I will consider some recommendations for ongoing research.

Main Findings

The literature review looked at the research in EE and mental health in ABI populations. A narrative systematic literature review was conducted with 9 identified papers. Searches were completed using 5 electronic databases using MeSH terms for ABI and search terms for EE. Six of the studies reviewed found statistically significant relationships between EE in the caregiving relationship, and psychological wellbeing in ABI populations. Two of the remaining studies found a relationship, but it did not reach statistical significance. Where EE was higher in the caregiving relationship there were negative psychological outcomes for the ABI survivor, caregiver or both. None of the included studies were rated the highest score for quality. Difficulties were identified in drawing comparisons across types of ABI with variations in how ABI was defined and participant demographic differences. Additionally in some studies EE and psychological well-being were not the primary aims of the study limiting what conclusions could be drawn.

The review found that whilst there are significant relationships supporting existing research into EE, there has yet to be a wealth of high-quality research in ABI. The results show some evidence to support the relationship between EE and ABI but not consistently. Further higher quality and more focussed research is required to develop this area more fully. The review highlighted several areas for improvement and directions of future research in this domain.

The empirical paper aimed to identify whether high levels of Expressed Emotion (EE) predicted burden in stroke caregivers and whether stroke knowledge moderated this relationship. EE has been explored in psychiatric and physical health populations including some research in other acquired brain injuries (Barrowclough & Hooley, 2003). There has also been research into the impact on the stroke survivor (Rashid et al., 2013), but it has not previously been investigated as a predictor of burden in the caregivers of stroke survivors. Burden was assessed with two measures; the Caregiver Burden Scale (CBS) assessing the impact of caregiving on the individual asking about elements of subjective burden and The Depression, Anxiety and Stress Scale (DASS-21) which is a measure of psychological distress and provided a measure of the psychological impact of caregiving. Significant correlations were identified between EE and both measures of caregiver burden. In regression analyses EE was found to significantly explain the variance in both measures of caregiver burden. Stroke knowledge was not found to be a significant moderator on the relationship between EE and caregiver burden in this study. Additionally, independent t-tests found that living in the same address as the stroke survivor resulted in significantly higher scores on measures of EE than living elsewhere. Further significant correlations around age indicated that younger participants were more knowledgeable and more distressed.

The results indicated that services should consider how to support caregivers in order to facilitate good outcomes for both the stroke survivor and the wellbeing of their caregiver.

Previous research has highlighted the importance of caregivers and how stroke recovery is at its best when family are healthy and supportive of the stroke survivor (Glass et al., 1993). Further exploration of stroke knowledge and appropriate measures is indicated.

Terminology

In completing the thesis, choices were made regarding the terminology used within the papers. In terms of the study participants, there are several terms which as used interchangeably to describe the role including: caregiver, carer, informal caregiver, family caregiver. All of the terms describe someone who “take[s] on responsibility for assisting another person without getting additional time or resources and are differentiated from formal caregivers who are trained and paid to provide care” (Hildebrand, 2016). Caregiver was chosen as the term for use within this study as it was felt to best encapsulate the role.

Working within a health setting and looking at research in relation to stroke and ABI the term ‘patient’ is frequently used. There are various views on the different terminology in this respect with some feeling ‘patient’ to be more appropriate for those under mental healthcare for parity with physical health (Priebe, 2021) whilst others advocate for terms such as ‘service user’ or ‘client’ (Neuberger & Tallis, 1999). In the case of this study the survivor is not the participant and it is unknown if they are currently within any mental health services or receiving ongoing medical care. Therefore, within this study, the decision was made to use the terms ABI survivor and stroke survivor in reference to these individuals.

In terms of EE, initially the terminology was discussed in terms of being a characteristic of the caregiver. In EE research, often the focus is on the negative impact of EE which can lead to blaming vocabulary towards the relatives/caregivers. More recently, there has been a shift towards viewing expressed emotion as a measure of the relationship and in doing so, adopting a less blaming vocabulary towards the caregiver (Hooley & Parker, 2006). A review of the work around psychoeducation and EE in schizophrenia specifically found that the literature suggests that family intervention and psychoeducation reduce levels of EE, decrease relapse rates, improve treatment outcomes and improve family relationships (Amaresha & Venkatasubramanian, 2012).

Recruitment

Recruitment approaches were chosen to maximise reach and engagement with the research and to access a variety of different participant groups. Recruitment was initially planned to take place via several methods. Social media was chosen to advertise the study to large groups of people. However, it was accepted that some potential participants may not use social media or be adept with completing online surveys and so the questionnaire packs were also made available as physical copies. They were made available through the local Stroke Association branch and via word of mouth. The Stroke Association branch agreed for the coordinators to provide questionnaire packs to interested potential participants.

Recruitment started prior to the start of Covid-19 pandemic but paused at the start of lockdown restrictions in March 2020. The Stroke association switched their messaging to a focus on Covid-19 and, on a personal note, in April 2020 I began a period of maternity leave following the birth of my second child. At this point only 45 responses had been fully completed. Recruitment was re-opened on conclusion of maternity leave in 2021 and the remainder of participants were collected so that the study was adequately powered.

There were no responses returned through the stroke association and only a small number through word of mouth, meaning that the majority of participants were recruited through social media. It was not possible to explore the reasons for the lack of engagement through The Stroke Association branch with the Covid-19 limitations in place. It should be noted that all face-to-face activities were paused at The Stroke Association, and coordinator focus was switched to telephone welfare support. Further recruitment happened at a later point, but this was solely from social media as restrictions were still in place. There were not sufficient numbers to compare the two participant groups from pre and post Covid-19.

As discussed in the research paper, social media recruitment can result in a significantly younger cohort of participants in contrast with more traditional recruitment methods (Frandsen et al., 2016). There is also a possibility that digital and online literacy improved for some during the course of Covid-19 through necessity of use in other areas of life.

Measure of stroke knowledge

Measures were selected during the planning phase of the research. A measure of stroke knowledge was included based on previous research around the impact of education for caregivers and additionally the links between EE and attributions (Barrowclough and Hooley, 2003). That is, if caregivers have a better understanding of the impact of stroke, could this reduce EE and in turn, mitigate the impact of high EE on carer burden and improve stroke survivor outcomes?

The completion of the empirical paper raised questions about the measures used, specifically with regards to stroke knowledge; namely, ‘What did the Stroke Care Information Test (SCIT) actually measure?’ Did it measure what we might expect to be the areas that caregivers might find the most distressing based on current research?

The SCIT is described as assessing stroke knowledge in relation to physical loss, cognitive and perceptual disorders, language impairment and sexuality (Evans et al., 1985). Exploration of the questions on SCIT in detailed post analysis found that the majority of questions were in reference to physical deficits following stroke and questions about the neuropsychological and psychological elements of stroke could have been more specific about the elements of stroke that are the most distressing. One example of this relates to the understanding of psychological reactions following stroke. Item 1 requires the respondent to comment on the potential causes of post-stroke depression. The ‘correct’ answer is given as ‘brain damage’, which is a reductive perspective that is perhaps not in keeping with research into loss, adjustment, family relationships and change, as well as the consequences of disability.

SCIT question examples:

1. Depression after stroke is usually due to;
    a. Reaction to losses
    b. Medication
    c. Family problems
    d. Brain damage

Considering the question above; the ‘correct’ answer according to scoring guidance is ‘d.’ however there could be arguments for other options to also be valid.

28. Aphasia means that a person;
    a. Is unable to learn
    b. Has difficulty communicating
    c. Chokes when eating
    d. Loses balance easily

Comparatively, item 28 around language requests a definition and has only one possible correct answer in ‘b.’

Neuropsychological aspects of stroke are not as straightforward as other elements and can be multifactorial in nature, an example being the interactive relationship between fatigue, cognition and mood.

There are indications that both the SCIT and other existing measures of Stroke Knowledge do not sufficiently cover the neuropsychological aspects of Stroke, and what are potentially the most distressing elements. Complexities of executive functioning and other neuropsychological aspects of stroke such as memory difficulties, mood and fatigue are more difficult and less intuitive for people to understand without a degree of specialist knowledge. Subsequently, they may be less likely to be associated with stroke changes, and more open to the interpretation that they are controllable by the survivor. In clinical practice, family members and informal caregivers show an understanding and awareness of some of the physical attributes of stroke such as weakness on one side or facial drop, but much less of an understanding of the neuropsychological elements. This is why education is an important facet of neuropsychological intervention. Research by Clark et al., (2004) found that where there is family conflict and high memory and behaviour change in the stroke survivor, the mental health of the caregiver is lower. Since the SCIT was developed our understanding of the neuropsychological sequalae of stroke has also improved so a new measure developed now might better capture these elements. Barrowclough et al (1987) emphasise the role of *functional knowledge* rather than family members merely knowing things. For example, some symptoms are hard to understand as a process of a health condition (e.g. anergia) than others (e.g. hemiplegia). This functional knowledge underlies the attributions that lead to expressed emotion behaviours (Barrowclough et al., 1987). Given that the measure was found to be comparable to others, further exploration of other existing measures and the type of stroke knowledge they assess would be beneficial with the potential to develop new measures in the future.

