THE UNIVERSITY OF HULL

Discrepant Illness Perceptions in Stroke Survivor-Partner Dyads: Relationship to Psychological Adjustment and Expressed Emotion

Being a Thesis submitted for the Degree of Doctor in Clinical Psychology

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by

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Overview

This research portfolio is divided into three parts:

Part one is a systematic literature review titled ‘Factors associated with relationship stability following brain injury: A systematic review of the literature’. Research frequently documents the negative effects of brain injury and the difficulties faced by survivors and their families. Couples in particular may experience a range of life changes and challenges, which have been shown to place considerable strain on the stability of their relationship. This systematic literature review explores the positive and negative factors associated with marital and relationship stability following acquired and traumatic brain injury, in order to examine what keeps couples together and what pushes them apart. The review process uncovered 18 studies that contained evidence relating to factors associated with relationship stability after brain injury. All studies were assessed for methodological quality and the strengths and weaknesses of papers are discussed. Findings revealed 20 different factors that may contribute to relationship stability following brain injury. Although the evidence for 14 of these factors appeared contradictory, six factors were identified with consistent evidence. The following may have important implications for the stability of relationships following brain injury: The extent of physical disability, particular neurobehavioural characteristics including mood swings and unpredictability, changes in communication between couples and finally, un-injured partners’ difficulty understanding the effects of the brain injury.

Part two is an empirical paper titled ‘Discrepant illness perceptions in stroke survivor-partner dyads: Relationship to psychological adjustment and expressed emotion’. Previous research has shown that relationships between couples can become strained after brain injury and that those partners who adopt a carer role may be more likely to express negative or critical reactions towards the person they care for. This study explores a cognitive component that may underlie the extent of carers expressed emotions: The difference or discrepancy between carers understanding of their partners stroke and stroke survivors understanding of their stroke. Findings from the health research literature have shown that following an illness event, patients and carers create unique personal models or illness perceptions around five distinct components, these include identity, cause, time-line, consequences and cure-control. This study investigates whether couples differ in their illness perceptions and if so, whether this relates to carers level of negative or critical reactions towards their partner (expressed emotion) and stroke survivors level of psychological adjustment (anxiety and depression). A correlational design was used to explore the associations between discrepant illness perceptions, expressed emotion and anxiety and depression. A total of 51 couples participated in the research and results showed that although the correlations between variables were not statistically significant, there was a statistically significant correlation between stroke survivors’ level of anxiety and partners’ level of expressed emotion. The implications and possible avenues for further research are discussed.

Part three contains the appendixes, which provide further information for the systematic literature review and empirical paper. A reflective statement on the process of carrying out the research is also provided.

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Part One: Systematic Literature Review

Part One: Systematic Literature Review

Factors Associated with Relationship Stability following Brain Injury:

A Systematic Review of the Literature

This paper is written in the format ready for submission to Brain Injury. Please see Appendix 1 for the author guidelines.

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REVIEW

Factors associated with relationship stability following brain injury: A systematic review of the literature

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Abstract

Primary objective: Previous research has shown that relationships between married couples and long-term partners can become strained after brain injury, often ending in separation or divorce. This systematic literature review examines the positive and negative factors associated with relationship stability following brain injury, in order to explore why some couples experience relationship breakdown and others remain close. The methodological quality of studies included in the review is assessed.

Method: A literature search was conducted on the 1st May 2009 using four electronic databases: PsycINFO, EMBASE, CINAHL and MEDLINE. Retrieved studies were accepted for review following examination of their abstracts according to inclusion and exclusion criteria. Accepted papers were hand-searched for further publications and key authors were contacted regarding current or on-going research in the area.

Results: 18 studies met the inclusion criteria and were further examined for methodological quality against a 16-item checklist. All papers were assessed by the author and two independent raters to ensure inter-rater reliability.

Conclusion: Though the design and methodological quality of papers varied, 20 factors were uncovered that may contribute to relationship stability following brain injury. These are discussed and areas for further investigation are explored.

Keywords: *Brain injury, relationship stability, marital stability.*

Introduction

Brain injury is the leading cause of disability in the world [1]. It is estimated that over 120 000 people in the UK are currently suffering the long-term effects of brain injury and this figure is expected to increase each year [2]. Acquired brain injury (ABI), which is damage to the brain occurring after birth, can be separated into two classifications: Non-traumatic brain injury, such as stroke, infection or tumour and traumatic brain injury (TBI), which occurs when an outside force to the head either penetrates into the brain or the impact to the skull causes internal damage. Though the causes and classifications of brain injury differ, it can be argued that problems resulting from ABI and TBI are comparable and affect the lives of the survivor and their family in similar ways [2]. For this reason, the following discussion of the difficulties encountered after ABI and TBI will be explored together under the term 'brain injury'.

There is no shortage of research highlighting the negative effects of brain injury and the challenges faced by individuals who can be subjected to a range of physical, cognitive, behavioural, psychological and psychosocial difficulties [3-6]. Such substantial life changes can have distressing consequences for survivors, yet these are rarely experienced in isolation. With the majority of survivors returning home after a period of hospitalisation or rehabilitation [7], it is not just the individual who faces significant challenges but also their family [8, 9]. According to family system theories, change in one person produces and is affected by change in all other members of the system, which can alter relationship patterns and lead to family dysfunction [10]. Research frequently documents the objective and subjective burden experienced by families supporting a brain injured member [11, 12] and both real and perceived stressors can place considerable strain on family relationships, particularly for partners [13].

Spouses or long-term partners of brain injured individuals commonly become the primary source of care, support and socialisation after injury [14]. Existing literature suggests that spouses express more difficulty coping with their partners’ injury than other members of the family because adopting a carer role differs fundamentally from a previous reciprocal position in the relationship [15, 16]. Partners, who may have children to care for as well, often have to cope alone without the emotional support, empathic communication and companionship of their partner [17]. Adapting to a new role can signal the loss of many other roles or commitments, including work, leisure activities and social life [18]. Such losses can lead to couples becoming social isolated and surviving alone together in an already strained and unstable relationship [19].

It is reported that being in a relationship with a partner who has suffered brain injury is considerably more difficult compared to other health difficulties such as chronic pain or spinal cord injury [20, 21]. Researchers explain the differences in terms of the unique neurobehavioural sequelae associated with brain injury, which can involve complex changes in an individual’s personality, behaviour, psychological, cognitive and social ability; all factors found to adversely affect important aspects of relationships [9, 22, 23]. Since specific neurobehavioural sequelae can show little improvement over time, couples can face a long-term struggle with adjustment and follow-up studies show high levels of distress in partners as long as 10 and 15 years post injury [24, 25, 26]. According to Wood et al. [22] and Panting and Merry [16], when the brain injured partner begins to reach a plateau in their rehabilitation and the permanence of problems become apparent, partners may begin to withdraw from the caring role, becoming less tolerant and less hopeful of any future improvements. It is at these times that couples may be particularly vulnerable to relationship breakdown.

Wood and Yurdakul [27] examined the change in relationship status of 131 couples where one partner had suffered brain injury. At an average of eight years follow-up, 49% of the sample had separated or divorced. Similar findings have been reported by Oddy et al. [28] and Tate et al. [29]. Similarly a national study of relationship status following TBI carried out in the UK in 1997 [30] showed that seven years post-injury, 30% of marriages had ended compared to a 14-18% divorce rate in the general population. It was concluded that brain injury doubles the likelihood of divorce, yet as the results did not take into account the high separation rates and since the study has not been replicated in the past 12 years, it is possible these statistics could be even higher. A number of researchers have found that separation and divorce rates are not dependent on injury severity [22, 31, 49]. This suggests that relationship breakdown is not simply due to a partners struggle to support a brain injured individual with significant impairments. When one partner in a couple suffers a brain injury, both partners experience a number of life changes and challenges, yet a complex interplay of factors may shape whether such challenges are faced together or managed separately. It is the purpose of this systematic literature review to explore these factors.

The rationale for this review stems from findings within two areas of research. Firstly, literature concerning non-injured couples has highlighted the importance of relationship stability and its benefits to both partners. ‘Stability’, as defined by relationship researchers, denotes constancy or steadiness rather than more positive attributes such as happiness. Karney et al. [33] suggests relationship stability is when ‘the quality does not vary much across time’ (p.481), so while couples may be in a stable relationship it does not necessarily imply that they are content. Nevertheless, evidence shows that individuals in stable relationships have better physical health irrespective of demographic features such as age, sex, race, education or income [34, 35]. They also have better psychological health as partnerships can provide stimulation, communication, emotional and social support, which are key protective factors [36, 37].

The second area of research contributing to the rationale for the review is the brain injury rehabilitation literature, which also advocates the importance of social support. Evidence has shown a strong correlation between the quality of social contact with a partner or close family member and physical and psychological adjustment after brain injury [38, 39]. It is likely that those brain injury survivors in stable relationships will have a better quality of social support, which could have considerable benefits to their overall rehabilitation, physical and psychological health. However, the existing literature does not provide a clear picture as to the specific factors that might contribute to stability in relationships and likely quality social contact.

It is the aim of this systematic literature review to examine positive and negative factors associated with marital and relationship stability following brain injury, to explore what keeps couples together and what pulls them apart. The methodological quality of reported studies will also be evaluated. It is hoped that findings may assist health professionals working with couples after brain injury, to be aware of the different static and dynamic factors that may put partners at risk of relationship breakdown. Also to provide possible avenues for intervention that will support couples and promote their health and well-being after brain injury.

Method

Prior to starting the systematic review, a number of health care evidence-based review databases were searched using the key words outlined below. This was done to ensure that the review would not be replicating existing or on-going work already in the area. The databases, searched on the 1st May 2009 included Bandolier [40], the Cochrane Database of Systematic Reviews (CDSR) [41], The National Institute for Health and Clinical Excellence (NICE) [42] and the Database of Promoting Health Effectiveness Reviews (DoPHER) [43]. However, no results were found indicating that a review in this area was justified. A systematic search of the literature was then conducted on the 1st and 29th May 2009 using the following databases: PsycINFO, CINAHL, EMBASE and MEDLINE. The key words used are outlined below.

Key words

Additional search terms were included to ensure that literature focusing on aspects of stable or instable relationships and marriages following brain injury were accessed. Journal titles and abstracts were searched using the terms; ‘brain injury’ OR ‘traumatic brain injury’ OR ‘acquired brain injury’, as well as the abbreviations ‘ABI’ OR ‘TBI’ AND ‘relationship stability’ OR ‘marital stability’ OR ‘stable relationship*’ OR ‘stable marriage*' OR 'relationship quality' OR 'marital quality' OR 'relationship satisfaction' OR 'marital satisfaction' OR 'relationship adjustment' OR 'marital adjustment'. The following terms were included in the search but with the prefix NOT to eliminate any unrelated studies: 'brain damage', as this may include studies covering hereditary, congenital or degenerative problems from birth, 'head trauma' and 'head injury', as these terms can involve damage to structures other than the brain and 'relationship status' and 'marital status', so that any literature including these terms as variables unrelated to the review question would not be included.

Specific limits were selected for each of the four databases to restrict retrieval to relevant literature. These included, papers written in the English Language and involving human subjects aged 18 years and older. Despite the limits, the databases still generated an unmanageable number of studies (n= 42 157), therefore, a different method of searching was developed to limit the retrieval rate further. This involved searching using individual sets of key words and subsequently removing any duplicated studies using an electronic filter within each database. The search terms and retrieval rates obtained are shown in table 1 on the next page.

Group 1 key word	Group 2 key word	Psycinfo hits	Cinahl hits	Embase hits	Medline hits	Total hits (duplicates removed)
'brain injury' AND	'relationship stability'	9	0	12	11	22
'brain injury' AND	'marital stability'	4	0	6	4	9
'brain injury AND	'stable relationship*'	11	0	22	30	41
'brain injury' AND	'stable marriage*'	0	4	0	0	3
'brain injury' AND	'relationship quality'	44	32	62	57	102
'brain injury' AND	'marital quality'	4	4	8	10	13
'brain injury' AND	'relationship satisfaction'	32	21	27	25	70
'brain injury' AND	'marital satisfaction'	7	5	6	6	12
'brain injury' AND	'relationship adjustment'	43	20	37	34	88
'brain injury AND	'marital adjustment'	0	0	0	0	0

Table 1. Key word search terms and retrieval rates.

By separating the key words and carrying out individual searches the total number of retrieved studies was reduced to a much more manageable figure (n= 360). The titles and abstracts of these studies were then examined against the following inclusion and exclusion criteria:

Inclusion criteria

This review included studies which met the following criteria:

- Studies involving participants who have experienced mild, moderate or severe brain injury, ABI or TBI and/or their spouse, partner or 'carer' as they are occasionally referred to in the literature. The different classifications of brain injury (e.g. ABI and TBI) were included to maximise the number of articles for selection.

- Studies which focus on or contain evidence of positive or negative relationship factors between the individual with brain injury and their spouse/partner/carer. These factors were judged to be represented by key words within the abstracts of the papers, which relate to the couple's marital or relationship quality, satisfaction, adjustment or stability.
- Studies utilising qualitative, quantitative and mixed design methods, in order to maximise the number of studies for selection.
- Studies published in referenced journals.

Exclusion criteria:

This review excluded studies which met the following criteria:

- Any study that does not include those who have a brain injury or their spouse/partner/carer as the primary participants.
- Studies which do not focus on or contain evidence of relationship factors between the individual with the brain injury and their spouse/partner/carer.
- Studies involving participants with a brain injury in an in-patient or rehabilitation setting who are cared for by staff.
- Case reports.
- Systematic literature reviews.
- Unpublished studies.
- Studies involving children and adolescents.
- Articles published in a language other than English.

The reference lists of all papers meeting the inclusion criteria (n= 16) were hand-searched to identify further relevant publications. Selected papers that met the inclusion criteria were accepted for review (n= 2). To ensure all relevant research had been included, key authors from retrieved literature were contacted requesting information about articles or studies in the area that were not currently available in the public domain. Although one publication was highlighted by an author, the paper had already been accepted for review.

Assessing the methodological quality of studies

Selected literature was further assessed for methodological quality using a 16-item checklist (see Appendix. 2), which can be used for reviewing both qualitative and quantitative studies. The checklist was based on the criteria devised by NICE 2009 (National Institute of Clinical Excellence UK) [44], which was originally adapted from two quality frameworks [45, 46]. For ease of scoring and comparison across studies a point scheme was used, where a maximum of 16 points was awarded to studies fulfilling all 16 criteria of methodological quality. In total, 18 studies were rated using the checklist and to ensure reliability of scores, the studies were further assessed by two independent raters (CW and CH), who are experienced in psychological research study and design (see Appendix 3). A Cohen's Kappa statistical test was then carried out to measure the level of agreement between the evaluations of raters using SPSS Version 16 [47]. Calculations highlighted that only two criteria had absolute agreement between the three raters. These were criteria 2a, appropriateness of the chosen design and methodology and criteria 6b, the relevance of findings to the stated aims (kappa 1.0, standard error 0.000, $p<0.000$). Though remaining calculations showed only moderate agreement, no studies were excluded on the basis of methodological quality.