Culture and Expressed Emotion

There has been considerable research into EE in Western cultures; however, it is worth considering the impact of culture and ethnicity on the construct. In their review Bhugra & McKenzie (2003) found that the data across cultures are inconsistent. They suggested normative data should be collected around baseline EE across cultures to facilitate understanding and exploration cross-culturally. Differing cultural attitudes toward involvement in relatives' lives as well as cultural differences in how individuals interact with each other may influence EE scores. It has been argued that 'emotional overinvolvement' can be incorrectly pathologised when viewed through a western, individualistic and secular lens; in more collective cultures 'over-involvement' and criticism may be viewed as constructive and culturally normal (Bhugra & McKenzie, 2003). In British-Pakistani families previous research has identified that a significantly higher cut-off was required to predict relapse rates in schizophrenia, highlighting the different cultural norms around involvement (Hashemi & Cochrane, 1999). Moreover, it seems that the critical comments component of EE has a positive association for African Americans with psychotic symptoms – the opposite to the relationship found in white populations (Gurak & Weisman de Mamani, 2017). The empirical paper within this thesis did not collect data around culture or ethnicity so it is not known what the impact of this may have been on the results. Within the literature review some data was provided on ethnicity of the participants but not for all studies. Where it was included, the populations studied were described by the authors as primarily white. Future research would benefit from inclusion of this information, and active recruitment across racial and cultural groups, in order to ascertain any influence on the results.

Inclusion of ABI in literature review

In developing the focus on the literature review element, the topic was widened to include ABI as opposed to just Stroke to ensure sufficient research to discuss. However, the variance in types of ABI and how it was defined within the studies meant that meta-analysis was not possible and it was difficult to make some comparisons. A simple example from within the data was the difference between mean age of stroke survivors in Rashid et al. (2012) in comparison with the combined mean age of all the TBI focussed studies, 67.35 and 36.01 years old respectively.

Thesis Journey

I had always hoped to have an element of neuropsychology in my thesis project given my professional background. Personally, the past five years have been challenging in a variety of ways. After a very personal loss in 2017 my first thesis idea, in homelessness and brain injury, fell through when the field supervisor (correctly) did not feel I was in the right place emotionally to continue with that particular project at that time. A second idea was started but did not progress as I always felt as though this was ‘someone else’s project’ and did not feel engaged with it. After the end of the clinical/taught part of training my third and final thesis idea was started with support from my new employer.

I had started working within stroke services at a local hospital and was fortunate that a colleague agreed to be my field supervisor. I utilised links with local stroke groups, my clinical work and my own learning in my role to begin to develop my final thesis idea. Frequently stroke survivors are accompanied to appointments by a family member or caregiver, which is a phenomena I had noted in brain injury services too. The relationship between the stroke survivor and informal caregiver was of interest in terms of how that relationship impacts both halves of the dyad. I had often noted psychological impacts on both the stroke survivor and their caregiver, and how these individual impacts contributed to the space between them. Exploration of the literature led to a growing interest of the impact of EE within physical health settings and a lack of research of EE within stroke populations. There was not sufficient research to complete the literature review solely on stroke and EE, so the decision was made to widen and include all forms of acquired brain injury.

Between then and now I have experienced so many milestones and challenges in my life including becoming a parent (twice), bereavements, health issues and a global pandemic all of which, in different ways, have influenced my thesis journey.

I learnt a lot about the impact of stroke and the importance of the informal caregiving role in recovery from stroke and ABI. I was fortunate enough to be added to several social media groups for caregivers to stroke survivors which provided me with a glimpse into this world and the things that cause caregivers the most distress. Frequently there was a huge sense of loss both for the changes in the stroke survivor but also the loss of the life they expected to have before becoming a caregiver. This is consistent with the finding that in carers of those with psychosis, grief scores are highly correlated with expressed emotion (Mulligan et al 2013).

It was also highlighted to me how undervalued caregivers are considering the positive impact they have on both the stroke survivor and their economic value to society.

The journey as a whole taught me the importance of balance in my own life. I am absolutely certain that I did not get this balance right all of the time and there are things I would do differently if I was to start over. Despite this, I have completed a piece of work I am proud of whilst working in a full time NHS role and managing to be the parent that I wanted to be. I have two children I am immensely proud of and I have continued to hold on to a sense of myself throughout this process.

Recommendations for Further Research

The study raised several areas to be considered for further research within this topic area.

- Across both papers, it was evident that more research in stroke in general is needed with more specific research with the caregivers of stroke survivors also indicated.
- There is a need for the development of a new measure of stroke knowledge with a focus on the neuropsychological sequelae of stroke. This would be beneficial in terms of research into what people understand about the outcomes of stroke as well as what elements of stroke care do family/informal caregivers find the most difficult to cope with. Additionally, this may have clinical utility, in supporting interventions to be targeted at the areas which challenge the most.
- Given the relationship found between expressed emotion and psychological outcomes for the informal caregiver in the current research, further research into this relationship would be beneficial, particularly between expressed emotion and the outcomes for the stroke survivor and informal caregiver individually, as well as dyadic outcomes such as relationship quality and dyadic adjustment. Further

information would support future research and direct interventions to support positive outcomes for both.

- Following the literature review there is additionally an argument for further, higher quality research into expressed emotion and psychological outcomes across ABI to develop further understanding.
- Given the heterogeneity in mechanisms of brain injury, symptoms and demographic variables of participants, further research looking at commonalities and differences across the population is indicated. This will support understanding in the area, but also support clinical knowledge as to what is important for people at different stages of their injury and lives. Additionally further research into the differing types of ABI is badly needed.
- Finally, there is little qualitative research in this area and it could be beneficial in considering areas of focus within further research options. The richness and variety of caregivers and survivor experiences cannot be adequately conveyed without the opportunity to ‘hear their voices’.

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Section 4: Ethics Forms

Clare Rooney*

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Lancaster University

Word count (exc. title page, abstract, appendices, figures and tables): 3007

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** Formatted to the British Journal of Health Psychology Guidelines

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

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

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

Title of Project: Moderation analysis of the impact of stroke knowledge on expressed emotion and caregiver burden

Name of applicant/researcher: Clare Rooney

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

2. Contact information for applicant:

E-mail: c.rooney1@lancaster.ac.uk OR dizz2211@hotmail.com **Telephone**: 07966676846
(please give a number on which you can be contacted at short notice)

Address: Division of Clinical Psychology, Furness College, Lancaster University, Lancaster, LA1 4YG

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

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:

Bill Sellwood – Research Supervisor

Róisín Cunningham – Field Supervisor

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

Bill Sellwood – Programme Director, Lancaster University Doctorate of Clinical Psychology Programme.

Róisín Cunningham – Clinical Psychologist, Aintree University Hospital NHS Foundation Trust.

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.

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

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

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? no

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? n o
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? yes
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 study aims to look at the impact of stroke knowledge on the caregiving relationship and caregiver burden.

Participants will be those who provide informal care to someone who has survived a stroke (such as family members). The study will be completed with approximately 70 participants who will be asked to complete either online or physical questionnaires. Participants will be recruited through social media and also local Stroke Association outlets. The questionnaires will assess:

- Demographic variables
- Measure of expressed emotion – a measure of caregivers' emotional and interpersonal reactions towards the stroke survivor
- Measure of symptom understanding
- Measures of caregiver burden – a measure of the subjective impact the caring role is having on the caregiver and also a measure of mood.

The results will then be analysed to discover if knowledge of stroke impact has an influence on the impact of EE. It will aim to investigate whether, if an individual is more knowledgeable about stroke, this reduces subjective caregiver burden.

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

Start date: December 2018 End date: December 2019

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):

Study participants with be those who self-identify as informal caregivers of a stroke survivor.
Inclusion criteria:
- Self-identification as an informal caregiver of a stroke survivor
- Over the age of 18

Exclusion criteria:
- English language abilities to a level to understand the information sheet, consent and questionnaires. This would be assumed based on ability to read and understand the instructions on the advert and information sheet.
- Stroke survivor with another primary neurological diagnosis other than stroke

An a priori analysis was calculated using G*power (Faul, Erdfelder, Buchner & Lang, 2009), using a multiple regression analysis with 7/8/9 predictors, a power of 80% and a conservative effect size of 0.25. This led to a sample size of 65/69/72. The effect size of 0.25 was chosen as the minimum effect size which is estimated to inform clinical interventions with regards to the impact of changes in these variables (α was set at 0.05).

Based on this, the minimum sample size will be 72 with an aim to gather in excess of this if possible within the time constraints of the study.

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).

Recruitment will be via two different methods. Firstly, study questionnaires will be converted to online questionnaire packs using Lancaster University Qualtrics system. The link for this will be shared on social media, on both Facebook and Twitter. Friends and followers will be encouraged to share the link on their pages. The Liverpool Stroke Recovery Partnership (LSRP) has provisionally agreed to support and share the link on their social media pages (subject to university ethical approval). The link will also be shared on other stroke organisation and stroke charity pages in order to access as many people with links to stroke as possible. Examples include; 'Stroke care for stroke caregivers' and 'National stroke association'. Through sharing it is expected that further relevant groups may be identified. Social media and online surveys were chosen for the potential wide access to potential participants in order to meet power requirements for the study. Please see protocol for full versions of documentation.

In terms of recruitment, whilst social media gives scope for advertising widely, it presumes access to technology, social media and the ability to confidently operate them. Stroke primarily affects older adults and the majority of caregivers tend to be spousal, therefore potentially someone of a similar age group. It is a possibility that some within the older generation are not regular users of social media and technology. To mitigate this, physical copies of the questionnaire packs will be located in local Stroke Association buildings and again The Liverpool Stroke Recovery Partnership has provisionally agreed to promote the research (subject to university ethical approval) to those who visit. In order to maintain anonymity, pre-paid envelopes will be available to participants in order to post their responses back to the research team should they choose. Participants can also opt to leave their responses at the location in a blank envelope which will be collected by the researcher from the locations in batches at regular intervals.

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

Questionnaires will be used to gain data via both an online survey method and physical copies, this will also include self-report questions for demographic and clinical data.

This will be a quantitative study using outcome measure scores for;
Stroke knowledge: Stoke Care Information Test (SCIT; Evans, Pomeroy, Van der Weele and Hammond, 1985)
Expressed emotion: The Family Questionnaire (FQ; Wiedemann, Rayki, Feinstein and Hahlweg, 2002)
Caregiver burden: Caregiver Burden Scale (CBS; Visser-Meily, Post, Riphagen and Lindeman, 2004)
and levels of psychological distress: Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995).

Stroke Care Information Test (SCIT) – A measure designed to assess family members' knowledge about stroke in the areas of physical loss, cognitive and perceptual disorders, language impairment, and sexuality. The test was found to have good reliability (Evans, Pomeroy, Van der Weele and Hammond, 1985) and is simple to administer. The SCIT contains 36 questions and has a score range of 0-36 with higher scores indicating greater knowledge. It should take approximately 10 minutes to complete. Example questions include;

31. A stroke on the left side of the brain usually results in;
    a. Language impairment
    b. Confusion
    c. Visual loss
    d. Left sided paralysis
32. A person who perseverates;
    a. Dwells on details
    b. Cannot concentrate
    c. Should not read
    d. Cannot stop performing

The Family Questionnaire (FQ) – This is a self-report measure from the relative perspective. Whilst the Camberwell Family Interview (CFI) is seen as the gold standard in assessment of expressed emotion FQ has been found to have good associations with CFI, however it has yet to be validated in relation to its ability to predict relapse (Wiedemann, Rayki, Feinstein and Hahlweg, 2002). It is short and easier to score and administer than the CFI. The FQ contains 20 questions, 10 for each subscale of critical comments (CC) and emotional overinvolvement (EOI), which are the two main variables of classification of EE, with Likert-Scale responses of ‘never/very rarely’, ‘rarely’, ‘often’ and ‘very

often'. Scores range from 1 to 4 for each item and the authors gave a cut-off point at 23 for high CC and 27 for high EOI. The measure should take approximately 5 minutes to complete.
Example questions include: 17. He/she is an important part of my life. 11. I regard my own needs as less important.

Caregiver Burden Scale – Measures to assess the impact of care-giving for the individual. The Caregiver burden scale was found to have good construct validity and test-retest stability (Visser-Meily, Post, Riphagen and Lindeman, 2004) and is again brief to administer and score. The caregiver burden scale asks about elements of both subjective and objective burden and these can be distinguished on analysis. The scale contains 22 items and are scored from 1 to 4 on a Likert-Scale (not at all, seldom, sometimes, often). Scores can range from 22 up to 88 with higher score being indicative of higher burden. The measure should take approximately 5 minutes to complete.
Example questions include: 7. Do you think your own health has suffered because you have been taking care of your relative? 15. Do you find it physically trying to take care of your relative?

DASS-21 –The DASS-21 is a measure of distress across three subscales of depression, anxiety and stress (Lovibond & Lovibond, 1995). It contains 21 items rated on a Likert-Scale (never, sometimes, often and almost always) scored from 0-3 with a max score on each subscale of 21 with higher scores indicative of higher distress. Given the previous research suggesting the impact on carer mental health measures of caregiver would provide an additional measure of the impact of caregiving on the individual therefore encompassing both their subjective view of the burden with some objective measures of mood. The measure should take approximately 5 minutes to complete.
Example questions include: 3. I couldn't seem to experience any positive feeling at all. 12. I found it difficult to relax.

Data will also be collected via self-report method for demographic variables such as age, gender, relationship to stroke survivor and clinical variables such as time since started caring for stroke survivor.

Descriptive statistics will be evaluated in order to describe sample characteristics. The distribution will also be analysed in order to assess normality and determine if parametric statistics would be appropriate.
The primary analysis is a regression to explore the factors that explain variance in caregiver burden. Stepwise analysis will be used.

The final step in the regression will explore the potential moderating effect of knowledge between expressed emotion and caregiver burden.

This analysis will be completed using SPSS software.

The inclusion of other predictors allows for comparison between these and stigma to identify which is the strongest predictor for psychological distress in this population.

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.

Once the online survey has begun then the information provided will be anonymous meaning that no personal identifiable information will be held. The study findings will be produced into a report which may be published, however no personal identifiable information will be included in the report.

For those completing physical copies of the questionnaire pack, there will be the option of returning the questionnaire packs in pre-paid envelopes to the university anonymously or they can be placed in a plain envelope and left at the location where they will be collected by the researcher at regular intervals.

If a participant wishes to access a copy of the results of the study then they can choose to provide their personal details to the research team. Their details will be held long enough to send out this information, then it will be destroyed and this information will be kept confidential and secure throughout the process. It will also be kept in a separate data file from the main project data, so as to ensure that participants cannot be identified if requesting a summary of the findings.

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

- The files on the computer will be encrypted (that is no-one other than the researchers will be able to access them) and the computer itself password protected.
- Lancaster University will keep the anonymised data for a period of 10 years after the study has finished.

The study will comply with the regulations set out in EU General Data Protection Regulation (GDPR) and the UK’s Data Protection Act 2018.

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.

N/A

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

N/A

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?

The raw data will not be publicly available and it will not be uploaded to PURE. The raw data will be encrypted and held electronically on the secure Lancaster University server by the DClinPsy Programme for 10 years following submission of the data.

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

The raw data will not be shared publicly. There are no plans to share data with other researchers.

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?

In terms of gaining valid consent, for the online survey, all participants will be aged 18 or over and will be provided with an information sheet which they will have the option of downloading and can ask questions by contacting the researcher prior to completing the survey and providing their consent. They will be unable to withdraw their data once the survey has begun as all data is not identifiable at this stage; this is outlined in the consent form.

For the physical questionnaire packs, each participant will be provided with an information sheet to keep and given the opportunity to ask questions by contacting the researcher prior to returning the questionnaires and providing consent. They will be asked to initial and sign a consent form to return with the pack and also be provided with a second copy of the consent form to keep. They will be unable to withdraw their data once the questionnaire pack has been returned as data will no longer be identifiable. This information will be outlined in the consent form.

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.

There is a small risk of distress to the participants in answering the questionnaires. There are no questions which are thought to be specifically likely to cause distress, however asking people in general about the burden of caring for a stroke survivor, their own mental health and also the relationship with the stroke survivor may be distressing dependent on the individual circumstances. In order to manage this risk, participants will be provided with details for further emotional support from either The Stroke Association, how to access to support from their GP or contact the university if they have any complaints. Additionally, participants recruited via the Liverpool Stroke Recovery Partnership (LSRP) will be able to access carer support groups. Information about advice and further sources of support will be provided at the end of the survey as part of the debrief procedure to ensure that participants are able to access support for any difficulties they are currently experiencing.