Results

Figure 1 on page 23 outlines the systematic review process including the numbers of studies retrieved, accepted or rejected at each stage. As the flow chart indicates, the initial database searches produced a vast number of results (n= 42 157), yet once individual key word searches were carried out and duplicate studies removed, the total number reduced considerably (n= 360). However, of the retrieved papers searched against the inclusion and exclusion criteria, the majority were rejected as most had a medical, neurological or neuropsychological focus unrelated to marital or relationship factors. This left few studies remaining (n= 16). However, after hand-searching and contacting key authors more studies were added (n = 2) leaving the total number of studies accepted for quality assessment and review at 18. Of these studies, two used a qualitative design, [31, 48], two used a mixed design [22, 62] and14 studies used a quantitative design [27, 49-61]. A total of 13 studies focused specifically on TBI [27, 31, 48, 49, 52-55, 57, 58, 60-62], two focused on ABI [50, 51], one on ‘head injury’ [56], one on ‘brain damage’ [59] and one on ‘head trauma’ [22]. Further characteristics of studies included for quality assessment and review are shown in table 2 on pages 23-24.

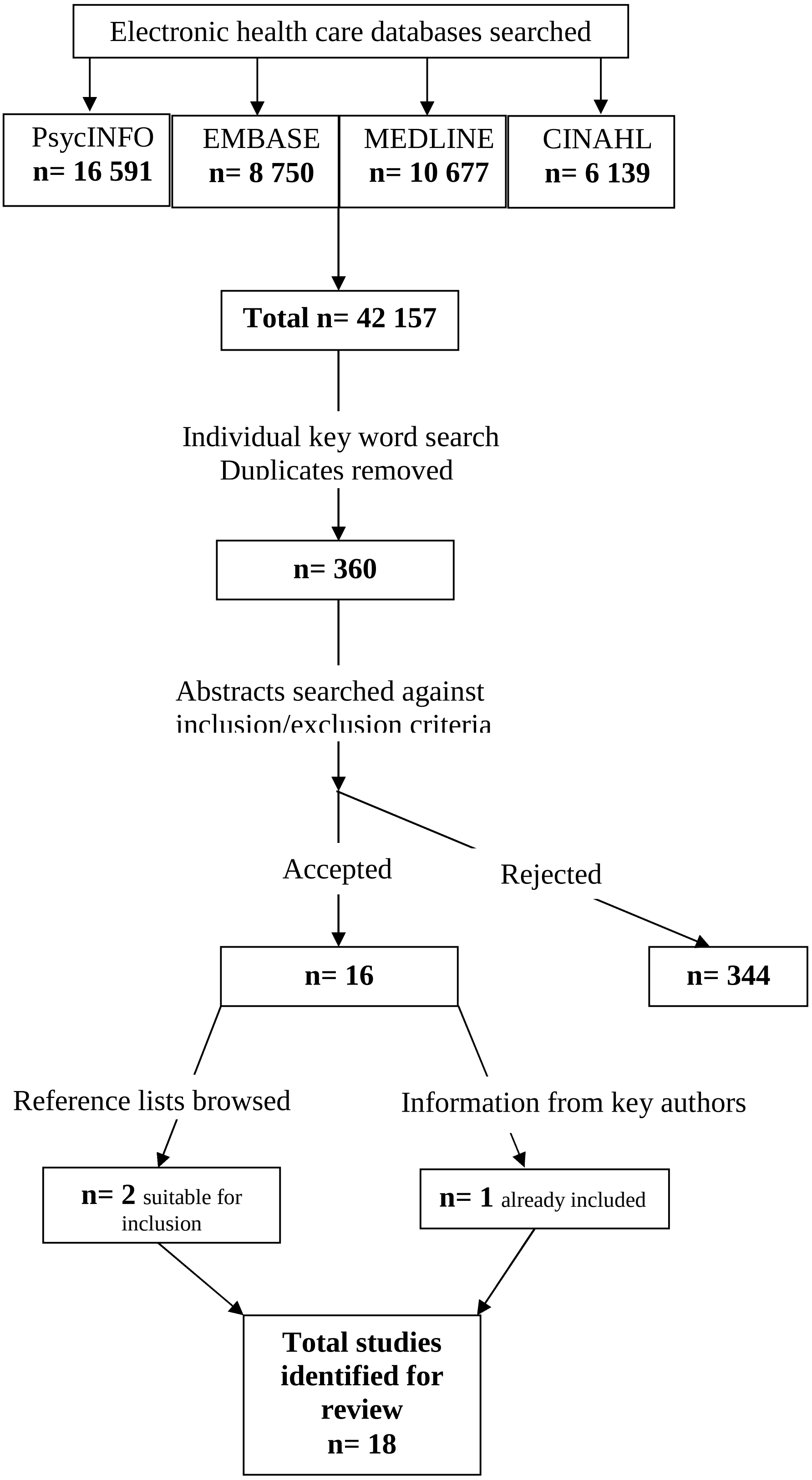

Figure 1. Systematic review process flow chart

INSERT TABLE 2

INSERT TABLE 2

Review findings

The factors associated with marital and relationship stability following brain injury are categorised according to findings obtained from the 18 studies accepted for review.

- *Age*

Anderson-Parente et al. [31] used a qualitative design to interview seven couples in stable marriages about the factors they felt kept them together after brain injury. All participants were ‘older adults’ (although no demographic information regarding the range or mean ages is provided) and authors concluded that relationship stability could be attributed to maturity in approaching marital problems. Wood and Yurdakul [27] highlight that maturity is an elusive concept to use as a measure of relationship stability and found no association between age and relationship status in two groups of 131 TBI survivors (those over 35 years and those under 35 years), a finding supported by Wood et al. [22]. Nevertheless, two recent studies [49, 52] found that the age of TBI survivors did predict relationship stability, with older individuals perceiving that they were in more stable relationships than younger individuals. However, both studies included TBI survivors with primarily moderate to severe injury and it could be argued that participants may have impairments in insight and misattributed the stability of their relationships.

- *Gender*

Wood and Yurdakul [27] explored whether female partners were more likely to stay in a relationship with their injured partner testing the assumptions that that females may accept the caring role easier. They found in those relationships that had ended, 45.3% of male partners left their injured partner compared to 47.1% of female partners, results were not statistically significant. Kreutzer et al. [52] and Wood et al. [22] also found no association between gender and the tendency to leave an injured partner. In contrast, Arango-Lasprilla et al. [49] reported that male TBI survivors were 1.95 times more likely to be in an unstable marriage than females TBI survivors over two years post injury. However, the authors used demographic information to explore the association between gender and marital stability rather than the influence of gender on a partner's decision to stay in or end a relationship. It is also important to note that in Arango-Lasprilla et al's study, only Caucasians, African-Americans, Hispanics, Asians and Native Americans were included, therefore, it is difficult to generalise the finding to other groups.

- *Children*

Wood and Yurdakul [27] examined the hypothesis that children may have a stabilising effect on relationships after brain injury. However, of the 25 couples who had children under 15 years of age, 15 couples were divorced (60% of the sample). The authors did not justify why couples with children under 15 years was used as the cut off point and it is possible that if couples with children under 18 years of age (i.e. not adult children) were included in the analysis, more of their 131 sample may have been included. Moore et al. [53] hypothesised that couples with greater numbers of children and children who were older would be more likely to separate after TBI. However, findings showed that number of children was not related to marital adjustment (using a measure of perceived agreement or disagreement in the relationship). It was those couples with 'younger children' (the authors do not specify mean age) who were more adjusted in their marriage. The authors concluded that having younger children contributed to financial pressures.

- *Perceived financial strains*

Moore et al. [53] found that the variable most closely associated with lower marital adjustment scores after TBI was perceived financial strain and noted that 43% of the TBI sample were unemployed at the time of interview. Peters et al. [56] found an association between a low degree of affection between couples where one partner had suffered a moderate to severe TBI and perceived financial strain. In contrast, Anderson-Parente et al. [31] highlighted that six out of seven stably married couples said they had experienced serious financial hardship resulting from the injury and non of the brain injured individuals were employed. However, as all participants were older adults it could be argued that they were not employed because of being at retirement age.

- *Length of relationship prior to injury*

Wood and Yurdakul [27], found that the length of time a couple were in a relationship prior to injury is inversely proportional to the likelihood of separation and divorce, with couples in stable relationships being together twice as long (on average 16 years). Wood and Yurdakul also found that relationship breakdown is least common in the first two years after injury and most common at or after five years. The authors propose that if a relationship survives 10 years the couple are likely to remain together indefinitely, yet there is limited research available to support this view. Wood et al. [22] found no significant difference between the length of relationship prior to injury and likelihood of separation when comparing the responses of couples in stable relationships and couples who had parted. However, Kreutzer et al. [52] replicated Wood and Yurkadul’s study ten years later with 120 TBI survivors and found that couples in surviving marital relationships had been together approximately three times longer than those whose marriages had ended.

- *Time since injury*

Wood and Yurdakul [27] noted that participants who maintained a stable relationship were an average of 4.81 years from the time of injury compared to separated or divorced participants, who were an average of 6.16 years post injury. Increases in time from the date of the injury and separation and divorce rates were statistically significant associations. The authors concluded that there is a ‘watershed for relationship breakdown’, which is between five to eight years post-injury. However, Wedcliffe and Ross [60] found that although deterioration in marital relationships was reported by those whose partners had sustained the injury between five to 10 years previously, the same was true for partners of individuals who had been injured relatively recently, between a period of five to 12 months. However, the authors based the results on self-report data from only 14 partners within a particular area of Johannesburg.

- *Cause of injury*

Kreutzer et al [52] found that participants who had sustained their TBI because of being a victim of a violent attack had more difficulty sustaining marriages than participants injured in other ways, such as through falls or road traffic accidents. This finding is supported by Arango-Lasprilla et al. [49] who calculated for their sample of 977 participants with TBI that the odds of being unstably married were 2.99 times greater for individuals whose brain injury was the result of violence compared to those whose injuries had a non-violent aetiology. Brain injury researchers have suggested that victims of violence have greater difficulty maintaining social integration, which creates isolation and withdrawal from social situations, even those interactions with friends and family members [64].

- *Severity of injury*

Kreutzer et al. [52] found an association between longer periods of unconsciousness on admission to hospital following TBI (used an indicator of injury severity) and likelihood of divorce. Similarly, Peters et al. [56] found that wives of severely brain injured patients (as measured by consciousness on admission to hospital and CT scan results) perceived more marital dysfunction in the areas of dyadic consensus, affectional expression and marital adjustment compared with wives of mildly injured husbands. Wood and Yurdakul [27] also found that TBI participants with post-traumatic amnesia (PTA) lasting greater than seven days accounted for 67.2% of all divorces and separations at follow up. However, as the data was skewed in favour of participants with very severe TBI, it is difficult to generalise from findings. Arango-Lasprilla [49] used two measures to assess injury severity among participants, the Glasgow Coma Scale (GCS) at admission to hospital and number of days with PTA. Results showed the odds of being in an unstable marriage was 2.27 times greater for TBI individuals with moderate GCS scores (ranging from 9-12) than for those with severe scores (ranging from 3-8). Similarly, Wood et al [22] who also used length of PTA as indicator of severity found no association with relationship stability. Finally, Anderson-Parente et al. [31] found that all seven stably married spouses reported that their brain injured partner had severe injuries, although as the study was qualitative, severity was not measured using a defined scale such as GCS or PTA.

- *Physical impairments*

Peters et al. [56] noted that wives of brain injured individuals reported poorer marital adjustment when their partners were more physically restricted (as measured using a structured interview of daily living). Similarly, Arango-Lasprilla et al. [49] found that with their sample of 751 Caucasian TBI survivors, when the Disability Rating Scale (a measure of every day functioning) increased, indicating more extensive disability, so to did the proportion of participants rating their marriage as unstable. This was in comparison to a minority group of 226 TBI participants, where increases in disability scores resulted in significant decreases in the proportion of those rating their marriage as unstable.

- *Race*

Kreutzer et al. [52] did not find race or ethnicity to be related to marital status at follow-up, however research in this area is very limited, so it is difficult to fully ascertain the influence of race on relationship stability.

- *Self-concept and perception of self*

Kravetz et al. [59] found a correlation between perceptions of marital vulnerability, the expression of dependency and fear of being abandoned, among a sample of male TBI survivors and their level of negative self concept, which are the critical thoughts, feelings and attitudes a person has about themselves. Although marital vulnerability scores for the brain injured group were not statistically significantly compared to scores for a control group of healthy male participants.

- *Neurobehavioural impairments*

Wood and Yurkadul [27] predicted that individuals with serious neurobehavioural sequalae would be admitted to specialist rehabilitation units and that this may contribute to relationship breakdown. They found that for the 19 out of 131 subjects who had been in rehabilitation for at least 6 months, 89.5% were either divorced or separated. Wood et al [22] explored the particular neurobehavioural sequelae that are most likely to increase the risk of relationship breakdown. The authors hypothesised that threatening and unpredictable characteristics would be seen in those brain injured individuals who had separated or divorced. Both the partners who had separated from their spouse and those still in a relationship rated aggression and quick temper as behaviours that placed considerable strain on relationship stability, however findings between the groups were not statistically significant. The only significant variable for each group was mood swings, suggesting unpredictability of temperament could be a determinant in the durability of a relationship.

- *Changes in sexual relationships*

Kreutzer and Zasler [58] asked 16 married male TBI survivors to complete a psychosexual assessment questionnaire, which contained questions about sexual behaviour, self-esteem and relationship characteristics. 30% of respondents who had low sexual behaviour ratings also reported a poor relationship with their wife relative to pre-injury. This finding is supported by Ponsford [57], who found 36% of the sample of male TBI individuals reported a decrease in the quality of their relationship with their sexual partner, significantly higher than for controls. Ponsford concluded that the physical changes that can occur after TBI, such as fatigue and decreased mobility, contribute to changes in self-esteem leading to difficulties engaging in sexual relationships. However, as Ponsford, Kreutzer and Zasler included only male TBI participants, it could be argued that findings may not be as reliable as those studies in which the perspective of both partners is taken into account, due to the likelihood of impaired self-perception, a common characteristic following TBI. Garden et al [61] did include partners in their study into sexual functioning after TBI and found that 53% of couples were satisfied with the changes in the sexual relationship. Nevertheless, this study compared pre and post-injury perceptions of sexual functioning and as Bray points out [63] retrospective data may be affected by memory and there is the likelihood of an exaggeration effect when making comparisons. Also, due to the sensitive nature of asking couples to talk about their sexual functioning, it is possible that some individuals may withhold information.