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).

There are no risks to the researchers as the study is primarily conducted online. The topic area is not a distressing one, although the client population could cause some distress to the upsetting nature of Stroke. Support is available to the researcher from research and field supervisors.

Physical questionnaire packs will be held at local branches of The Stroke Association and participants will have the option to post back the packs or leave them at the location. The packs left at the locations will be collected regularly by the research team. There are no specific risks to the researcher associated with attending these locations.

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 will be no direct benefit to the participants for taking part in the study.

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

There are no incentives or payments being offered to participants as part of this study.

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.

Once the online survey has begun then the information provided will be anonymous meaning that no personal identifiable information will be held.

No personal identifiable information will be collected as part of the physical questionnaire packs so as these are returned either via pre-paid envelope or collected from locations, there will be no personal identifiable information will be held.

Should any participants wish to be informed about the results of the study then they can choose to provide their personal details so that this information can be sent to them Their details will only be held long enough to send out this information, then it will be destroyed and their personal information will be kept confidential throughout the process.

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

The field supervisor (Roisin Cunningham) has had regular contact with staff and volunteers at the stroke association. The Stroke Association members have highlighted this a key topic or exploration during discussion and are supporting the implementation of this initial survey. In addition, the Stroke association itself has highlighted the impact of stroke on family caregivers and wider relationships with the person affected (State of the Nation; Stroke Statistics, Stroke Association, 2018). We will be liaising closely with the local Stroke Association group regarding the implementation of the project.

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

Following completion, the study findings will be submitted as my DClinPsy thesis and will be presented to peers and staff at Lancaster University. This presentation will be available on the University's website for the public to access. There may also be the opportunity to publish the findings in the Stroke Association and Liverpool Stroke Recovery Partnership newsletters and on their websites, along with any other support services that have been approached. The findings may also be put forward for publication in a peer reviewed journal and/or presented at conferences.

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: signature

Applicant electronic signature: C Rooney Date 21/12/18

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): Bill Sellwood Date application discussed 21/12/18

Submission Guidance

1. **Submit your FHMREC application by email to Diane Hopkins (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**

Thesis Protocol

Title: Moderation analysis of the impact of stroke knowledge on expressed emotion and caregiver burden
Name of applicant/supervisors/affiliations/version number: **Applicant:** Clare Rooney, Trainee Clinical Psychologist, Lancaster University (Probationer Clinical Psychologist, Aintree University Hospital NHS Foundation Trust) **Field Supervisor:** Dr Róisín Cunningham, Clinical Psychologist, Clinical Health Psychology Department, Aintree University Hospital NHS Foundation Trust **Research Supervisor:** Prof. Bill Sellwood, Course Director, Division of Health Research, Lancaster University **Version number:** Two

Introduction:

A stroke is life-threatening and happens when the blood supply in part of the brain is cut off and it is reported that approximately 100,000 people per year have a stroke and this number is increasing (Royal College of Physicians Sentinel Stroke National Audit Programme; SSNAP, 2017). Stroke is a major cause of ongoing disability leaving people with a range of difficulties including cognitive, physical, emotional and language deficits (Rigby, Gubitz and Phillips, 2009). Whilst some people make a good recovery, many are left needing either formal or informal care support. Many are supported by informal caregivers such as spouses, adult offspring or other relatives.

Informal caregivers are important both socially and economically. Cost savings in the USA were calculated as over 6 billion dollars saved through utilisation of informal carers (across conditions) (Hickenbottom et al. 2002). It is also estimated that 15.8 billion per year was saved by informal carers looking after stroke survivors in the UK (Patel et al., 2018) saving money spent on care and also enabling stroke survivors to return to living in the community (Patel et al. 2018). Despite this there is a huge cost to the individual caregiver, with the burden of care giving being linked with higher incidence of depression, anxiety (Carnwath and Johnson, 1987; Wade, Legh-Smith and Hewer, 1986) and poor life satisfaction as well as increased mortality (Schulz and Beach, 1999). Caregiver burden is associated with poor psychological outcomes for the caregiver including depression (Schulz, Boerner, Shear, Zhang and Gitlin, 2006) so it would be important to consider the psychological impact. The impact can begin from as little as one-month post-stroke and continue for many years (Jones, Charlesworth and Hendra, 2000). Often the caregiver is in the role involuntarily and without formal training. Stroke recovery is at its best when family are healthy and supportive of the stroke survivor (Glass, Matchar, Belyea and Feussner, 1993).

Expressed Emotion (EE) is a measure of the family environment and quality of family relationships. Specifically, EE looks at the extent to which family members express critical, hostile or emotionally overinvolved attitudes towards an unwell family member. Much of the research has focussed on the impact of EE in psychiatric conditions (E Sa, Wearden, Hartley, Emsley and Barrowcough, 2016) and found that high levels of EE are associated with higher risk of relapse in those conditions. More recently research has found that EE also has an impact in physical health conditions including chronic illness (Rosland, Heisler and Piette, 2011), traumatic brain injury (Weddell, 2010) and also evidence that having high EE caregivers are associated with increased incidence of post stroke depression for the stroke survivor (Rashid, Clarke and Rogish, 2013). In a review of the influence of EE in dementia populations it was found that relatives rated as high EE were more likely to attribute the problems as being personal and controllable by the patient. (Safavi, Berry & Wearden, 2017). Given that evidence shows that EE can have a negative impact on the outcomes for stroke survivors, it is important to consider what would reduce this impact. Whilst EE can be discussed as a characteristic of the relative in question, it is most appropriate to consider it a measure of the relationship between the patient and the relative (Hooley and Parker, 2006).

Low et al. (1999) found caregivers in stroke have poorer psychological health than the general population and this was influenced by factors such as the severity of disability, quality of relationship and extent of cognitive/behavioural difficulties. Informal carers' ability to cope has found to be positively influenced by more strategies and more information/education about the condition (Evans, Matlock, Bishop, Stranahan and Pederson, 1988; Kalra et al. 2004; McCullagh, Brigstocke, Donaldson and Kalra, 2005). Better patient mental health and cognitive function were associated with better carer mental health (Tooth et al. 2005). In research with physical health, family members who are rated low EE hold rational understanding and recognition of behaviours as symptoms of illness whereas those with high EE are often more anxious and fearful about the illness and have an increased desire for control (Barrowclough and Hooley, 2003). If caregivers have a better understanding of the impact of stroke, could this mitigate the impact of high EE on carer burden. Barrowclough and Hooley (2003) found carers' beliefs and attributions were a mediating factor in controlling behaviour and the resulting risk of relapse. They argued for the development of interventions to help relatives to not blame the unwell person and be more flexible in their approach.

Rationale:

This research aims to discover if knowledge of stroke moderates the relationship between expressed emotion and caregiver burden in stroke. By assessing levels of existing knowledge alongside measures of EE and carer burden it would enable exploration of these links and if functional knowledge is a moderating factor for high EE in carers of stroke survivors. It is felt that increased knowledge could reduce the negative attributions associated with high EE which may then improve rehab outcomes for the stroke survivor as well the relationship with the caregiver. If these improvements are found, it would therefore reduce caregiver burden.

Given the importance of informal caregivers and the role they play, it should be a priority for services to identify ways to work towards reducing the impact of caregiver burden. If stroke knowledge was a moderating factor in reducing caregiver burden, then it would justify the importance of further support for carers and potentially the development of a family intervention model in stroke rehabilitation and care.

Research Question:

The research question posed for this study is: Does caregiver knowledge of stroke moderate the impact of expressed emotion in caregiver burden?

Research Design:

This will be a quantitative study using outcome measure scores for;

Stroke knowledge: Stoke Care Information Test (SCIT; Evans, Pomeroy, Van der Weele and Hammond, 1985)

Expressed emotion: The Family Questionnaire (FQ; Wiedemann, Rayki, Feinstein and Hahlweg, 2002)

Caregiver burden: Caregiver Burden Scale (CBS; Visser-Meily, Post, Riphagen and Lindeman, 2004) and levels of psychological distress: Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995).

Stroke Care Information Test (SCIT) – A measure designed to assess family members' knowledge about stroke in the areas of physical loss, cognitive and perceptual disorders, language impairment, and sexuality. The test was found to have good reliability (Evans, Pomeroy, Van der Weele and Hammond, 1985) and is simple to administer. The SCIT contains 36 questions and has a score range of 0-36 with higher scores indicating greater knowledge.