- *Perceptions of loss*

Lezak [66] described position of people living with a brain injured partner as being in a ‘social limbo’ as they are unable to grieve properly yet unable to end the relationship without the burden of shame and guilt. Landau and Hissett [48] explored the sense of loss and ambiguity couples experience after mild TBI and the impact their perceptions have on relational breakdown using a qualitative design. They found that all of the TBI participants (the authors refer to a ‘small group’) described identity ambiguity, a sense of loss of self and family members reported confusion, conflict and boundary ambiguity, which is a lack verification of the loss and a sense of being unable to grieve. The authors concluded that these perceptions of loss may contribute to relational breakdown. However, as participants' included not just spouses and partners but parents, siblings and adult children, all of which will have a different relationship to the brain injured individual, it is very difficult to make generalisations on the findings.

- *Emotional responsiveness*

Wedcliffe and Ross [60] noted that 10 out of 14 spouses of TBI survivors reported that their partners were unable to fulfil their emotional needs or provide them with emotional support. Although these findings were not correlated with participants' ratings of marital stability, so it is difficult to ascertain the extent to which a lack of emotional support relates to relationship difficulties. However, Gosling and Oddy [54] assessed marital and sexual satisfaction among female partners of severely head injured males and did find an association between poor marital satisfaction ratings and reports of a lack of expressed affection and emotional responsiveness in their brain injured partner. According to Lezak [67], the ability for partners to support each other emotionally is integral to a stable marriage.

- *Insight and socio-emotional skills*

In order to ensure all relevant literature had been included in the review, key authors were contacted requesting information about studies in the area that were not yet available in the public domain. R. Wood [22] provided information about research that was currently being undertaken, which looks at whether brain injured partners' ability to recognise or express emotion and thereby experience and display empathy, contributes to the longevity of relationships. Burridge et al. [50] explored a similar association between relationship satisfaction, socio-emotional skill and level of insight following ABI; findings were compared to a chronic pain group and healthy controls. Participants in the ABI group had less insight into their socio-emotional skill (as measured using self and informant ratings on The Socio-Emotional Questionnaire; SEQ [65]) and significantly poorer insight and empathic skill compared to both control groups. Burridge et al. noted that brain injured partners tended to rate themselves as more skilled than their partner and there were larger discrepancies in SEQ scores compared to the chronic pain and healthy control couples. The authors highlighted the importance of obtaining information from both the brain injured individuals and their partners for reliability of findings.

- *Family coping*

Anderson-Parente et al. [31] found that when spouses chose to focus on the positive aspects of their relationship couples reported being closer. Moore at al. [53] hypothesised that different patterns of family coping may moderate marital adjustment and collected information from 57 couples where the husbands had suffered a TBI. Results showed that spouses in the high-use coping strategy group, as measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPES) [68] reported greater marital adjustment. Authors concluded that couples who use high amounts of F-COPES (measured coping strategies) have better marital adjustment than those who use low coping strategies.

- *Problem-solving ability*

The finding that those who use coping strategies have better marital adjustment could imply that individuals who are able to problem-solve may overcome relationship difficulties or conflicts more successfully. This was explored in a recent study by Shanmugham et al. [51] who examined the prospective associations of problem-solving abilities and perceptions of relationship satisfaction in carers of stroke survivors. Participants included 39 spouses/partners, 15 adult children, one was a parent and seven participants classified as being in ‘other relationships’. Correlational analyses of demographic and self-report information showed that there was no significant association between relationship satisfaction and problem-solving scores. These findings were independent of the degree of functional impairment experienced by the brain injured family member. It is possible that results were insignificant because of a number of methodological flaws. Firstly, as the participants involved family carers ranging from partners to parents, the relationship they have with the care recipient is likely to differ greatly and research indicates that spouses have more difficulty coping with their partners brain injury than parents do if their adult child is injured [12, 18, 20].

- *Communication changes*

In Wedcliffe and Ross’s [60] study, 11 partners of ABI individuals were asked to describe changes in their partner which had placed the most impact on the relationship after injury. Analysis of the responses revealed a common theme of changes in the couples communication, however the majority of partners referred to problems with speech and language rather than factors such as difficulty getting along. 50% of partners said that they felt that the communication changes meant that they did not know their partner and found it difficult to know how they were feeling and thinking. Peters et al. [56] found 55 wives of TBI survivors reported difficulty in reaching agreement with their partner and Resnick [62], explored marital and family stability following TBI and found that interview responses from family members also indicated a decrease in open family communication.

- *Lack of understanding/ information*

Participants in Resnick's study [62] also stressed that they felt they did not understand their brain injured family members' difficulties because of the communication problems and because of the lack of support and information from health professionals. Family members reported that they were unsure how the relative was thinking and feeling. Gosling and Oddy [54] used a mixed design study to explore sexual relationships following head injury from the point of view of the non-injured spouse. Transcripts also revealed that partners reported that they struggled to interpret how their partner was feeling and to make sense of the cognitive and behavioural effects of the brain injury.

Discussion

The review findings highlight that there are a number of factors which may contribute to relationship stability or instability following brain injury. In total, 20 factors were identified, with each providing insight into the possible influences on a couple's decision to either stay together or separate after brain injury. To summarise, the factors included the age, gender and race of a couple, the influence of children, perceived financial strains, the length of a relationship prior to injury and time since the onset of the injury, the cause and severity of the injury, the extent of physical and neurobehavioural impairments, changes in sexual relationships, changes in the injured partners perception of self, level of insight, socio-emotional skills and emotional responsiveness, changes in communication between couples, the level of coping and problem-solving ability in the family, perceptions of a sense of loss among partners and family members as well as a lack of understanding and information regarding the effects of the brain injury.

On the one hand, reviewed studies have provided information to either confirm or disprove various hypotheses surrounding the reasons behind relationship breakdown after brain injury. Yet on the other hand, the majority of findings appear to be contradictory, making it very difficult to draw firm conclusions about the actual factors contributing to relationship stability. There are a number of possible explanations for the differences in findings and these are mostly due to the variations in research design and methodology across studies and subsequent limitations of these. A brief summary of the main variations is provided to show how a body of research with similar aims may produce very different findings.

Firstly, as table 2 on pages 23-24 shows, the studies accepted for review included different groups of participants, from a nationwide sample of 977 TBI survivors [49] to a ‘small sample’ of couples [31]. While some studies included only those who had experienced a brain injury [27, 52, 57, 58], others included only the injured persons spouse [56, 60] or family members [51, 62], making comparison across studies very difficult. There are also potential limitations with each of these samples of participants. Including only those individuals who have had a brain injury raises three issues: The variation in the severities of the brain injuries and associated difficulties, the possibility of participants having impaired memory, insight or awareness, which are frequent effects of brain injury [69] and could prevent participants providing accurate responses, and the likelihood of skewed data towards younger male participants as TBI in particular occurs more frequently in this population [70].

Despite the problems described above, gathering information from only spouses or long-term partners may too give an inaccurate picture of the couples' relationship, especially as the majority of studies with partners included retrospective ratings or accounts of previous relationship stability [22, 50, 52, 54-56, 60]. Such perceptions may be prone to denial, which is often used as a coping strategy in the initial months following the injury [54] or social desirability bias and responding in a way that is perceived as 'acceptable' to the researchers. Authors have argued that any study assessing the impact of brain injury on marital relationship must include the view points of both spouses to ensure accurate reflections of the past or present situation [61].

Another point which may account for the contradiction in findings is the variation in the definitions of 'relationship stability' and related measures. For example, some studies have defined stability in terms of 'marital adjustment' [53, 55] and used a standardised measure such as the Dyadic Adjustment Scale (DAS) [71], which assesses the amount of agreement or disagreement between couples. Another study has defined stability in terms of how close couples are [56] and used the Personal Assessment of Intimacy in Relationships measure (PAIR) [72]. Other studies have measured the quality of a relationship between couples [50, 54] using the Golombok and Rust Inventory of Marital State measure (GRIMS) [73], while some have used a qualitative approach to collect detailed information on participants perceptions of what a stable relationship is [31, 60, 61]. Other studies have included a basic Likert scale of stability [51] or simply obtained a couple's current relationship status to assess stability in terms of whether they are still together [27, 49]. Clearly such variation in the definition of stability makes it very difficult to draw comparisons across studies.

The final explanation for the variations in review findings are the differences in methodological quality scores. As table 2 on pages 23-24 shows, average scores between the three raters ranged from 5.6 points [61] to a maximum of 16 points, which was only obtained by one study [51]. Although methodological quality was not used as an exclusion criteria in this review, such variation in scores and with only one study receiving full points from all three raters demonstrates that the remaining 17 out of 18 studies have not met important methodological criteria. It is likely that this will influence the reliability of results and any subsequent conclusions drawn.

Despite the limitations discussed, evaluation of studies highlights a number of standards for further research in this area. Firstly, it would be important for future studies to carefully consider the definition and measure of relationship stability to allow cross-comparison with other studies. Secondly, none of the studies accepted for review included a longitudinal design, yet assessing relationship stability at interval periods over a particular time span may provide more insight into the changes in stability over time. Thirdly, future studies may wish to focus on including both the brain injured individual and their partner together in the research, to obtain accurate information whilst controlling for the possibility of impaired self-awareness or memory in the injured partner. Another important point is that some studies have chosen to focus only on those couples who are married, yet this may limit a large proportion of couples in long-term relationships from being included. Future research should consider these couples as well as partners in a homosexual relationship, as this is an area which remains unexplored.

Other directions for future research may include carrying out studies with survivors of ABI as this group are currently under-represented in the research literature. The reason for this may be due to the nature of ABI, in which multiple areas of the brain may be damaged, unlike TBI which usually affects one specific area. As it can be more difficult to group ABI participants into similar cohorts because of the complexity in determining the exact brain structures that are damaged, researchers may be more inclined to exclude ABI all together meaning this population is still relatively unexplored. A further area for investigation is to focus not just on couples who stay together but to also include the views of couples who part after injury. However, it may be very difficult to obtain willing participants due to the sensitive nature of asking couples about their relationships after separation, particularly when partners may be experiencing feelings of guilt or loss. Finally, another research challenge is to not just explore those factors affecting relationship stability but to identify the factors that may be responsive to therapeutic intervention. Unfortunately, there is very little research available on possible ways to minimise the impact of negative factors contributing to relationship breakdown, perhaps because of the inconsistency among findings. Nevertheless, the following discussion may help to provide some insight into possible factors that could be targeted.

Though the majority of reviewed studies provided contradictory information regarding the factors associated with relationship stability, six factors were uncovered which had limited yet supporting evidence. The first finding is that if a brain injury is caused by a violent attack, individuals are shown to have difficulty sustaining relationships [49, 56], perhaps due to social withdrawal [64]. The second finding is that those brain injury survivors may who experience severe physical disability have more unstable relationships with their partners [49, 56]. It is suggested that physical disability may increase dependency on a spouse or partner and limit opportunities for employment [56]. The third finding is that couples who have perceived financial strains are more likely to have poorer marital adjustment [53] and show less affection towards each other [56]. No explanations have been put forward for this link, however it is possible that those brain injury survivors who are unable to continue at work may be more physically or psychologically impaired, which may be a factor in couples perceptions of relationship difficulties.

The fourth finding highlights the importance of neurobehavioural characteristics, in particular the extent of partners' mood swings and unpredictability, which has been found to be a determinant in the stability of a relationship [22, 27]. It is proposed that unpredictable changes in mood may create a sense of helplessness in uninjured partners who may be unable to prepare for sudden changes in temperament and behaviour [22]. The fifth factor shown to affect relationship stability is changes in communication between couples, either because of speech and language difficulties resulting from the injury [60] or because of a difficulty reaching consensus and being unable to discuss problems openly without disagreement [56]. The sense of incongruity or divergence in couples' perceptions appears to be important as the final factor shown to inhibit relationship stability is the finding that lack of information about the brain injured individuals' difficulties leads to problems understanding the person after brain injury and distinguishing the cognitive, emotional, psychological and behavioural effects of the injury [54, 62].

Of the six factors described, three are static or unchangeable; these include the cause of brain injury and the severity of physical or neurobehavioural disability. Two of the factors may be either static or dynamic (variable), these include financial strains and changes in communication, which could potentially be helped with financial support or therapy. However the final factor, the lack of understanding and information partners felt they had about the effects of the brain injury, is the only one that can be changed relatively easily. This may offer evidence in support of interventions aimed at providing couples with information about the injury and its effects. As Landau and Hissett [48] pointed out in their study, misinformation or a lack of thorough assessment of the injury by health professionals can cause families to set their expectations of what the person can do too high. This can then cause injured partners to feel frustrated, unsupported and helpless and families left more confused, which the authors suggested could contribute to relational breakdown. Therefore, early assessment and interventions aimed at providing families with information and education about the injury could be a key factor in preventing relationship difficulties.

A number of authors of reviewed studies have proposed that their research findings advocate the value of marital and relationship counselling, to help couples come to terms with the changes experienced, or as Wedcliffe and Ross [60] suggest to ‘conserve marriages’. However, there is a tendency in the research literature to view ‘stability’ as a goal or something that can be achieved through relationship counselling. Yet stability, a term that denotes constancy and permanence, does not necessarily mean that couples who choose to stay together after injury are enjoying a satisfying and fulfilling relationship. Gosling & Oddy [54] have raised an important question; could relationship counselling interventions actually put subtle moral pressure on couples to stay together.

What appears to be important is for health professionals to provide thorough, multi-disciplinary assessment of the extent of brain damage and associated problems. This information should be passed on sensitively to the injured individual and their partner or close family members so that they can begin to understand the effects of the injury together. As Lezak observed, families cope more effectively with a relative's behaviour when they have knowledge about the nature of changes associated with brain injury [67]. It is possible that this form of intervention may have more success than offering relationship counselling, support very few couples actively seek after brain injury [54]. Such a short-term, un-intrusive, education and information-giving intervention may create a shared understanding of the problems that can occur after brain injury, which may help to prevent conflict and the distress of relationship breakdown.

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Part Two: Empirical Paper

Discrepant Illness Perceptions in Stroke Survivor-Partner Dyads: Relationship to Psychological Adjustment and Expressed Emotion

This paper is written in the format ready for submission to Brain Injury. Please see Appendix 1. for the author guidelines.

Word count: 10, 442

Discrepant illness perceptions in stroke survivor-partner dyads: Relationship to psychological adjustment and expressed emotion

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Abstract

Primary objectives: Previous research has shown that relationships between couples can become strained after brain injury and that those partners who adopt a carer role may be more likely to express negative or critical reactions towards the partner they care for. This study explores a cognitive component that may underlie the extent of carers expressed emotions: The difference or discrepancy between carers understanding of their partners stroke and stroke survivors understanding of their stroke.