The Family Questionnaire (FQ) – This is a self-report measure from the relative perspective. Whilst the Camberwell Family Interview (CFI) is seen as the gold standard in assessment of expressed emotion but the FQ has been found to have good associations with CFI, however it has yet to be validated in relation to its ability to predict relapse (Wiedemann, Rayki, Feinstein and Hahlweg, 2002). It is short and easier to score and administer than the CFI. The FQ contains 20 questions, 10 for each subscale of CC and EOI with Likert-Scale responses of ‘never/very rarely’, ‘rarely’, ‘often’ and ‘very often’. Scores range from 1 to 4 for each item and the authors gave a cut-off point at 23 for high CC and 27 for high EOI

Caregiver Burden Scale – Measures to assess the impact of care-giving for the individual. The Caregiver burden scale was found to have good construct validity and test-retest stability (Visser-Meily, Post, Riphagen and Lindeman, 2004) and is again brief to administer and score. The caregiver burden scale asks about elements of both subjective and objective burden and these can be distinguished on analysis. The scale contains 22 items and are scored from 1 to 4 on a Likert-Scale (not at all, seldom, sometimes, often). Scores can range from 22 up to 88 with higher score being indicative of higher burden.

DASS-21 –The DASS-21 is a measure of distress across three subscales of depression, anxiety and stress (Lovibond & Lovibond, 1995). It contains 21 items rated on a Likert-Scale (never, sometimes, often and almost always) scored from 0-3 with a max score on each subscale of 21 with higher scores indicative of higher distress. Given the previous research suggesting the impact on carer mental health measures of caregiver would provide an additional measure of the impact of caregiving on the individual therefore encompassing both their subjective view of the burden with some objective measures of mood.

Demographic predictors will also be included in the analysis (age, gender, relationship, living status) as well as the length of time they have been providing care to the stroke survivor and if there are any formal care arrangements. (See Appendix F)

The primary analysis is a regression to explore the factors that explain variance in caregiver burden. Stepwise analysis will be used.

The final step in the regression will explore the potential moderating effect of knowledge between expressed emotion and caregiver burden.

This analysis will be completed using SPSS software.

Participants:

Study participants with be those who self-identify as informal caregivers of a stroke survivor.

Inclusion criteria:

- Self-identification as an informal caregiver of a stroke survivor
- Over the age of 18

Exclusion criteria:

- English language abilities to a level to understand the information sheet, consent and questionnaires. This would be assumed based on ability to read and understand the instructions on the advert and information sheet.
- Stroke survivor with another primary neurological diagnosis other than stroke

An a priori analysis was calculated using G*power (Faul, Erdfelder, Buchner & Lang, 2009), using a multiple regression analysis with 7/8/9 predictors, a power of 80% and a conservative effect size of 0.25. This led to a sample size of 65/69/72. The effect size of 0.25 was chosen as the minimum effect size which would be clinically relevant and therefore all effect sizes stronger than this would be adequately powered (α was set at 0.05).

Materials:

Stationery will be required for advertising materials (see Appendix A).

A participant information sheet (see Appendix B), consent form (see Appendix C and D) and debrief sheet (see Appendix E) will be required.
An electronic version of each of the questionnaires, including the self-report measures, will be required to input to the online survey
Qualtrics software will be required to deliver the survey online.

Recruitment:
Recruitment will be via two different methods. Firstly, study questionnaires will be converted to online questionnaire packs using Lancaster University Qualtrics system. The link for this will be shared on social media, including Facebook and Twitter, particularly on Stroke pages. The Liverpool Stroke Recovery Partnership has provisionally agreed to support and share the link on their social media pages (subject to university ethical approval).
Secondly, physical copies of the questionnaire packs will be located in local Stroke Association buildings and again The Liverpool Stroke Recovery Partnership has provisionally agreed to promote the research (subject to university ethical approval) to those who visit. In order to maintain anonymity, participants will be provided with pre-paid envelopes in order to post their responses back to the research team.
The questionnaire packs should take approximately 20-30 minutes to complete.

Procedure:
Questionnaires will be used to gain data via both an online survey method and physical copies, this will also include self-report questions for demographic and clinical data.
These questionnaires will assess levels of stroke knowledge (SCTI; Evans, Pomeroy, Van der Weele and Hammond, 1985), levels of EE (Cole and Kazarian, 1988; Wiedemann, Rayki, Feinstein and Hahlweg, 2002) levels of caregiver burden (CBS, Visser-Meily, Post, Riphagen and Lindeman, 2004) and also an additional measure of psychological distress (DASS-21; Lovibond & Lovibond, 1995).

Data will also be collected via self-report method for demographic variables such as age, gender, relationship to stroke survivor and clinical variables such as time since started caring for stroke survivor. (See Appendix F)

Once the survey has begun then the information provided will be anonymous meaning that no personal identifiable information will be held. The study findings will be produced into a report which may be published, however no personal identifiable information will be included in the report.

If a participant wishes to access a copy of the results of the study then their personal details will be held long enough to send out this information, then it will be destroyed and this information will be kept confidential throughout the process. The data collected for this study will be stored securely and only the researchers conducting this study will have access to these data:

- The files on the computer will be encrypted (that is no-one other than the researchers will be able to access them) and the computer itself password protected.
- Lancaster University will keep the anonymised data for a period of 10 years after the study has finished.

Data Analysis:

Descriptive statistics will be evaluated in order to describe sample characteristics. The distribution will also be analysed in order to assess normality and determine if parametric statistics would be appropriate.

The primary analysis is a regression to explore the factors that explain variance in caregiver burden. Stepwise analysis will be used.

The final step in the regression will explore the potential moderating effect of knowledge between expressed emotion and caregiver burden.

This analysis will be completed using SPSS software.

The inclusion of other predictors allows for comparison between these and stigma to identify which is the strongest predictor for psychological distress in this population.

Practical Issues:

In terms of recruitment, whilst social media gives scope for advertising widely, it presumes access to technology, social media and the ability to confidently operate them. Stroke primarily affects older adults and the majority of caregivers tend to be spousal, therefore potentially someone of a similar age group. It is a possibility that some within the older generation are not regular users of social media and technology. Several strategies will be used in order to mitigate this issue; firstly; there will be physical copies of the questionnaire packs available at local branches of The Stroke Association so the reliance on social media is reduced. Secondly, online advertising will be aimed at support services and through social media to access as many participants as possible. It is hoped that other family members may recommend the primary informal caregiver take part in the study even if they themselves do not have access to social media. Finally, I would ideally also attend meetings/groups at Stroke Association outlets in order to collect data and ensure that everything is fully explained to participants. (The Liverpool Stroke Recovery Partnership have agreed to promote the research subject to ethical approval both online and in locations).

Dissemination:

Following completion, the study findings will be submitted as my DClinPsy thesis and will be presented to peers and staff at Lancaster University. This presentation will be available on the University's website for the public to access. There may also be the opportunity to publish the findings in the Stroke Association and Liverpool Stroke Recovery Partnership newsletters and on their websites, along with any other support services that have been approached. The findings may also be put forward for publication in a peer reviewed journal and/or presented at conferences.

Ethical issues:

Confidentiality of participants will be maintained as once the survey has begun then the information provided will be anonymised meaning that no personal identifiable information will be held. Participants will be provided with an information sheet outlining the proposed research and informed consent will be gained before the survey commences. Participants will be unable to withdraw their data once the survey has begun as all data is not identifiable at this stage, this is outlined in the consent form (see Appendix C and D).

There is a small risk of distress to the participants in answering the questionnaires. In order to manage this risk, participants will be provided with details for further emotional support from either The Stroke Association, how to access to support from their GP or contact the university if they have any complaints. Additionally, participants recruited via the LSRP will be able to access carer support groups. Information about advice and further sources of support will be provided at the end of the survey as part of the debrief procedure to ensure that participants are able to access support for any difficulties they are currently experiencing.

In terms of gaining valid consent, all participants will be aged 18 or over and will be provided with an information sheet which they will have the option of downloading and can ask questions by contacting the researcher prior to completing the survey and providing their consent. They will be unable to withdraw their data once the survey has begun as all data is not identifiable at this stage; this is outlined in the consent form (see Appendix C and D).

In terms of advice giving and debriefing, participants will be shown a debrief sheet, which includes contact details of the researcher. For online participants, following completion of the survey there will be the option of downloading this, whilst for other participants physical copies will be provided with the questionnaire pack. They will have the opportunity to ask questions or raise concerns directly with the researcher or through the complaints procedure outlined. Further sources of support and advice will also be provided at this stage in case they require further support.

Timescale:

November 2018 – Submit documents in November for consideration at December committee. Gain ethical approval; keep reflective diary of process; keep notes and copies of all documents relevant to process.

December 2018 – June 2019 – Conduct data collection for main study; write draft introduction and method sections; keep notes of data collection; keep reflective diary.

June 2019 – July 2019 – Analyse data; hand in draft introduction and methods; write draft abstract, results and discussion.

July 2019 – August 2019 - Hand in complete first draft of research paper by end of November; keep checking for new, relevant references; complete reflective diary; produce appendices; write draft thesis abstract.

September 2019 – October 2019 – Complete final version of research paper; collate and finalise appendices; finalise thesis abstract; complete cover sheet; hand in complete draft thesis to Programme by end of March; soft-bind and hand in final thesis by deadline.

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Appendix 4-A: *Study Advert*

Do you provide care for a stroke survivor?

If you are 18 years and older and identify as the caregiver of a stroke survivor you can be a participant in this research.

--------- Stroke Knowledge and the Caregiving Relationship -------

What is the study about?

This research aims to explore the impact of stoke knowledge on the caregiving relationship.

Does a good understanding of stroke help with adjusting to the psychological impact of being a caregiver of a stroke survivor as well as its impact on relationships?

The aim is to get more insight into psychological support for those who are caregivers of stroke survivors.

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

If you decide you would like to take part, you will be asked to complete a survey with questions about your understanding of stroke as well as your relationship with the stroke survivor and how much being a caregiver impacts on you. It should take you about 20-25 minutes to complete and it does not need to be completed at one sitting. Please ask someone you trust to help you complete it if you feel like you need assistance.

Interested in taking part in this research?

If you would like to take part in this research, please click the following link to access the online survey: XXXXXXXXXXX

Or alternatively for further information contact the main researcher: **Clare Rooney** on c.rooney1@lancaster.ac.uk or phone **01524 592970**.

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Lancaster
University

Appendix 4-B: *Participant Information Sheet*

Participant Information Sheet

What is the impact of stroke knowledge on the caregiving relationship?

My name is Clare Rooney and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

Does a good understanding of stroke help with adjusting to the psychological impact of being a caregiver of a stroke survivor as well as its impact on relationships?

What is the study about?

This research aims to explore the impact of stoke knowledge on the caregiving relationship. The study will be asking caregivers of stroke survivors to answer questions about their knowledge of stroke, the impact of being a caregiver and also their relationship with the stroke survivor. The aim of the study is to get more insight into psychological support for those who are caregivers of stroke survivors.

Can I take part in the study?

The study requires information from the primary caregivers of stroke survivors aged 18 or over who are able to read and understand English.

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

If you decide you would like to take part, you will be asked to complete a survey involving questionnaires which will assess different topics. There will be one looking at your knowledge of stroke, which includes questions about the physical loss after stroke, as well as cognitive and perceptual problems a stroke survivor might experience. Another will look at your relationship with the stroke survivor and how you react to their difficulties. Finally, there is a measure of how much caregiving impacts on you, including questions such as the time it takes you, how much it impacts on your health and the economic impact for you. There will also be questions about the psychological impact of being a caregiver. The survey will also request some information such as your age, gender and the time since you started to provide care for a stroke survivor. If you agree to take part in the research, you can do so with an online survey. You do not need to complete all of the survey in one sitting, you can return to it later if you need a break, simply follow the online instructions. There is also an option to complete physical copies of the survey which are available at local Stroke Association outlets. You have the choice to return these in a pre-paid envelope or leave them for collection at the location. For either option, you can ask someone to help you complete the questionnaires if you need any assistance.

Do I have to take part?

No. It’s completely up to you to decide if you take part; taking part in this research is completely voluntary. You will have the opportunity to ask questions and raise concerns at any time. If you agree to take part in the research, once the online survey has started then the information provided will be anonymised meaning that no personal identifiable information will be held. Due to this, you will not be able to withdraw your data once you have begun the online survey as it will not be possible to identify your responses. If you choose to complete the physical questionnaires, once these have been sent back to the research team again you will not be able to withdraw your responses as the information will be anonymous.

Will my data be identifiable?

Once the survey has begun then the information provided will be anonymous meaning that no personal identifiable information will be held. The study findings will be produced into a report which is to be submitted as a thesis forming part of my clinical psychology doctorate qualification. The thesis may be published, however no personal identifiable information will be included within it. If a participant wants to access a copy of the results of the study then they will be asked to provide their personal details so this can be sent. Their details will kept separate from the main database so as to preserve anonymity of data. The information will only be held long enough to send out this information, then it will be destroyed and this information will be kept confidential throughout the process. The data collected for this study will be stored securely on university computers and only the researchers conducting this study will have access to this data:

- The files on the university computers will be encrypted (that is no-one other than the researchers will be able to access them) and the computer itself password protected.
- Lancaster University will keep your anonymised data for a period of 10 years after the study has finished.

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.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and/ or presented at conferences. A presentation will be available on the Lancaster University website for the public to access. There may also be the opportunity to publish the findings in the Stroke Association and Liverpool Stroke Recovery Partnership newsletters and on their websites. If any other services are involved in the promotion of the study, they may also be offered to opportunity to publish the findings in relevant publications.

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 contact 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.

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:

Clare Rooney
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster, UK
LA1 4YG
Email: c.rooney1@lancaster.ac.uk
Tel: +44 01524 592970

Or

Research Supervisor:
Professor Bill Sellwood,
Course Director
Division of Health Research
Furness Building
Lancaster University
Lancaster, UK
LA1 4YG
Email: b.sellwood@lancaster.ac.uk
Tel: +44 (0)1524 593998

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Catherine Walshe
Tel: +44 (0)1524 510124
Email: c.walshe@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster, UK
LA1 4YG

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

Professor Roger Pickup
Associate Dean for Research
Tel: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University
Lancaster, UK
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.

The Stroke Association
Stroke Association House
240 City Road,
London
EC1V 2PR
Tel: (+44) 0303 3033 100
Website: www.stroke.org.uk

Liverpool Stroke Recovery Partnership (Local Stroke Association)
The Community Centre
Formosa Drive
Fazakerly
Liverpool
L10 7LQ
Tel: 0151 305 0023
Email: Julie.connolly@stroke.org.uk

Carers UK
20 Great Dover Street
London
SE1 4LX
Tel: 020 7378 4999
Email: info@carersuk.org
Website: https://www.carersuk.org/

Your local G.P. surgery can also provide advice and direct you to local services to support you in times of distress.

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Appendix 4-C: *Consent Form*

Online Consent Form

What is the impact of stroke knowledge on the caregiving relationship?

Does a good understanding of stroke help with adjusting to the psychological impact of being a caregiver of a stroke survivor as well as its impact on relationships?

We are asking if you would like to take part in a research project which aims to investigate the relationship between caregiver burden, stroke knowledge and expressed emotion for the caregivers of stroke survivors.
Before you consent to participating in the study we ask that you read the participant information sheet and then, if you agree to continue, click each statement below to say you agree. If you have any questions or queries before signing the consent form please contact the principal investigator, Clare Rooney on the details given on the participant information sheet.

Before proceeding to the survey, I confirm that:

- ☐ I have read the participant information sheet and understand what is expected of me within this study.
- ☐ I am over the age of 18
- ☐ I confirm I am the informal carer of a stroke survivor
- ☐ I confirm that I understand that any responses/information I give will remain anonymous.
- ☐ I confirm that I understand that once I begin this survey that my responses will be anonymous and therefore cannot be withdrawn from the study.
- ☐ My participation is voluntary.
- ☐ I consent for the information I provide to be discussed with the researcher’s supervisor at Lancaster University.
- ☐ I consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished.
- ☐ I consent to take part in the study.

Appendix 4-D – Physical consent form

Appendix D
Physical Consent Form

What is the impact of stroke knowledge on the caregiving relationship?

Does a good understanding of stroke help with adjusting to the psychological impact of being a caregiver of a stroke survivor as well as its impact on relationships?

We are asking if you would like to take part in a research project which aims to investigate the relationship between caregiver burden, stroke knowledge and expressed emotion for the caregivers of stroke survivors.
Before you consent to participating in the study, we ask that you read the participant information sheet and tick each box below if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Clare Rooney via the contact details provided on the information sheet.