Method: A cross-sectional, correlational design was used to explore the associations between stroke survivors and their partners illness perceptions (identity, time-line, consequence, control, illness coherence, emotional representations and cause), stroke survivors level of psychological adjustment (anxiety and depression) and partners level of expressed emotion. A total of 51 couples participated in the research.

Results: Although correlations between illness perceptions, psychological adjustment and expressed emotion were not statistically significant, there was a statistically significant correlation between anxiety and depression variables (r = 0.55, n = 51, p<0.01) and stroke survivors’ anxiety and partners’ expressed emotion (r = 0.40, n = 42, p<0.01).

Conclusion: Results indicated areas for further investigation, in particular the possible link between carers expressed emotion and their partners level of psychological adjustment.

Keywords: *Stroke, illness perceptions, psychological adjustment, expressed emotion*

Introduction

Stroke is the leading cause of disability in the world [1] and an estimated 150 000 people experience a stroke each year in the UK [2]. Statistics indicate that approximately one-third of people who suffer a stroke die within the first six months, another third recover to their former level of functioning and the remaining survivors may make improvements but will endure severe disability for the rest of their lives [3]. According to The Stroke Association, a UK charity that funds research into stroke prevention, treatment and rehabilitation, there are an estimated 250 000 stroke survivors in the UK, currently living with serious physical and psychological impairments [2]. The consequences of stroke depend largely on the type and location of the brain damage, however, every stroke is unique and no two survivors will experience the same effects. Stroke can have multiple outcomes, including physical and motor deficits [4], cognitive impairments, such as memory loss, problems with thinking and attention [5], behavioural difficulties, which may include fatigue, lack of motivation and irritability [6] and psychological problems, with emotionalism, anxiety and depression being the most common [7].

The psychological effects of stroke can be particularly damaging for survivors, with findings indicating that the presence of depression can slow recovery of physical function, [8] limit rehabilitation [9] and even increase mortality rates [10]. Whereas other physical and cognitive symptoms have been found to improve over time, depression and anxiety have shown to persist and can even increase. Findings suggest that two years post-stroke, lesion location is no longer a significant factor in the aetiology of depression and anxiety and social dysfunction and isolation is attributed to deteriorations in psychological health [11]. Social support is a crucial factor in rehabilitation and adjustment to stroke, with research consistently highlighting the benefits of quality social interactions with others [12, 13]. However, following stroke the complex interplay of cognitive, behavioural and psychological difficulties can manifest in personality changes, which have been linked to social isolation and withdrawal [14]. Stone et al. [14] found that partners, family and friends of stroke survivors have expressed difficulty maintaining a relationship with someone they perceive to be ‘a different person’. Unfortunately, this means some stroke survivors can become deprived of valuable social interactions and support.

Few stroke survivors remain in hospital or in-patient rehabilitation services following initial treatment, so it is often the responsibility of informal carers, most commonly a patients’ spouse or partner, to fulfil the long-term care and rehabilitation needs of the stroke survivor [15]. When partners are forced to adopt a carer role they can become faced with a number of lifestyle changes and there is no shortage of research highlighting the negative physical, psychological, emotional, financial and social strains that may be encountered [16]. Relationships can also become strained, which may even exacerbate difficulties for survivors and their partners [17]. According to Barrowclough and Hooley [18], when people experience a range of difficulties as a result of having to care for a partner or family member, they are more likely to display negative emotional reactions towards that person. This can have a direct impact on the level of social and emotional support their partner receives and physical and psychological adjustment to the consequences of stroke can be limited for both survivor and carer.

The extent of carers’ negative emotional reactions towards their partner is an important yet difficult concept to assess [19]. However, research exploring the attitudes of relatives living with a family member with schizophrenia has provided a way to quantify critical, hostile and emotional feelings expressed towards an ill or injured family member. This measure is called Expressed Emotion (EE) [20, 21, 22] and has been successfully applied to the investigation of a range of different physical, mental and neurological difficulties, including stroke. Weddell (1987) [23] found that those family carers who had high-EE contributed to the psychological distress of their stroke surviving partner. This association was independent of the severity of stroke or functional or cognitive deficits. Weddell concluded that when stroke survivors may already feel a sense of incompetence and helplessness after the injury, they may be particularly sensitive to criticisms from those they depend on, also that negative attitudes are more common in distressed couples facing life challenges.

Not all carers respond to their partner in a critical or hostile manner following illness or injury, however, some report feeling emotionally closer to their partner and increase the frequency and intensity of their interactions. This behaviour pattern has been termed ‘emotional over-involvement’ (EOI) in the EE literature [21, 22], which has been found to interfere with levels of autonomy required for optimal adjustment. Therefore, although a good quality social support is associated with better physical outcome and quality of life, over-protectiveness on the part of a carer can prevent patients thriving emotionally and inhibit physical independence following hospitalisation [24]. According to Mitchley et al. [25] the type of emotional reactions carers express towards their partner depends on the perceptions and appraisals that are made about the observed behavioural difficulties. For example, a carer may be particularly critical if they believe that their partner can control their behaviour but chooses not to, or if they perceive that negative cognitions are motivated by hostile intentions. Similar findings have been highlighted by Cohen et al [26] and Thompson and Pitts [27], who noticed that some carers tended to perceive that the consequences of an illness as less serious than patients claimed and were more critical of their partner. In contrast, other carers who judged that the consequence of their partners' illness or injury was far more serious than patients themselves did were not critical but their behaviour led to passive coping on the part of the patient, which can be just as damaging in terms of rehabilitation.

According to Leventhal et al's self-regulation model [28], following an illness event, patients and carers create personal models or representations of the illness and its effects around five distinct cognitive components. These include; identity –ideas about the label of the illness and associated symptoms, cause–beliefs about the likely cause or causes of the illness, time-line–thoughts about the likely duration of their health problems, consequences–the beliefs about the illness severity, expected effects and impact on physical, social and psychological functioning and finally cure control –ideas about whether the condition can be cured or controlled. Recent overviews of research in this area, across a range of different clinical conditions and methodologies, confirm the consistency and validity of these five components, which are thought to come in to play as soon as patients experience their initial symptoms and typically change with illness progression, development of new symptoms and treatment responses [29].

Heijmans, De Ridder and Bensing [30] have highlighted that although the number of studies into illness perceptions has rapidly increased over the past five years, research has predominantly focused on patients’ beliefs about their own health problems and the views of partners and family members has been largely ignored. However, a recent study by Lobban, Barrowclough and Jones [31] explored discrepancies in appraisals between patients diagnosed with schizophrenia and their relatives, to test the hypothesis that high-EE on the part of the carer is associated with a discrepancy in the beliefs about what a person can do. Results showed that there was greater discrepancy between illness models of schizophrenia in dyads involving a high-EE relative than in dyads involving a low-EE relative. Kuipers et al. [32] recently developed the work carried out by Lobban et al. and found that discrepant views about illness consequences were related to greater anxiety, depression and lower self-esteem in patients, while discrepant views on controllability were associated with greater distress, depression and lower self esteem in carers.

No study to date has examined possible discrepancies in illness perceptions between stroke survivors and their partners, despite the links being seemingly present in other chronic health conditions. The present study aims to investigate whether there are discrepancies in illness perceptions between stroke survivors and their partners, in order to examine whether divergent appraisals of stroke and its effects, relate to partners levels of EE (criticism, hostility and emotional over-involvement) and survivors level of psychological adjustment (anxiety and depression). It is hoped that the findings will assist health professionals working with families after stroke, to be aware of the similarities or differences in the ways people make sense of and understand stroke and its consequences. The findings of this study may also help to provide possible avenues for psychological intervention, to help survivors and their carers adjust to the many life changes and challenges that are so often experienced after stroke.

A cross-sectional, correlational design was used to address the following research questions:

1) Are there discrepancies in illness perceptions between stroke survivors and their partners?

2) Is there a relationship between discrepancies in illness perceptions and partners' level of EE?

3) Is there a relationship between discrepancies in illness perceptions and stroke survivors' level of psychological adjustment (anxiety and depression)?

Method

Participants

Participants were recruited through a Community Stroke Team based at an NHS hospital in the North of England between November 2008 and April 2009. To determine how many participants needed to be recruited for a clinically significant effect, a power estimation was calculated. The Number Cruncher Statistical System [33] predicted that a sample size of 50 dyads would yield 80% power to detect a correlation of r^1=0.38 or larger, using a two-sided hypothesis test with a significance level of 0.05. The value r^1=0.38 is the population correlation or predicted effect size, which is an estimate of the strength of a relationship between the variables under investigation, rather than clinical significance. According to Cohen [34], in correlational studies when *r* equals between 0.30 and 0.49, it is considered a 'medium' effect size, meaning the inclusion of 50 dyads in the present study allows a degree of confidence that the research questions under investigation will be observed by the sample data. This finding is supported by Wilson VanVoorhis and Morgan [35] who suggest that 50 participants or more must be included in studies employing a correlational design. In total, 51 stroke survivors and 51 partners were included in the study, with all couples meeting the following inclusion criteria:

Inclusion criteria for stroke survivors

Participants were invited to take part if they had a confirmed clinical diagnosis of stroke or CVA (cerebrovascular accident) as stated in the patient records. They also needed to be able to communicate verbally in English, without translation or interpretation from another person. It was a requirement that participants had to have been in a relationship with their spouse or partner for over a year prior to the onset of the stroke and to have lived at home together for a minimum of one year post discharge from hospital or inpatient rehabilitation services.

Exclusion criteria for stroke survivors

Participants were not invited to take part if they had suffered a Transient Ischaemic Attack (TIA) or ‘mini-stroke’ or if they had suffered a severe stroke and were at risk of death. Survivors who lived in a residential setting, spent more than 12 weeks per year in respite, or lived at home but had more than 28 hours support a week from a care agency could not be included. They could also not take part if their patient records stated evidence of dyarthria, apraxia, severe speech and language difficulties or if they could not speak English. Patients who had suffered a stroke but also had a confirmed clinical diagnosis of another significant physical or mental health problem (e.g. dementia, ME, bi-polar disorder) were also excluded.

Inclusion criteria for partners

In order for couples to be included in the research together, partners had to have been in a relationship with the stroke survivor for over a year prior to the onset of stroke and be living together at home for a minimum of one year post discharge. Partners had to be able to speak English and be identified in patient records as the main source of support for the stroke survivor.

Description of the sample

51 stroke survivors participated in the study, 33 were male (64.7% of the sample) and 18 were female (35.3% of the sample). For male stroke survivors, ages ranged between 48 to 78 years with a mean age of 65.6 and for female survivors, ages ranged between 34 to 85 years with a mean age of 63.8. The overall age of stroke survivors ranged from 34 to 85 years with a mean age of 64.9 (sd 9.25). Of the 51 partners who participated, 18 were male (35.3% of the sample) and 33 were female (64.7% of the sample). For male partners, ages ranged between 41 to 85 years, with a mean age of 65.1 and for female partners, ages ranged between 43 to 76 years with a mean age of 62.0. The overall age of partners ranged from 41 to 85 years with a mean age of 63.1 (sd 9.45).

For stroke survivors (n=51), the length of time individuals spent in hospital or rehabilitation services ranged between not being admitted to spending up to seven months as an in-patient. The mean length of time survivors spent in hospital or rehabilitation was 5.82 (sd 7.15), which equates to between 5 and 6 weeks. Only five survivors (9.8% of the sample) received support from an outside care agency, ranging between visits by carers once a week to visits seven days a week. The mean amount of care time was 3.80 (sd 2.95), which equates to receiving visits from carers between three and four times each week. Only three survivors received respite care (5.9% of the sample) and the mean time in respite was 3.33 (sd 1.154), which equates to between three weeks and a month in respite each year.

All participants (n = 102) lived in Northern England and the vast majority were white-British, with the exception on one Italian stroke survivor and one Afro-Caribbean partner.

Measures for stroke survivors

Assessing self-awareness

Self-awareness is the ability to understand oneself and recognise personal strengths, weaknesses, capabilities and difficulties. It involves a cognitive process of integrating information from external reality and inner experience. Impaired self-awareness or anosognosia is a common outcome following neurological disorders such as stroke, particularly where damage to the right cerebral hemisphere, prefrontal or parieto-temporal brain structures exists [36]. However, though brain damage is often considered the sole cause of awareness deficits, psychological disorders of self-awareness also occur, where patients deny any existence of impairments but have no specific damage to the core brain structures outlined above. The extent of impaired self-awareness following stroke varies widely, from an inability to recognise disabilities, to difficulties understanding the severity of the brain injury or its impact on daily living to over-estimating the rate of recovery and making unrealistic plans for the future [37].

The present study includes self-report questionnaires, which require stroke survivors to respond to a range of questions and statements about the stroke and their perceptions of the cause, consequences and difficulties following the stroke. The questionnaires rely on views about behaviour pre and post stroke as well as feelings and ideas about the expected long and short-term effects of the stroke. Due to the high incidences of impaired self-awareness following stroke it is possible that a percentage of participants included may have found it difficult to self-monitor or recognise changes in the self post stroke. This presented a potential confounding variable, which may mediate survivors' ratings of illness perceptions and psychological adjustment. Therefore, the following measure was included to assess potential impairments in self-awareness and to use survivors awareness scores as a covariate with partial correlation statistics so that the effects of the impaired self-awareness on other scores could be controlled.

The Patient Competency Rating Scale (PCRS) [38] is a standardised self-report questionnaire developed to evaluate patents level of self-awareness after brain injury. The PCRS contains 30-items covering four domains: activities of daily living, behavioural and emotional function, cognitive abilities and physical function. The questionnaire asks the individual to use a 5-point Likert scale to rate their degree of difficulty in a variety of tasks within the four domains, e.g. '1 = can't do' to '5 = can do with ease'. Individuals' responses are compared to those of a partner, who rates their partner's ability on 30 identical items. Discrepancy scores are then calculated by taking the partners' total PCRS score from the patients' total PCRS score. A lack of self-awareness is defined as when the patient overestimates their ability at completing the various tasks compared to their partners' perception of their ability. Those patients who under-estimate their behavioural skills may do so as a results of emotional stress, anxiety or depression [39]. Findings from PCRS reliability studies are encouraging, with data revealing acceptable test-retest reliability for 17 TBI patients ($r = 0.97$ $p<0.05$) and their relatives ($r = 0.92$ $p<0.05$) [40]. Please see Appendix 13 an example PCRS as given to stroke survivors.

Assessing illness perceptions

Leventhal et al's [28] Self Regulation Model (SRM) has been selected as the theoretical framework from which illness perceptions will be explored in the present study. The model has been extensively used for a range of different physical and mental health problems and is currently the most widely used framework in health research [31]. Unlike other illness appraisal models, the SRM acknowledges the importance of social factors and the role of significant others during the formation of personal illness representations, which Leventhal et al. [41] define as, 'implicit, common-sense beliefs about illness' (pg. 10). The model, which is likened to an information- processing system, proposes that as soon as initial symptoms are encountered, personal views and emotional reactions are developed about the experience, which guides coping and behavioural responses. Much of the self-regulation system operates automatically and without conscious awareness through a number of stages:

The initial illness perception is one of ‘identity’ or the formation of a personal definition or label for the health threat and symptoms. Then beliefs about the ‘cause’ or the factors responsible for the onset of symptoms develop as do thoughts about the possible ‘consequence’ or effects of the health problem. According to the SRM, people also have perceptions about the expected duration of the problem and the course it will take, referred to by Leventhal et al [28] as ‘timeline’, which may be perceived as acute or chronic and episodic or cyclical. Finally, ideas are developed about ‘control’ and how the problem will be managed, both personally and with treatment.

The Illness Perception Questionnaire-Revised (IPQ-R) [42] is a 73-item self-report measure that is directly based on Leventhal et al’s [28] theoretical model and covers the five stages of illness perception highlighted in the SRM. The revised version of the questionnaire also assesses two further stages in the development of illness perceptions, ‘emotional representations’, or responses to the health threat and ‘illness coherence’ or sense of understanding of the problem. The IPQ-R is being used in the current study as there are two versions of the questionnaire, one for those experiencing the health threat and one for a family member or significant other. The measure can also be adapted for specific health problems or illnesses so that is relevant those responding to the questions. The IPQ-R has also demonstrated good internal reliability, retest reliability, discriminant and predictive validity [42]. However, the psychometric properties of the IPQ-R are based on data using eight illness groups; brain injury and stroke were not included in these analyses. Nevertheless, there are now a number of published studies which have used the IPQ-R with various health problems that have also not been validated against psychometric analyses, including a study exploring illness perceptions after mild head injury [43] and one focusing on carer appraisals of non-acute stroke [44]. Please see Appendix 15 for the IPQ-R given to stroke survivors.

Assessing psychological adjustment

The onset of stroke can result in significant life changes for survivors. According to Patterson [45], psychological adjustment depends on the individual's ability to adapt to the transitions resulting from the stroke. However, psychological adjustment is an on-going process that involves the gradual acknowledgement of the challenges and difficulties caused by the stroke whilst regulating emotional distress. Psychological problems frequently occur after stroke, with anxiety and depression being the most common [7]. Prevalence rates for these symptoms are higher than in age and sex-matched controls [46] and other disabling illnesses [47], highlighting the significance of psychological distress after stroke. Secondly, the presence of anxiety and depression can have a disabling impact on survivors, particularly in terms of physical recovery and rehabilitation [8, 9], which are essential for the person's sense of competence and preservation of a positive sense of self. Psychological adjustment is a key issue in the stroke research literature for the reasons outlined above and it is being included as a variable for investigation in the present study to assess whether there is an association between survivors psychological adjustment and shared perceptions about stroke.

The Hospital Anxiety and Depression Scale (HADS) [48], is a 14-item, self-report measure of anxiety and depression that was included to determine stroke survivors levels of psychological adjustment. The HADS has been used extensively in health research, including stroke [49] and provides an accurate representation of psychological adjustment as the measure excludes questions regarding somatic symptoms, such as dizziness, headaches, pain, fatigue, insomnia and lethargy-which are commonly experienced after stroke. The psychometric properties of the HADS also demonstrate factorial, discriminant and concurrent validity and reliability with internal consistency of 0.80-0.93, (Chronbach alphas) [50]. Please see Appendix 17 for an example HADS as given to stroke survivors.

Measures for partners

Assessing self-awareness

The PCRS [38], as previously described on page 64 was also given to partners. Please see Appendix 14 for the relatives' version of the measure.

Assessing illness perceptions

The IPQ-R [42], as previously described on page 66 was also given to partners. Please see Appendix 16 for the relatives' version of the measure.

Assessing Expressed Emotion

Expressed Emotion (EE) describes the attitudes and feelings a family member communicates about an ill or injured relative during an interview with a researcher to assess the patient-relative relationship [51]. The prevailing model of EE is based on Brown et al's [20] early formulation, whereby EE causes stress for the patient and this induces physiological arousal, which may increase the individual’s propensity to develop physical and/or psychological symptoms. When the individual displays such symptoms they are considered to have relapsed. EE has received extensive research attention since the term was first introduced in 1972 and has been assessed in a number of chronic illnesses, including stroke [23].

The Five Minute Speech Sample (FMSS) [52] is a measure of EE based on Brown et al’s [20] theoretical model. It was included to assess partners critical or emotionally over-involved (EOI) expressions about the stroke survivors. The FMSS is a promising alternative to the Camberwell Family Interview (CFI) [22], a semi-structured interview which is considered the ‘gold-standard measure of EE’ (pg.387) [51]. However, the CFI requires researchers to obtain a minimum of 70 hours training in order to use and score the interview and the measure takes approximately two hours to administer and up to four hours to code [52], making the method of assessment rather arduous. The FMSS is one of the most widely used alternative measures of EE as it has been validated against the CFI [52] yet requires family members to talk about their thoughts and feelings for only 5 uninterrupted minutes. The speech is recorded then coded (which takes approximately 20 minutes) into a ‘high EE critical’ rating, a ‘high EE EOI’, a ‘high EE critical and EOI’ rating or low-EE, where none of the ratings for the high-EE criteria apply. Please see Appendix 18 for the specific administration and scoring instructions.

A requirement of the FMSS is that researchers are trained in coding the speech samples. However, training courses for the FMSS do not currently exist in the UK and due to research budget limitations it was not possible to complete a course abroad. Consultation with an experienced EE researcher, who has conducted and published a number of studies using CFI and FMSS data, indicated that it would be possible to code the speech samples without formal training and to instead work from the comprehensive FMSS administration and coding manual [53]. It was also advised to carry out practice speech samples to become familiar with using the manual and to transcribe all speech samples to assist coding. In order to assess whether the EE ratings were accurate, ten speech samples, transcriptions and EE ratings were requested for secondary blind rating by a trained EE researcher. As all ten tapes received the same EE ratings, inter-rater reliability was confirmed. As there were 42 speech samples to code in the present study it was felt that setting up a supervision group may be helpful to discuss any coding issues or difficulties. The group, which was led by a research psychologist trained in the FMSS, met on three separate occasions during the course of the data analysis process.

Procedure

Following ethical approval (see Appendix 5 for the confirmation letter), the patient records of stroke survivors, which were held at the Community Stroke Team hospital department, were assessed against the inclusion and exclusion criteria as stated in the method section. In total, 118 patients were identified that met the criteria. The list of potential participants was taken to one of the monthly multi-disciplinary meetings in order to seek professional opinion on the suitability of contacting identified patients. Of these, 13 patients were identified that would not be suitable for participation, reasons for exclusion included death, people that had since moved into a residential setting or were no longer with their partner. The 105 remaining potential participants and their partners were then sent a cover letter (see Appendix 7) and an information pack that provided further information about participating in the study (see Appendix 8 and 9).

Participants were informed in the cover letter that the primary researcher would contact them in approximately a week from receiving the letter, to provide couples with time to consider and discuss with each other whether they wanted to take part. After this time, couples were telephoned and asked whether they had had the chance to read the information and if so whether they wanted to take part. In total 51 couples were willing to participate (48.5% of the identified participants). For the remaining 54 couples, 30 did not want to take part, 11 could not be contacted on the telephone, five stroke survivors had been widowed and eight stroke survivors had since died. The CST were informed straight away of changes in patients circumstances. Of those couples who agreed to take part, an appointment was arranged for a time and place that would be convenient. 50 couples requested to be seen at their home and only one couple wanted to meet at the hospital.

At research appointments, both the stroke survivor and partner were met together so that time could be spent going through the procedure and providing any further information if requested. Written consent was then obtained from both partners (see Appendix 10 and 11) and stroke survivors were invited to take part first, without the partner in the room. Stroke survivors were asked to complete three self-report measures, the PCRS, the IPQ-R and then the HADS. The researcher remained in the room while the stroke survivors completed the measures, this was to provide any support with reading or writing responses and to ensure that the participants were able to complete the tasks. When the stroke survivor had completed all three measures, the researcher met with the partner, who was asked to complete a demographic information sheet (see Appendix 12) and two self-report measures, the PCRS and the IPQ-R. On completion of the self-report measures, the FMSS was administered. The procedures for data collection with the stroke survivor and partner lasted approximately one hour.

Statistical analysis

Analyses were conducted using SPSS version 16.0 for Windows. Discrepancy scores for the nine illness perception dimensions were calculated for each dyad by subtracting the stroke survivors score from their partners score. The positive and negative signs were then removed from total discrepancy scores as it is the magnitude rather than the direction of discrepancy that is the focus of the investigation. Further discrepancy calculations were carried out for the PCRS scores for each dyad by subtracting the partners score from the stroke survivors score. This allowed impaired self-awareness to be inferred from positive scores, which indicate that the survivor has over-estimated their abilities compared to informants ratings. To explore discrepancies between partner and survivor scores across the nine domains of the IPQ-R (research question one), it was necessary use descriptive statistics to calculate the distribution of scores for each variable. To further test the normality of the distribution of variables, a one-sample Kolmogorov-Smirnov test was carried out, which compared the data to a reference probability distribution. The information obtained from these calculations was used to guide the selection of further statistical analyses required to investigate the relationship between variables.

A Pearson correlation coefficient was used to assess the degree of association between couples illness perception discrepancy scores, EE and psychological adjustment (research question two and three). Due to the lack of previous research evidence in the area of investigation and the exploratory nature of the study, a two-tailed significance level was selected for correlations, whereby p<0.01. As nine participants did not want to complete the FMSS during research appointments, correlations between illness perception discrepancy scores and EE were not based on the full data set but on n=42 (removing the nine participants out of the analyses). Finally, as it was hypothesised that some stroke survivors in the sample may have impaired self-awareness, the PCRS discrepancy scores were selected as a control variable using first order partial correlation. This allowed the association between illness perception discrepancies, EE and psychological adjustment to be assessed whilst controlling for the effect of impaired self-awareness.

Results

Descriptive statistics

The following tables provide general information about the data to demonstrate trends in participants' responses. The first table shows the number of stroke survivors who over- or under-estimated their ability, as inferred from positive discrepancy scores on the PCRS after subtracting the partners score from the stroke survivors score. According to the data, the majority of stroke survivors over-estimated their ability (63 percent of the sample), which may indicate that these participants have impaired self-awareness.

Over-estimated ability	**Under-estimated ability**	**Equal scores**
32 (63% of sample)	17 (33% of sample)	2 (4% of sample)

Table 1. Number of stroke survivors (n = 51) who over/under-estimated their ability on the PCRS compared to partners.

The next table shows stroke survivors' psychological adjustment scores as measured by the HADS. According to Zigmond and Snaith [48], scores between 0 to 7 on both the anxiety and depression scales of the HADS represent 'normal functioning'. Scores between 8 to 10 on both scales indicate 'borderline clinical disorder' and scores between 11 and 21 on both scales indicate 'probable clinical disorder'. As the table below shows, the majority of stroke survivors scored in the normal functioning range for both anxiety (53 percent of the sample) and depression (72 percent of the sample).

Anxiety			**Depression**		
Normal functioning	Borderline clinical disorder	Probable clinical disorder	Normal functioning	Borderline clinical disorder	Probable clinical disorder
27 (53% of sample)	13 (25% of sample)	11 (22% of sample)	37 (72% of sample)	5 (10% of sample)	9 (18% of sample)

Table 2. Number of stroke survivors (n = 51) within each anxiety and depression category based on HADS scores.

The third table provides data for partners' EE ratings as measured by the FMSS. This information is based on n = 42, as nine participants did not complete the speech sample. Of these participants, 20 were rated as being in the low EE category and 22 were rated as being in the high EE category. The high EE category has three subgroups, 'critical', 'EOI' and 'critical and EOI' and the information below highlights that majority of partners were in the high EE, EOI subgroup (64 percent of the sample).

High EE		
Critical	**EOI**	**Critical & EOI**
2 (9% of sample)	14 (64% of sample)	6 (27% of sample)

Table 3. Number of partners (n = 42) within each high EE category.

To examine the distribution of participants illness perception discrepancy scores, skewness and kurtosis statistics were calculated to quantify the shape of the distribution of observed data compared to the normal distribution or bell curve. The data is also presented graphically in appendix 23.

Illness perception discrepancy domain	**Mean discrepancy score**	**Skewness**	**Kurtosis**	**Kolmogorov-Smirnov (Z)**
Identity	2.27	1.30	1.65	1.59 (sig. 0.01)
Timeline Acute/Chronic	3.88	0.85	0.48	0.93 (sig. 0.35)
Timeline Cyclical/Episodic	2.90	0.74	-0.22	1.27 (sig. 0.08)
Consequence	3.90	1.35	2.55	1.20 (sig. 0.12)
Personal Control	4.06	1.55	2.89	1.03 (sig. 0.24)
Treatment Control	3.18	0.65	-0.12	1.11 (sig. 0.17)
Illness Coherence	4.22	1.08	0.55	1.07 (sig. 0.21)
Emotional Representations	4.33	1.04	1.16	1.07 (sig. 0.21)

Table 4. Normal distribution data (to 2 decimal places) for illness perception discrepancy scores between dyads (n = 51).

A skewness statistic of 0 indicates that the distribution of data is perfectly symmetrical and fits the normal distribution or bell curve. As table 4 above shows, none of the variables scored 0. However, the timeline acute/chronic (0.85), timeline cyclical/episodic (0.74) and treatment control (0.65) variables had a score below 1, indicating more symmetrical distributions. A kurtosis statistic of 0 indicates that the distribution of data fits the normal distribution in terms of steepness, whereby positive scores indicate a steeper gradient distribution and negative scores represent flatter gradient distribution. Again, results show that none of the illness perception discrepancy variables fit the distribution perfectly, although the timeline acute/chronic (0.48), timeline cyclical/episodic (-0.22), treatment control (-0.12) and illness coherence (0.55) variables had a score below 1, indicating a better fit to the normal distribution. The cause illness perception variable was not included in the calculations as the data is nominal and does not represent a frequency distribution.

To examine the extent to which the illness perception discrepancy domains were significant from the normal distribution, a one-sample Kolmogorov-Smirnov test was used to measure the goodness-of-fit. The Z score represents the probability that the observed distribution (illness perception discrepancy domains) are significantly deviant from the normal distribution. Concluding that the observed distribution may be drawn from the normal distribution requires that the Z score is not significant using a two-tailed test of significance whereby $p<0.01$. As the results in table 4 on the previous page show, all eight illness perception discrepancy scores are non-significant, which indicates that the observed distribution may be drawn from the normal distribution. This result highlighted that parametric statistical analyses would be required to investigate further relationships between variables.