	Please tick each statement
1. I confirm that I have read the information sheet and fully understand what is expected of me within this study	☐
2. I confirm that I am over 18	☐
3. I confirm that I am the informal carer of a stroke survivor	☐
4. I confirm that I have had the opportunity to ask any questions and to have them answered.	☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time, up until I return my survey to the researcher, without giving any reason, without my medical care or legal rights being affected.	☐
6. I understand that once I have sent the survey back, my data will be anonymised and incorporated it will not be possible for it to be withdrawn.	☐
7. I understand that the data from my questionnaires will be pooled with other participants' responses, anonymised and may be published.	☐
8. I understand that the researcher will discuss data with their supervisor as needed.	☐
9. I consent to Lancaster University keeping anonymised data for 10 years after the study has finished.	☐
10. I consent to take part in the above study.	☐

Date ___________

Appendix 4-E: *Debrief Sheet*

Debrief Sheet:

What is the impact of stroke knowledge on the caregiving relationship?

Does a good understanding of stroke help with adjusting to the psychological impact of being a caregiver of a stroke survivor as well as its impact on relationships?

Thank you very much your participation in this research; your time and effort has been greatly appreciated.

This study is aiming to explore the relationship between stroke knowledge, expressed emotion and caregiver burden. Expressed emotion is a measure of caregivers' emotional and interpersonal reactions towards the stroke survivor and caregiver burden is a measure of the subjective impact the caring role is having on the caregiver. The study aims to find out if the level of knowledge about stroke that a caregiver has, impacts on levels of expressed emotion and therefore caregiver burden.

Given the importance of informal caregivers and the role they play, it should be a priority for services to identify ways to work towards reducing the impact of caregiver burden. If stroke knowledge was a moderating factor in reducing caregiver burden, then it would justify the importance of further support for carers and potentially the development of a family intervention model in stroke rehabilitation and care.

If you would like to receive the results of this study or if you have any questions then please get in contact using the details below.

Contact Details
Clare Rooney
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster
LA1 4YG
UK
Email: c.rooney1@lancaster.ac.uk
Tel: +44 01524 592970

Or,

Research Supervisor:
Professor Bill Sellwood,
Course Director
Division of Health Research
Furness Building
Lancaster University
Lancaster, UK
LA1 4YG
Email: b.sellwood@lancaster.ac.uk
Tel: +44 (0)1524 593998

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Catherine Walshe
Tel: +44 (0)1524 510124
Email: c.walshe@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster, UK
LA1 4YG

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

Professor Roger Pickup
Associate Dean for Research
Tel: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University
Lancaster, UK
LA1 4YG

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.

The Stroke Association
Stroke Association House
240 City Road,
London
EC1V 2PR
Tel: (+44) 0303 3033 100
Website: www.stroke.org.uk

Liverpool Stroke Recovery Partnership (Local Stroke Association)
The Community Centre
Formosa Drive
Fazakerly
Liverpool
L10 7LQ
Tel: 0151 305 0023
Email: Julie.connolly@stroke.org.uk

Carers UK
20 Great Dover Street
London
SE1 4LX
Tel: 020 7378 4999
Email: info@carersuk.org
Website: https://www.carersuk.org/

Your local G.P. surgery can also provide advice and direct you to local services to support you in times of distress.

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

To download a copy of this Debrief Sheet please click on the link below:
Debrief Sheet

Doctorate in
Clinical Psychology
Lancaster
University

Appendix4-F: *Self-Report Questionnaire*

Self-Report Questionnaire

1. What is your age?
    a. 18-29
    b. 30-39
    c. 40-49
    d. 50-59
    e. 60-69
    f. 70-79
    g. 80-89
    h. 90+

2. What is your gender?
    a. Male
    b. Female

3. What is your relationship to the stroke survivor?
    a. Spouse
    b. Child
    c. Parent
    d. Sibling
    e. Other family member
    f. Other, please state: ____

4. How long has it been since you started to provide care for a stroke survivor in years and months?

5. Do you currently live at the same address at the stroke survivor?

7. What is your employment status?
    a. Employed, full time
    b. Employed, part time
    c. Self employed
    d. Unemployed
    e. Retired
    f. Unable to work
    g. Other, please state: ____

6. Do you have any formal care support for the stroke survivor?

Appendix 4-G : *Study Introduction Note*

Thank you very much for agreeing to take part in this research.

There are five short questionnaires to complete, please carefully read and follow the individual instructions on each one.

Please complete the questionnaires, taking care to answer all of the questions. If you would like to speak to someone about the research or ask any questions, please use the contact details on the participant information sheet.

Once you have completed the questionnaires please return them to a member of the stroke association team. Please detach and keep the participant information sheet and debrief sheet for your own records.

Thank you again.

Appendix 4-H: *DASS-21*

DASS-21

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

The rating scale is as follows:

0	Did not apply to me at all
1	Applied to me to some degree, or some of the time
2	Applied to me to a considerable degree or a good part of time
3	Applied to me very much or most of the time

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

	was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn’t worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

Appendix 4-I : *The Family Questionnaire (FQ)* **The Family Questionnaire**

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the stroke survivor in this way. There are no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question and mark only one response per question.

		Never	Rarely	Often	Very Often
1	I tend to neglect myself because of him/her				
2	I have to keep asking him/her to do things				
3	I often think about what is to become of him/her				
4	He/she irritates me				
5	I keep thinking about the reasons for his/her illness				
6	I have to try not to criticise him/her				
7	I can’t sleep because of him/her				
8	It’s hard for us to agree on things				
9	When something about him/her bothers me, I keep it to myself				
10	He/she does not appreciate what I do for him/her				
11	I regard my own needs as less important				
12	He/she sometimes gets on my nerves				
13	I’m very worried about him/her				
14	He/she does some things out of spite				
15	I thought I would become ill myself				
16	When he/she constantly wants something from me, it annoys me				
17	He/she is an important part of my life				
18	I have to insist that he/she behave differently				
19	I have given up important things in order to be able to help him/her				
20	I’m often angry with him/her				

Appendix 4-J: *Stroke Care Information Test*

Stoke Care Information Test

This questionnaire is about your knowledge of stroke and its impact. For each question, circle the letter of the most correct answer.

1. Depression after stroke is usually due to;
    e. Reaction to losses
    f. Medication
    g. Family problems
    h. Brain damage
2. The number one risk factor leading to stroke is;
    a. Age
    b. High blood pressure
    c. Stress
    d. Being overweight
3. The likelihood of a second stroke is;
    a. Slightly less than before
    b. Over 75
    c. Cannot be determined
    d. Reduced with good health care
4. Predicting stroke recovery can be best done by;
    a. Observing walking
    b. Waiting several weeks
    c. Observing initial improvement
    d. Knowing condition prior to the stroke
5. Most people who have a stroke will feel depressed;
    a. For several weeks
    b. As they realise their limitations
    c. For several years
    d. About being in the hospital
6. Stroke patients with severe language disorder;
    a. Understand normal conversation
    b. Remember what they read
    c. Rarely lose all language
    d. Cannot recognise familiar objects
7. Information on sexual ability after stroke is;
    a. Available from informed hospital staff
    b. Scarce
    c. Unnecessary
    d. Too sensitive for discussion
8. After the initial phase of stroke recovery, desire for sex;
    a. Is reduced
    b. Can be replaced by exercises
    c. Returns to normal
    d. Cannot be satisfied
9. After stroke, sexual functioning;

   a. Is usually impaired
   b. Returns to normal
   c. Is rarely possible
   d. Should be avoided
10. Most patients who cannot understand language;
    a. Do not understand demonstration either
    b. Still enjoy reading
    c. Understand their native tongue
    d. Benefit from demonstration
11. A person recovering from memory loss;
    a. Will benefit from reminders
    b. May hallucinate past events
    c. Will remember recent events first
    d. Should not go out of the house alone
12. Decreased motivation in stroke patients is due to;
    a. Poor attention span
    b. Inability to initiate activity
    c. Loss of energy
    d. Their diet
13. Sexual performance after stroke is usually;
    a. Altered
    b. Not advisable
    c. Not a problem
    d. Absent
14. Recovery from paralysis caused by stroke usually begins;
    a. In the hip
    b. In the lower leg
    c. In the shoulder
    d. By strengthening the unaffected side
15. Proper positioning in bed can prevent;
    a. A second stroke
    b. Contractures
    c. Headaches
    d. Bladder incontinence
16. Which of the following is not a learning impairment;
    a. Paralysis
    b. Distractibility
    c. Short attention span
    d. Memory loss
17. A person who has lost the sense of touch;
    a. Cannot feel pain
    b. Will forget more easily
    c. Should eat alone
    d. Might do dangerous things
18. A person who has lost the sense of touch should;
    a. Not be reminded of this deficit
    b. Be taught safety precautions
    c. Help out in the kitchen