Inferential statistics

The Pearson correlation coefficient was used to assess the degree of association between illness perception discrepancy scores, EE and psychological adjustment. Partial correlation was also calculated to assess the relationship between variables whilst controlling for the effect of impaired self-awareness (PCRS discrepancy scores was the selected control variable). Please see table 5 and 6 on the next pages and appendix 25 and 26 for data output.

Illness perception discrepancy domain	**Anxiety correlations** *(r)*	**Anxiety partial correlations**	**Depression correlations** *(r)*	**Depression partial correlations**
Identity	0.20 (sig. 0.17)	0.18 (sig. 0.21)	0.25 (sig. 0.08)	0.26 (sig. 0.07)
Timeline Acute/Chronic	0.11 (sig. 0.44)	0.07 (sig. 0.62)	0.10 (sig. 0.50)	0.12 (sig. 0.41)
Timeline Cyclical/Episodic	0.05 (sig. 0.75)	0.07 (sig. 0.63)	-0.16 (sig. 0.28)	-0.17 (sig. 0.25)
Consequence	0.05 (sig. 0.75)	0.05 (sig. 0.75)	-0.26 (sig. 0.07)	-0.26 (sig. 0.07)
Personal Control	-0.04 (sig. 0.79)	-0.06 (sig. 0.70)	-0.06 (sig. 0.68)	-0.05 (sig. 0.71)
Treatment Control	0.16 (sig. 0.26)	0.15 (sig. 0.31)	0.03 (sig. 0.84)	0.04 (sig. 0.81)
Illness Coherence	0.25 (sig. 0.08)	0.24 (sig. 0.09)	0.17 (sig. 0.25)	0.17 (sig. 0.24)
Emotional Representations	-0.11 (sig. 0.46)	-0.11 (sig. 0.45)	-0.16 (sig. 0.26)	-0.16 (sig. 0.27)
Cause	0.30 (sig. 0.03)	0.29 (sig. 0.04)	0.18 (sig. 0.20)	0.19 (sig. 0.18)

Table 5. Pearson correlations and partial correlations (with PCRS discrepancies as the control variable) between illness perception discrepancy scores, anxiety and depression (all data to 2 decimal places, two-tailed significance).

Table 5 above shows very weak correlations between illness perception discrepancy domains and stroke survivors' psychological adjustment (anxiety and depression). Results are also not statistically significant at the probability level $p<0.01$. When the effects of possible impaired self-awareness are controlled using partial correlation, this has very little influence on correlations, as relationships between variables remain weak and results are not statistically significant.

Illness perception discrepancy domain	**EE correlations** *(r)*	**EE partial correlations**
Identity	0.05 (sig. 0.78)	0.04 (sig. 0.82)
Timeline Acute/Chronic	0.18 (sig. 0.27)	0.16 (sig. 0.31)
Timeline Cyclical/Episodic	-0.17 (sig. 0.29)	-0.16 (sig. 0.32)
Consequence	-0.18 (sig. 0.26)	-0.18 (sig. 0.27)
Personal Control	-0.01 (sig. 0.97)	-0.02 (sig. 0.92)
Treatment Control	0.09 (sig. 0.56)	0.08 (sig. 0.61)
Illness Coherence	0.18 (sig. 0.26)	0.18 (sig. 0.25)
Emotional Representations	-0.33 (sig. 0.04)	-0.32 (sig. 0.04)
Cause	0.27 (sig. 0.09)	0.26 (sig. 0.10)

Table 6. Pearson correlations and partial correlations (with PCRS discrepancies as the control variable) between illness perception discrepancy scores and EE (all data to 2 decimal places, two-tailed significance).

Similarly to the results displayed in table 5, table 6 also shows weak correlations between illness perception discrepancy domains and partners EE ratings. Results are not statistically significant at the 0.01 probability level and when the effects of possible impaired self-awareness on illness perception scores are controlled, this has very little influence on correlations, with relationships remaining unchanged or differing very slightly. Nevertheless, despite the results presented, examination of the SPSS correlation matrices, as show in appendix 25, highlight moderate correlations between anxiety and depression ($r = 0.55$, n=51, $p<0.01$) and anxiety and EE ($r = 0.40$, n= 42, $p<0.01$). It would be expected that anxiety and depression might correlate given that they both assess constructs of psychological adjustment. However, the association between stroke survivors' anxiety levels and partners' EE was unexpected.

Discussion

This study aimed to explore whether there were discrepancies in illness perceptions between stroke survivors and their partners and if a relationship existed between illness discrepancies, partners’ EE and stroke survivors’ psychological adjustment. The data presented highlights that discrepancies are present across all nine domains of illness perception. However, the association between the nine domains, EE and psychological adjustment is weak and results were not statistically significant. Though the findings do not necessarily imply that there is no clinical importance between the variables examined, there is currently insufficient evidence available to be able to draw conclusions about the ways stroke survivors and their partners make sense of stroke and the impact this has on partners’ critical or emotionally involved attitudes or stroke survivors’ levels of anxiety and depression.

A moderate positive correlation was found between stroke survivors’ anxiety and partners’ EE ($r = 0.40$, $n = 42$, $p<0.01$). Though links between EE and psychological adjustment were not initially the focus of the investigation, this result may provide some important information. It would be possible to hypothesise that stroke survivors living in a family environment with a high EE partner, who may express critical attitudes and controlling behaviours, are more anxious than survivors living with a low EE partner. Further research in this area would be warranted to confirm this hypothesis however. Couples research involving a stroke surviving partner has received very little research attention compared to other neurological conditions such as dementia or TBI. There are a number of possible reasons for this, which will be explained in the following discussion along with a critique of the strengths and limitations of the present study. Possible avenues for future investigation will also be highlighted.

Assessing self-awareness after stroke

Reduced self-awareness is objectively defined as occurring when patients' ratings of their difficulties are higher than clinical staff and/or relatives ratings as well as formal neuropsychological test results [53, 54, 55]. None of the stroke survivors who participated in the study had clinician rated measures of awareness or available neuropsychological information in their records. Collecting such information would have proved costly and time-consuming, especially given the availability of questionnaire resources. However, the PCRS is not specifically a measure of self-awareness, as Leathem et al. 1998 [55] suggest it should only be used as a 'guide to patients' awareness of their difficulties' (pg. 694). Also, though the PCRS has been used extensively with groups with moderate and severe TBI, little is known about those with mild or acquired brain injury (ABI), including stroke. To the authors' knowledge, there is currently only one study that has evaluated the psychometric properties of the PCRS in stroke [56]. In future studies, the PCRS may be replaced with a self and informant questionnaire which has been used in ABI and stroke populations. The Awareness Questionnaire (AQ) [57] and the Dysexecutive Questionnaire (DEX) [58] are such examples.

Despite the potential to select other measure of awareness in a follow-up investigation, according to Allen and Rough [59] self and informant questionnaires used to assess awareness should be included with caution. The authors claim that control groups may not respond with any more accuracy than clinical groups and suggest that informants disclosures of their partners pre and post-brain injury functioning may be vague or inaccurate. Their responses may too be influenced by reduced awareness, which may serve a psychological function of denial or minimisation of the disability to protect against the impact of reality and loss of pre-injury status [59]. Patients and partners responses may also be influenced by low mood, fatigue and increased stress levels, which are commonly observed in patients and their partners coping with brain injury [60]. Decreased awareness is also associated with the length of time post-injury, as patients and their partners may have very unrealistic expectation soon after injury, which Brooks and McKinlay [61] suggests acts as a ‘protective buffer’ from having to accept the likelihood of long-term physical and psychological changes in the patient. Finally, it may be questioned why attempts to measure awareness are even pursued at all. It could be argued that in assessing awareness, underlying assumptions exist that survivors of brain injury have distorted perceptions are unable to provide reliable accounts of their experiences pre and post injury [62, 63, 64]. Perhaps rather than rating patients awareness on a scale and comparing scores with an informant, what is important is to accept peoples’ personal appraisals of their difficulties and acknowledge that the extent to which such challenging are perceived are unique to each person. As Tyerman and Humphrey state [65] ‘it is the subjective impairment which represents distressing reality for these patients’ (pg. 14).

Assessing Expressed Emotion

Inclusion of the FMSS as a measure of EE also raises a number of points for discussion. Though the FMSS has been validated against the CFI, Hooley and Parker [51] examined the data and noticed that approximately 20 percent of participants rated as low EE with the FMSS were classified as high EE using the CFI. The authors concluded that high EE family members can be under-identified by the FMSS. The FMSS administration and scoring manual specifically instructs researchers to be conservative when rating and if in any doubt to refrain from issuing ratings that would lead to a high

EE criteria. Magna et al. [52] advise administering the CFI to one-third of the low EE group in order to be accurate that the correct ratings are being assigned. However, as this procedure was not carried out in the present study, it would be likely to assume that a percentage of low EE participants should actually be in the high EE group.

Classifying participants into either high or low EE groups can be problematic for other reasons. Firstly, it may give the impression that those in low EE families are experiencing few difficulties and coping well with the effects of the stroke, when this may not necessarily be the case. Secondly, dichotomising EE as opposed to exploring the individual variables that constitute the rating, prevents distinction between participants who are 'critical', 'EOI' or both 'critical and EOI', which may be inherently different particularly when examined from an attributional perspective [66, 67]. The central hypothesis of Hooleys attribution model of EE [66, 68] is that critical relatives have underlying beliefs that patients could do more to control their illness. All published investigations to date have confirmed this hypothesis (see Barrowclough and Hooley 2003 for a review [18]) demonstrating high EE critical relatives consistently attribute patients problems to be controllable, stable and internal (the event was caused because of the patient), compared to EOI and low EE relatives. According to Hooley [66] and Barrowclough et al. [69], relatives high in EOI rarely blame patients for their behaviour instead viewing them as a victim to factors out of their control. Research has even shown no differences between high EOI relatives and low EE relatives with regard to their attributions about control [69, 70, 71].

The FMSS administration and coding manual states that if the respondent cries or is unable to speak due to emotional sentiment they are given an 'emotional display' rating, which instantly creates an EOI high EE profile. However, in the present study, even participants who spent time during the interview talking about their partners' qualities or identifying positive characteristics would still receive a high EE rating if they showed emotion, which seems incongruent. Research shows that having a high EOI may sometimes be associated with better outcomes [18], perhaps because EOI behaviour (intrusive and controlling) might actually induce patients to behave in ways more beneficial to their condition. Hooley [72] has questioned whether EOI may be more common in women and this hypothesis appears to fit with data from the present study. 65 percent of the total sample of partners were women and of the 64 percent of high EE people who rated as EOI, 55 percent were female, compared to only 0.9 per cent of males. Therefore the imbalance between male and female partners may account for the high number of EOI ratings rather than other factors such as illness perception discrepancies.

Open-ended and unstructured interviews such as the FMSS allow respondents to give their spontaneous views and opinions about their relationship with their partner. However, the extent to which participants are open in their responses is questionable. Social desirability bias or responding in a way that is deemed to be socially acceptable by others, which may be conscious or unconscious [73], will certainly affect the reliability of FMSS ratings. Similarly, those participants who aim to show the researcher how bad things are may over-exaggerate their views. Crowne and Marlowe and other psychoanalytically oriented researchers argue that many important feeling and experiences are unconscious and protected by defence mechanisms, such as repression or denial. In the present study 42 participants out of 51 completed the FMSS (82% completion rate), with nine people not wanting to do this part of the research. It is possible that they did not want to disclose information they felt was private or deemed the FMSS to be too intrusive, which may support the view that important feelings are protected by defence mechanisms. Obtaining reasons for people's decision not to complete the FMSS may have provided an important insight into partners underlying thoughts. However, of those who completed the FMSS, it may be questioned whether the attitudes expressed were truly reflective of the real life interactions with their partners. Hahlweg et al. [74], Hooley [75] and Miklowitz et al. [76] explored this by videotaping patients and their family members during a face to face interaction and using independent raters to code observed behaviours. Findings show that some participants rated as low EE were more critical during face-to-face interactions, prompting questions about the reliability of EE measures.

A major conceptual problem that has dominated the EE research literature for over 50 years is what the FMSS and other assessments of EE actually measure. For example, how much does an EE rating tell the researcher about the relative, the patient or the family system more broadly? The early models of EE [21] conceptualised the construct in terms of relatives' traits. Low EE relatives were described as tolerant, nonintrusive and sensitive and high EE relatives were described as intolerant, intrusive and insensitive. However, this is a simplistic model and ignores the influence of the patients' attitudes and behaviours and the reciprocity of interactions between couples. Another issue that has caused considerable debate is the direction of causality and whether an increase in problematic symptoms or behaviour on the part of the patient causes the relative to become stressed and subsequently express critical or over-involved attitudes. Alternatively, whether high EE attitudes on the part of the relative causes the patient to become stressed which contributes to their problematic symptoms or behaviour. These questions have been the focus of debate for many years, yet despite extensive research to elucidate what the construct of EE actually is, findings appear contradictory or inconclusive. On the one hand, important questions about EE remain unanswered, yet on the other hand, research consistently highlights the links between EE and the relapse process, a finding should not be overlooked.

EE research has been a catalyst for the development of family based interventions, which have been successful in reducing high EE behaviour and relapse rates [77, 78] At the core of intervention is psychoeducation, which involves providing clear information to the patient and their family about the onset of the illness, its expected course and symptoms as well as the challenges that may be faced by the whole family and how these may be overcome. By offering families early information and support, it is hoped that the negative attributions that can lead to high EE attitudes and behaviours are prevented or minimised. The skills needed to cope with a family member's illness is not necessarily intuitive and over time, family members' confusion or frustration to help the person may easily evolve into critical comments and controlling behaviours. Even trained health professionals can develop high-EE attitudes as research by Moore et al. [79] has shown a link between high EE professionals and relapse rates in in-patient settings.

Further EE research with stroke survivors and their families is necessary in the future. The vast majority of EE studies are based on groups with psychopathology (e.g. schizophrenia, bi-polar, anorexia) whereby patients may have had period of hospitalisation and subsequent relapse whilst living at home, yet it is likely that they will eventually enter a period of symptomatic improvement or recovery. This is not the case for stroke survivors, who can adjust to the changes but may never fully recover and their symptoms may remain stable throughout their lifetime. There are not yet enough research findings to enable firm conclusions to be drawn about the predictive power of EE in various health conditions, such as stroke, though there is a clinical need to identify survivors who may struggle to adapt to the effects of the stroke in their home environment. Future research may consider including stroke survivors and their partners or families as well as using longitudinal methodologies or test-re-test designs in order to assess stability or changes in EE over time.

Assessing illness perceptions

Inclusion of the IPQ-R as a measure of illness perceptions was done so because of its close links to the SRM [28], upon which the nine illness perception domains explored in this study were based. However, the IPQ-R is validated against only eight illness groups and brain injury was not included any of the psychometric analyses. Although one published study has used the IPQ-R in non-acute stroke research, it was the illness perceptions of carers that formed the focus of the investigation [37]. To the authors' knowledge, published research on the use of the IPQ-R with stroke survivors themselves does not exist, which warrants the question why? Considering the extensive use of the IPQ-R in many other health groups and the dramatic increase in illness perception research since the introduction of the IPQ in 1996 [80], it seems puzzling why investigation with those who have suffered a brain injury and their family has been overlooked. Other health threats which have received significant research attention, such as asthma [81, 82] psoriasis [83, 84, 85], chronic pain [86, 87] and diabetes [88, 89, 90, 91], are problems that tend to affect a specified area of the body and the occurrence of physical symptoms may follow predictable patterns that can be anticipated and managed. The onset of stroke on the other hand is sudden, unexpected and can cause widespread damage, affecting physical and cognitive ability, psychological and behavioural well-being as well as changes to the persons' social network, their personality and views of the self and the world [92]. The various physical, cognitive and emotional difficulties caused by stroke are highly interlinked and cannot be pin-pointed to a specific site of lesion location. No two survivors will experience the effects of the stroke; it is a complex brain injury that is unique to each individual survivor. It is possible that the multi-faceted nature of stroke has deterred researchers from exploring illness perception work, which may explain the absence of literature in this area.

Considering the points raised above it may also be questioned how applicable the IPQ-R is to health threats such as stroke, which is not specifically an 'illness'. For example, some of the 'cure-control' questions ask participants to respond to treatment questions such as item 20, "my treatment will effective in curing the effects of the stroke". Yet unlike asthma, psoriasis, chronic pain and diabetes, in which treatment typically consists of medication to minimise the effects of physical symptoms, stroke treatment is less well defined. According to the 2007 National Stroke Strategy [93], a guidance document for health services, stroke management (rather than treatment) involves preventative action to reduce the risk of a further stroke, health monitoring, symptom control and the promotion of well-being. It may have been beneficial to modify the IPQ-R by replacing the word 'treatment' with 'management' in the 'cure-control' section so that the questions can be more relevant to those responding. Secondly, in the 'cause' section, the following risk factors for stroke could have been included to make the options more applicable to stroke, these include; high blood pressure, high cholesterol, prior stroke or TIA, diabetes, carotid or artery disease and heart disease.

Finally, though the IPQ-R is directly based on Leventhal et al's [28] theoretical model and covers the nine stages of illness perception as highlighted in the SRM, the measure is rather lengthy at 73-items. During data collection is became apparent that survivors found the questionnaire over-facing. Some people lost concentration or interest towards the end of the questionnaire and were observed either leaving questions out or selecting the middle option "neither agree nor disagree" perhaps for ease and speed of completion. Others were observed becoming slightly distressed when reading the statements, perhaps because this was the first time they have had to think about the extent of their difficulties combined with the realisation that their stroke would affect them for the rest of their lives. In a follow-up investigation it may be very worthwhile to use the Brief Illness Perception Questionnaire (Brief IPQ) [94], which contains only nine-items. The psychometric properties of the measure show good test-retest reliability and concurrent validity when compared against the full IPQ-R. However, data has been obtained from participants within six specific illness groups and as with the IPQ-R, those who have suffered a brain injury were not included in the analyses. There is also an absence of research into the use of the Brief IPQ with brain injury populations in the illness perception literature. Nevertheless, despite these issues, using the Brief IPQ in the present study would have halved the data collection process time considerably, to the benefit of the authors and possibly those who participated in the research.

Scoring the Brief IPQ would take approximately 5 minutes for each dyad compared to the 30 minutes it took to score a dyad using the IPQ-R in the present study. On top of this, discrepancy scores for each of the nine separate domains of illness perceptions had to be calculated, rather than an overall discrepancy score out of nine if the Brief IPQ had been used. The study of discrepancies in illness perceptions is a relatively new area of research with only four published studies exploring this area to date [30, 31, 32, 83]. Each of these studies used the full IPQ and calculated straightforward difference scores by subtracting the partners score from the patients score or vice versa. Difference scores have been criticised for their low reliability [95], though this critique concerns discrepancies between two scores obtained from one participant in pre- and pro-test designs. Nevertheless, an alternative method of calculating discrepancy would be to classify scores into three groups: The number of items where the patient rating is higher than the partner rating, the number of items in which the patient and partners ratings are equal and the number of items in which the patients rating is lower than the partners rating. According to Prigatano and Altman, 1990 [39], patients scores may then be classified into three groups on the basis of which score is highest. However, this method produces larger quantities of data and can overlook the actual magnitude of difference between ratings on individual IPQ-R items.

In the present study, discrepancy ratings were based on survivor and partner scores for each of the nine domains of illness perceptions (identity, timeline acute/chronic, consequences, personal control, treatment control, illness coherence, timeline cyclical/episodic, emotional representations and cause). Each domain was calculated separately to further explore the individual components that form peoples' representations of stroke. Four of the domains (timeline acute/chronic, consequences, personal control, emotional representations) have six items on the IPQ-R, two of the domains (treatment control, illness coherence) have five items on the IPQ-R and one domain (timeline cyclical/episodic) has only four items on the IPQ-R. Not only do the domains have relatively few items, thus reducing the overall discrepancy between survivors and partners, but the timeline and control domains in particular have a different number of items, making direct comparisons between these domains inaccurate. To highlight, participants 1a and 1b have a discrepancy score of 6 for the timeline acute/chronic domain and a discrepancy score of 3 for the timeline cyclical domain. When there are more questions on the IPQ-R for the timeline acute/chronic domain it is to be expected that these discrepancy scores will be higher but do not necessarily imply more difference in opinion between survivors and partners.

Previous studies exploring discrepancies in illness perceptions [30, 31, 32], though conducted after the development of the IPQ-R have used the original IPQ measure, which has only five domains. Though inclusion of all nine illness perception domains in the present study produced large quantities of data, this was the first discrepancy study to use the revised IPQ which includes the added subscales as recommended by research into inconsistencies in studies using the IPQ [42]. According to Moss-Morris et al. [42], the original measure overlooked the differentiation between the control variables (personal and treatment control) as well as the timeline variables (acute/chronic and cyclical timeline). The original IPQ also ignored important components of Leventhal et al's [28] SRM, namely participants responses to illness, prompting the inclusion of the emotional representations domain in the IPQ-R and participants understanding of the illness, prompting the inclusion of the illness coherence domain in the IPQ-R. These findings demonstrate that the present study, in using the IPQ-R, may be considered more theoretically based than those studies including the original IPQ measure.

Two previous discrepancy studies [31, 32] have excluded the cause domain from analyses, perhaps because of the ambiguity in how the information obtained from participants can be calculated into discrepancy scores. The cause domain was included in the present study due to the potential value of exploring participants' perceptions of the cause of stroke, particularly given the nature of the sudden onset of stroke. To calculate discrepancy, survivor and partners verbatim responses to the question "list the most important factor that you believe caused your/ your partners stroke" were compared. Those couples who wrote identical or very similar responses, e.g. responses mentioned the words 'diet' or 'eating fatty foods', they would be assigned a score of 0 to represent 'no discrepancy'. Those couples who responded with different ideas about cause were assigned a score of 1 to represent a discrepancy in their perceptions. On the one hand the aim of this method was to provide a snapshot of couples cause perceptions, yet on the other hand, the IPQ-R scoring criteria (appendix 21) recommends that cause items should not be scored as a scale and the extent to which this method provides reliable data that can be generalised from remains to be answered. Also, other methods of scoring the cause dimension may have provided more accuracy, such as using factor analysis to reveal beliefs about biological causes (immune dysfunction), psychological causes (stress) and environmental cause (pollution in the environment) [30].

Areas for future illness perception research

According to Heijmans et al. (1999) [30] spousal illness perceptions may not only be moderated by factors such as the characteristics of the health problem itself (symptoms, cause, treatability) but also the quality of the marital relationship. This variable was not explored in the present study but could potentially have been a confound to the associations between illness perceptions, psychological adjustment and EE. Future investigations may wish to replicate the present study but replace the PCRS for a standardised measures such as the Personal Assessment of Intimacy in Relationships (PAIR) [96] or Dyadic Adjustment Scale (DAS) [97] for couples in a relationship or the Golombok and Rust Inventory of Marital State measure (GRIMS) [98] for those couples who are married. One of the inclusion criteria for the present study was that couples were in a long-term relationship (a minimum of a year prior to the onset of the stroke) and included those both those in a marital relationship and those cohabiting. All dyads in the present study were heterosexual and though homosexual couples were invited to take part none volunteered. Future studies may aim to include more same sex couples in the research. Secondly, as with the exploration of EE in couples, longitudinal or test-retest designs would be an important area for future research. Leventhal et al. [28] states that illness perceptions are highly transient and operate on a “moment-by-moment basis” (pg. 219). As people’s illness models are constantly evolving it is highly likely that survivor and partner illness perceptions change considerably. To study the process of mutual influence between couples over time would certainly present a more accurate view of the way people make sense of and deal with stroke.

Illness perceptions based on illness information

According to Leventhal et al. [28], there are three sources of information that people use for the formation and elaboration of illness perceptions: Cultural illness information, personal illness experience and social communication about illness. Social communication about a health threat between a patient and their close friends and family is crucial in the development of illness perceptions. Research has shown that a persons’ social network does not only influence the beliefs and perceptions held by patients, but also their behaviours and the course of the illness itself [27, 99, 100]. This may explain why vast illness perception discrepancies between survivors and partners were not observed in the present study because patients and partners alike can be influenced in the way they view the health threat by those in their social network. Social communication with health professionals is also very important. The language medical and care staff use around the patient and their family may cause initial distress, worry and the development of health beliefs that are inaccurate. Health related behaviour clearly depends on peoples understanding of the information they hear or are provided with. However, as Weinman and Petrie [100] point out, ‘patient models of their illness are, by their nature, private’ and that during consultations with health professionals, patients are reluctant to discuss their beliefs about their illness because they fear conflict or risk appearing confused. Perhaps the Brief IPQ measure could be used by health professionals in the future to further understand the way patients and significant family members make sense of the problem and to provide information that may help them to understand the problem. As Lezak observed, families cope more effectively with a relative’s behaviour when they have knowledge about the nature of changes associated with brain injury [67]. Such knowledge and improved coping may in-turn may reduce levels of EE within a family and create a supportive environment in which stroke survivors may begin to adjust to the effects of the brain injury.

The finding that in the absence of professional knowledge, people with ABI and their families draw upon idiosyncratic sources of meaning to assist in their sense-making [84], highlights the importance of providing families with early information and psychoeducation interventions, delivered by trained health care professionals. As with any sudden and severe illness, stroke can have major psychological impact on the individual affected and their wider family and guidelines published by the British Psychological Society (2002) recommend that Clinical Psychologists play a pivotal role in supporting stroke survivors and their families at each stages of stroke care, from immediate care to longer-term assistance. However, as this research demonstrates, providing early information about the stroke and the other nine illness perception domains may be vital to helping patients, partners, families and other health professionals involved develop a more unified view of the problem and a shared understanding of how promote physical and psychological well-being for the whole family.

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Part Three: Appendixes

Appendix 1. Instructions for authors submitting to Brain Injury

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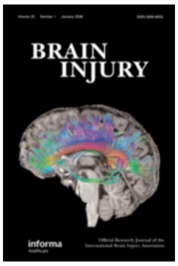

Title: Brain Injury
ISSN: 1362-301X (electronic) 0269-9052 (paper)
Publication Frequency: 14 issues per year
Subjects: Neurological Rehabilitation; Neuroscience; Rehabilitation Medicine; Stroke;
Publisher: Informa Healthcare

Instructions for Authors

General Guidelines

This journal covers all aspects of brain injury from basic science, neurological techniques and outcomes to vocational aspects, with studies of rehabilitation and outcome of both patients and their families. It addresses both adult and paediatric issues and it embraces issues such as family and peer relationships, effects of alcohol and drugs, communication problems and management techniques and creating new programmes. ***Brain Injury*** uses case studies to illustrate different approaches to a subject, and provides a forum for the appraisal of theories which may influence future research. ***Brain Injury*** is the official research journal of the *International Brain Injury Association*.

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All submissions should be made online at ***Brain Injury's*** Manuscript Central site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

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Brain Injury considers all manuscripts on the strict condition that they have been submitted only to ***Brain Injury***, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which ***Brain Injury*** incurs, and their papers will not be published.

- Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence.
- In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.
- For all manuscripts, gender-, race-, and creed-inclusive language is mandatory.
- Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).
- *Ethics of Experimentation*: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.
- Abstracts are required for all papers submitted, they should not exceed 200 words and should precede the text of a paper; see 'Abstracts'.
- Accepted manuscripts in their final, revised versions, should also be submitted as electronic word processing files on disk; see 'Electronic Processing'.
- Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

Electronic Processing

We welcome figures sent electronically, but care and attention to these guidelines are essential as importing graphics packages can often be problematic.

- Figures must be saved individually and separate to text. Please do not embed figures in the paper file.
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- Figures should be produced as near to the finished size as possible.
- All figures must be numbered in the order in which they appear in the paper (e.g. figure 1, figure 2). In multi-part figures, each part should be labelled (e.g. figure 1(a), figure 1(b)).
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- The filename for the graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).

Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

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Structured abstracts are required for all papers, and should be submitted as detailed below, following the title and author's name and address, preceding the main text.

For papers reporting original research, state the **primary objective** and any hypothesis tested; describe the **research design** and your reasons for adopting that methodology; state the **methods and procedures** employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central **experimental interventions**; state the **main outcomes and results**, including relevant data; and state the **conclusions** that might be drawn from these data and results, including their implications for further research or application/practice.

For review essays, state the **primary objective** of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the **main outcomes and results** of your review; and state the **conclusions** that might be drawn, including their implications for further research or application/practice.

The abstract should not exceed 200 words.

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When reporting studies on unanaesthetized animals or on humans, indicate that the procedures followed were in accordance with institutional guidelines.

Specific permission for facial photographs of patients is required. A letter of consent must accompany the photographs of patients in which a possibility of identification exists. It is not sufficient to cover the eyes to mask identity.

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Special care should be taken with mathematical scripts, especially subscripts and superscripts and differentiation between the letter 'ell' and the figure one, and the letter 'oh 'and the figure zero. If your keyboard does not have the characters you need, it is preferable to use longhand, in which case it is important to differentiate between capital and small letters, K, k and x and other similar groups of letters. Special symbols should be highlighted in the text and explained in the margin. In some cases it is helpful to supply annotated lists of symbols for the guidance of the sub-editor and the typesetter, and/or a 'Nomenclature' section preceding the 'Introduction'.

For simple fractions in the text, the solidus / should be used instead of a horizontal line, care being taken to insert parentheses where necessary to avoid ambiguity, for example, I /(n-1). Exceptions are the proper fractions available as single type on a keyboard.