   d. Smoke moderately

19. Which of the following is a physical loss;
    a. Forgetting
    b. Poor concentration
    c. Falling
    d. Paralysis
20. If a person is paralysed on one side of the body, you should;
    a. Assist by supporting the affected side
    b. Not mention the problem
    c. Eliminate noise
    d. Sit close to the patient
21. Passive range of motion exercises mean that;
    a. Patient sits whilst exercising
    b. The limb is moved by force other than itself
    c. Someone must assist
    d. Limbs remain motionless
22. Hemiplegia means;
    a. Poor blood clotting
    b. Weakness in both legs
    c. Paralysis on one side of the body
    d. Inability to speak
23. Family members should encourage the patient to get dressed;
    a. Without frustration
    b. With help from one person
    c. As often as possible
    d. With as little assistance as needed
24. A patient who is weak may benefit from;
    a. Hand rails on stairs
    b. Scatter rugs
    c. Shirt buttons
    d. Reclining chair
25. After initial recovery from stroke, interest in sex is;
    a. More than before
    b. Less than before
    c. Same as before
    d. Unknown
26. Emotional lability means that a person;
    a. Has difficulty controlling emotions
    b. Is emotionless
    c. Is depressed
    d. Feels no emotion
27. A person who is labile may not;
    a. Recognise friends
    b. Detect other’s moods
    c. Benefit from encouragement
    d. Express actual feelings reliably
28. Aphasia means that a person;
    a. Is unable to learn

- b. Has difficulty communicating
- c. Chokes when eating
- d. Loses balance easily

29. Stroke patients may sound emotionless because;
    - a. Cannot feel emotion
    - b. Express emotion unreliably
    - c. Tire easily
    - d. Cannot remember emotion
30. Demonstrating instructions to stroke patients may be necessary because of;
    - a. Hearing loss
    - b. Personality changes
    - c. Slowness
    - d. Language problems
31. A stroke on the left side of the brain usually results in;
    - a. Language impairment
    - b. Confusion
    - c. Visual loss
    - d. Left sided paralysis
32. A person who perseverates;
    - a. Dwells on details
    - b. Cannot concentrate
    - c. Should not read
    - d. Cannot stop performing
33. Memory loss is most easily detected by;
    - a. Old learning
    - b. Performance of old habits
    - c. New learning
    - d. Driving ability
34. Perceptual error may lead to inability to;
    - a. Recall colours
    - b. Use familiar objects
    - c. Experience pain
    - d. Remember faces
35. The most common result of stroke is;
    - a. Diabetes
    - b. Loss of appetite
    - c. Learning impairment
    - d. Poor bladder control
36. A stroke on the right side of the brain usually means the person will be;
    - a. Unable to speak
    - b. Impulsive
    - c. Paralysed on the right side
    - d. Incontinent

Appendix K: *Caregiver Burden Scale (CBS)*

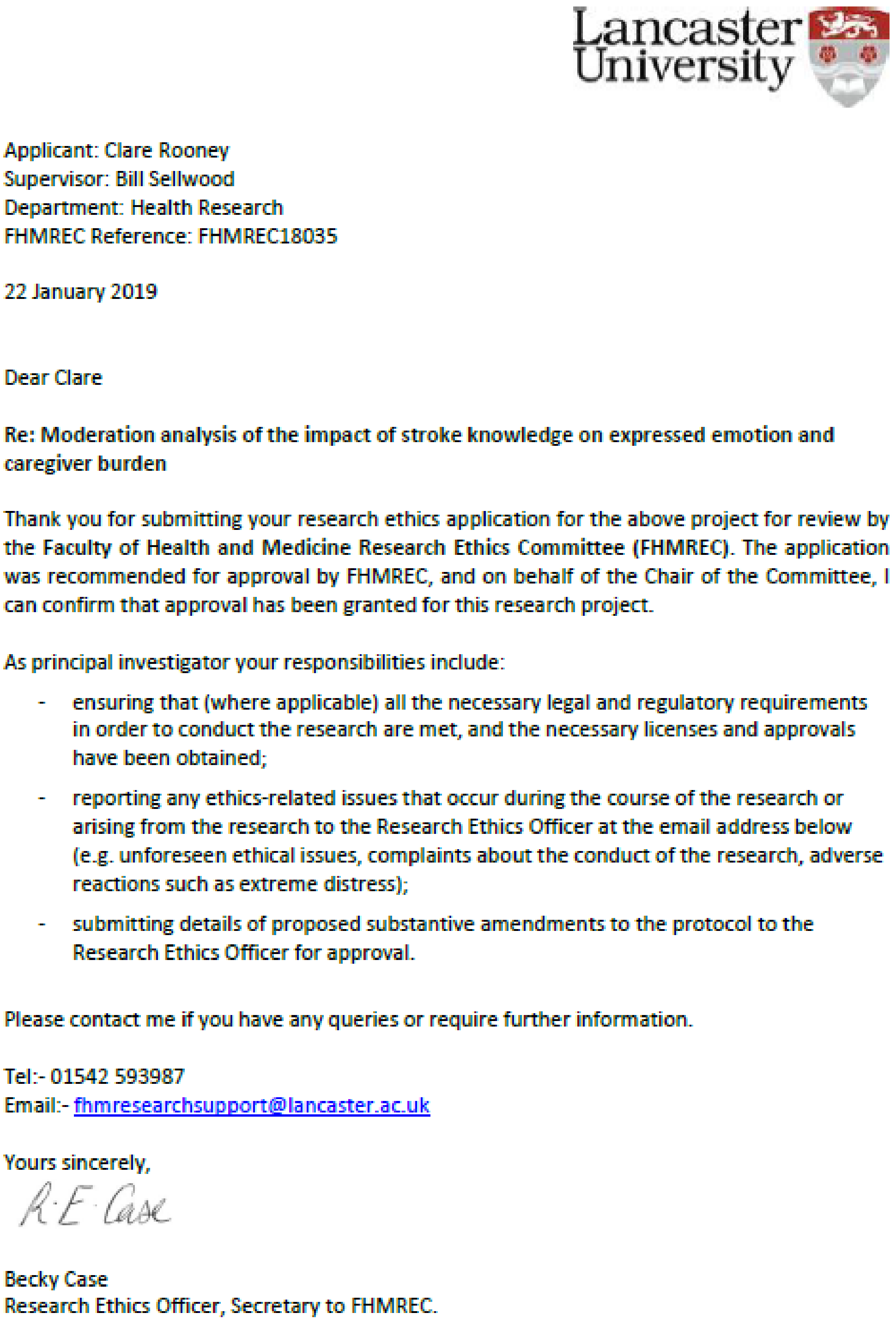
Caregiver Burden Scale

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, mark how often you feel that way; not at all, seldom, sometimes or often. There are no right or wrong answers.

		Not at all	Seldom	Sometimes	Often
1	Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?				
2	Do you think you have to shoulder too much responsibility for your relative welfare?				
3	Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?				
4	Do you feel tired and worn out?				
5	Do you feel tied down by your relative’s problem?				
6	Do you find it mentally trying to take care of your relative?				
7	Do you think your own health has suffered because you have been taking care of your relative?				
8	Do you think you spend so much time with your relative that the time for yourself is insufficient?				
9	Do you avoid inviting friends and acquaintances home because of your relative’s problem?				
10	Has your social life, eg with family and friends, been lessened?				
11	Has your relative’s problem prevented you from doing what you had planned to do in this phase of your life?				
12	Have you a feeling that life has treated you unfairly?				
13	Had you expected that life would be different than it is at your age?				
14	Do you feel lonely and isolated because of your relative’s problem?				
15	Do you find it physically trying to take care of your relative?				
16	Have you experienced economic sacrifice because you have been taking care of your relative?				
17	Are you sometimes ashamed of your relative’s behaviour?				
18	Do you ever feel offended and angry with your relative?				
19	Do you feel embarrassed by your relative’s behaviour?				
20	Does the physical environment make it troublesome for you taking care of your relative?				
21	Do you worry about not taking care of your relative in the proper way?				

22	Is there anything in the neighbourhood of your relative’s home making it troublesome for you to take care of your relative?				

Appendix 4-L: FHMREC Ethics Approval Letter



Lancaster University

Applicant: Clare Rooney
Supervisor: Bill Sellwood
Department: Health Research
FHMREC Reference: FHMREC18035

22 January 2019

Dear Clare

Re: Moderation analysis of the impact of stroke knowledge on expressed emotion and caregiver burden

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.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.