Full formulae or equations should be displayed, that is, written on a separate line. Horizontal lines are preferable to solidi, for example:

$\underline{6}1+ 5h +q$

$3n + 3yz^2$

But: $\underline{a/b + c/d + a/d}$

$P = (a^2 + b^2)(c^2 + d^2)$

The solidus is not generally used for units: ms - 1 not m/s, but note electrons/s, counts/channel, etc.

Displayed equations referred to in the text should be numbered serially (1, 2, etc.) on the right hand side of the page. Short expressions not referred to by any number will usually be incorporated in the text.

Symbols should not be underlined to indicate fonts except for tensors, vectors and matrices, which are indicated with a wavy line in the manuscript (not with a straight arrow or arrow above) and rendered in heavy type in print: upright sans serif **r** (tensor), sloping serif ***r*** (vector) upright serif **r** (matrix).

Typographical requirements must be clearly indicated at their first occurrence, e.g. Greek, Roman, script, sans serif, bold, italic. Authors will be charged for corrections at proof stage resulting from a failure to do so.

Braces, brackets and parentheses are used in the order {[( )]}, except where mathematical convention dictates otherwise (i.e. square brackets for commutators and anticommutators)

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All authors are asked to take account of the diverse audience of ***Brain Injury*** . Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience. However, note also that ***Brain Injury*** does not aspire to be international in the ways that McDonald's restaurants or Hilton Hotels are 'international'; we much prefer papers that, where appropriate, reflect the particularities of each higher education system.

Some specific points of style for the text of original papers, reviews, and case studies follow:

1. ***Brain Injury*** prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
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3. Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.
4. Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
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8. Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.
9. All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
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Notes on tables and figures

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0.

1. Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).
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Insert table 2 about here

3. Each table and/or figure must have a title that explains its purpose without reference to the text.
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Thus tables and figures must be referred to in the text and numbered in order of appearance. Each table should have a descriptive title and each column an appropriate heading.

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References should be cited using the numerical system (e.g. [3], [5-9]). They should be listed separately at the end of the paper in the order in which they appear in the text. 'Ibid.' (and the like) are not used when repeating citations.

Acknowledgements

Any acknowledgements authors wish to make should be included in a separate headed section at the end of the manuscript.

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1. The following header material should appear in all reviews in the following order (note also the punctuation):

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Edited by Fred M. Newmann (Teachers College Press, New York, 1992), 240 pp., $38.00 (hbk), ISBN 8077-3183-8, $17.95 (pbk), ISBN 8077-3182-X.

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Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. Science 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. The pharmacological basis of therapeutics. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] Loker WM. "Campesinos" and the crisis of modernization in Latin America. Jour of Pol Ecol [serial online] 1996; 3(1). Available: http://www.library.arizona.edu/ej/jpe/volume_3/ascii-lokeriso.txt via the INTERNET. Accessed 1996 Aug 11.

Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: http://bmj.bmjjournals.com/

Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: http://www.cdcnpin.org/db/public/dnmain.htm

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Appendix 2. Quality Checklist

The checklist below is a revised version of the criteria developed by NICE (2009).

Title of study:
Author:
Reviewer:

Questions	Yes (1)	No (0)
Criteria 1: Aims of the study 1a) Are the aims, objectives, hypotheses or research questions to be addressed in the study clearly described?		
1b) Does the study provide an explanation, justification or rationale for the area of investigation?		
Criteria 2: Study design 2a) Is the chosen design and methodology appropriate to address the stated aims, objectives, hypotheses or research questions?		
2b) Are the main outcomes to be measured clearly described in the introduction or method sections?		
Criteria 3: Participants/ samples 3a) Are the characteristics of participants or samples included in the study clearly described?		
3b) Is the recruitment or sampling strategy appropriate to the aims, objectives, hypotheses or research questions to be addressed?		
Criteria 4: Data collection 4a) Are data collection methods clearly described?		
4b) Is the collected data appropriate to address the aims, objectives, hypotheses or research questions?		
Criteria 5: Data analysis 5a) Are the analysis or statistical techniques used appropriate to the data?		
5b) Does the study describe attempts made to assess the validity and reliability of the data analysis?		
Criteria 6: Findings 6a) Does the study provide a clear and coherent statement of findings?		
6b) Are the findings relevant to the aims, objectives, hypotheses or research questions of the study?		
Criteria 7: Conclusions/ implications 7a) Are the conclusions drawn adequate enough to provide a clear link between the data and interpretation of results?		
7b) Are the implications and clinical relevance of the study clearly reported?		
Criteria 8: Discussion 8a) Is there adequate discussion of limitations of the study?		
8b) Are possible areas for future investigations explored?		

Appendix 3. Quality Ratings

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Appendix 3. Quality Ratings

Appendix 4. Ethical approval confirmation letter

(Removed for hard binding)

Appendix 5. Research and Development approval confirmation letter

(Removed for hard binding)

Appendix 6. Honorary Contract with Hull and East Yorkshire Hospitals NHS

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Appendix 7. Cover Letter for Stroke Survivors and their Partners

Miss R. C. Avison
Trainee Clinical Psychologist
Department of Clinical Psychology
The University of Hull
HU6 7RX

R.Avison@psy.hull.ac.uk

Dear......................and......................

I am a 6th Year Trainee Clinical Psychologist at the University of Hull and am currently carrying out a research study with the Community Stroke Team at Westwood Hospital, Beverley.

The research investigates people's thoughts about the causes and effects of stroke among stroke survivors and their partners. I am writing to invite you to take part in the study as you have been selected as suitable participants by your Community Stroke Nurse.

Please note that taking part is entirely voluntary so you do not have to take part if you do not want to. This would by no means affect any care you might receive from the Community Stroke Team.

I have enclosed two Participant Information Sheets, which provide answers to any questions you may have about the research. You would also be welcome to contact me or the Community Stroke Team if you have further queries about any aspect of the study.

I will contact you by telephone in about a week from now to see if you have had chance to read through the information and have a think about whether you would like to take part.

In the mean time, thank you very much for taking the time to read this letter and the enclosed information.

Yours sincerely

Rachel Avison

Participant Information Sheet for Stroke Survivors

‘Perceptions of the causes and effects of stroke among stroke survivors and their partners’

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish or ask us if there is anything that is not clear or if you would like more information. Thank you for taking the time to read the information.

What is the purpose of this study?

The onset of stroke can lead to a number of problems, which vary from person to person. According to psychological theory, following an experience such as stroke, people think about their problems in their own unique way and form a personal ‘illness perception’, which can influence how they feel and what they do. Research has shown that there can be differences between a patient’s perception and their partner’s perception, yet no study has ever investigated the differences in illness perceptions between stroke survivors and their partners. This research projects aims to find out whether differences in couples illness perceptions relate to stroke survivors’ levels of anxiety and depression and partners’ thoughts and feelings towards the survivor. We hope that this investigation will help us to better understand the ways in which people think about stroke and the effect this can have on how they feel and what they do, as well as contributing to the development of services for stroke survivors and their families.

Why have I been invited?

We are inviting people in the Hull and East Yorkshire area who have suffered a stroke along with their spouse/partner. You have been invited to take part as you have been selected as a suitable participant by your Community Stroke Nurse as you have experienced a stroke and live at home with your spouse/partner who provides care and support. We are inviting approximately 50 stroke survivors and 50 spouses/partners to take part in this study.

Do I have to take part?

Taking part in the research is entirely voluntary so it is up to you to decide. You do not have to take part if you do not want to and you would be free to withdraw at any time without giving a reason, this would by no means affect the care you or your partner receives from the Community Stroke Team.

What will happen if I decide to take part?

The primary researcher, Rachel Avison, will contact you in approximately seven days time to see if you would like to take part. If after reading this information sheet you decide that you would like to take part in the study, a time and place convenient to you can be arranged to meet (e.g. at your home, or at Westwood Hospital or The Department of Clinical Psychology at Hull University). As the sessions are confidential, we ask that partners, friends or other family members are not in the same room when you are taking part in the study.

The study will require 45 minutes of your time, during which you will be asked to do three different things:

1) Fill in a questionnaire that asks you to judge your ability at doing a variety of tasks.
2) Fill in a questionnaire which asks you questions about your symptoms, experiences since having the stroke and your thoughts about possible causes of the stroke.
3) Fill in a questionnaire which asks you to rate how you have been feeling in the past week.

The primary researcher will meet with you and your partner at separate times but please note that this study requires information from both stroke survivors *and* their partners, therefore both you and your partner would have to agree to take part otherwise no information can be collected. Should either you or your partner decide to withdraw from the study, this would mean that both of you would no longer be required to continue and any information provided by you or your partner would not be included in the research.

Are there any possible risks or disadvantages of taking part?

No. There are no perceived risks to this study. It is not unusual for some people to feel a bit lower in mood after completing the questionnaires and talking about any difficulties that have been experienced. However, at the end of the study there will be time available to talk about anything that may have been difficult for you during the study and if after this time it is felt that you are experiencing lower mood or a previously unrecognised level of distress then the primary researcher will discuss this with you and decide with you who else involved in your care should also know this information. Should the primary researcher have any concerns about the information you or your partner provide or other issues, then these concerns will be raised with you and passed on to the Community Stroke Team.

What are the possible benefits of taking part?

We cannot guarantee that taking part in this study will benefit you personally and directly. However, the information we receive from this study will assist us in understanding the ways in which stroke survivors and their partners think about their stroke and the effect this can have on feelings of anxiety and depression. Such valuable information can be shared with other health professionals and may contribute to the development of health and psychological services for stroke survivors and their families in the future.

Will my taking part in this study be kept confidential?

Yes. Throughout this study your name and address will be kept anonymous. Each participant will be only recorded and identified by a number. Disclosure of your name and participation in this study would only be done strictly with your written consent. The audio recordings and questionnaires gathered in this research will be kept in a locked filing cabinet in the Department of Clinical Psychology at the University of Hull. The questionnaires will be kept for five years after the study has finished and the audio recording will be destroyed after four months of recording . The filing cabinet can only be accessed by the primary researcher and the research supervisor.

What will happen to the results of this study?

It is hoped that this study will expand our knowledge and understanding of possible differences in illness perceptions between stroke survivors and their partners. It is the purpose of this study to publish the results in an academic psychology journal; however, no individual participants will be identified in any published work.

Who is conducting, supervising and funding this research?

This study will be conducted by Rachel Avison, Trainee Clinical Psychologist and primary researcher, as part of the academic requirements of the Clinical Psychology Doctorate course at The University of Hull. The research will be supervised by Dr Chris Clarke, Consultant Clinical Psychologist and Clinical Lecturer at the University of Hull. The research is funded by the Department of Clinical Psychology at The University of Hull and is sponsored by Humber Mental Health NHS Teaching Trust.

Who has reviewed this study?

This study has been reviewed and approved by the South Humber Research Ethics Committee.

Contact for further information.

If you would like any further information on the study then please do not hesitate to contact:

Rachel Avison, Trainee Clinical Psychologist & primary researcher
Department of Clinical Psychology
The University of Hull
Hull
HU6 7RX

Tel: 07709112241
Email: R.Avison@psy.hull.ac.uk

Thank you for taking the time to read through the participant information

Appendix 9. Participant Information Sheet for Partners

Participant Information Sheet for Partners

'Perceptions of the causes and effects of stroke among stroke survivors and their partners'

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish or ask us if there is anything that is not clear or if you would like more information. Thank you for taking the time to read the information.

What is the purpose of this study?

The onset of stroke can lead to a number of problems, which vary from person to person. According to psychological theory, following an experience such as stroke, people think about their problems in their own unique way and form a personal 'illness perception', which can influence how they feel and what they do. Research has shown that there can be differences between a patient's perception and their partner's perception, yet no study has ever investigated the differences in illness perceptions between stroke survivors and their partners. This research projects aims to find out whether differences in couples illness perceptions relate to stroke survivors' levels of anxiety and depression and partners' thoughts and feelings towards the survivor. We hope that this investigation will help us to better understand the ways in which people think about stroke and the effect this can have on how they feel and what they do, as well as contributing to the development of services for stroke survivors and their families.

Why have I been invited?

We are inviting people in the Hull and East Yorkshire area who have suffered a stroke along with their spouse/partner. You have been invited to take part as you have been selected as a suitable participant by your partners Community Stroke Nurse as you live at home with your partner and are currently the main source of care and support for them. We are inviting approximately 50 stroke survivors and 50 spouses/partners to take part in this study.

Do I have to take part?

Taking part in the research is entirely voluntary so it is up to you to decide. You do not have to take part if you do not want to and you would be free to withdraw at any time without giving a reason, this would by no means affect the care you or your partner receives from the Community Stroke Team.

What will happen if I decide to take part?

The primary researcher, Rachel Avison, will contact you in approximately seven days time to see if you would like to take part. If after reading this information sheet you decide that you would like to take part in the study, a time and place convenient to you can be arranged to meet (e.g. at your home, or at Westwood Hospital or The Department of Clinical Psychology at Hull University). As the sessions are confidential, we ask that partners, friends or other family members are not in the same room when you are taking part in the study.

The study will require 45 minutes of your time, during which you will be asked to do three different things:

1) Fill in a questionnaire that asks you to judge your partners ability at doing a variety of tasks.
2) Fill in a questionnaire which asks you questions about your partner's symptoms, their experiences since having the stroke and your thoughts about possible causes of your partner's stroke.
3) Finally, you will be asked to talk for five uninterrupted minutes on your thoughts and views about your partner and the effects of their stroke. This will be recoded using a digital dictaphone. As the session is confidential, we ask that your partner, friends or family members are not present when you are completing the questionnaires and talking about your thoughts and feelings.

The primary researcher will meet with you and your partner at separate times but please note that this study requires information from both stroke survivors *and* their partners, therefore both you and your partner would have to agree to take part otherwise no information can be collected. Should either you or your partner decide to withdraw from the study, this would mean that both of you would no longer be required to continue and any information provided by you or your partner would not be included in the research.

Are there any possible risks or disadvantages of taking part?

No. There are no perceived risks to this study. It is not unusual for some people to feel a bit lower in mood after completing the questionnaires and talking about any difficulties that have experienced. However, at the end of the study there will be time available to talk about anything that may have been difficult for you during the study and if after this time it is felt that you are experiencing lower mood or a previously unrecognised level of distress then the primary researcher will discuss this with you and decide with you who else involved in your care should also know this information. Should the primary researcher have any concerns about the information you or your partner provide or other issues, then these concerns will be raised with you and passed on to the Community Stroke Team.

What are the possible benefits of taking part?

We cannot guarantee that taking part in this study will benefit you personally and directly. However, the information we receive from this study will assist us in understanding the ways in which people think about their partner's stroke and the effect this can have on their thoughts, feelings and emotional response towards their partner. Such valuable information can be shared with other health professionals and may contribute to the development of health and psychological services for stroke survivors and their families in the future.

Will my taking part in this study be kept confidential?

Yes. Throughout this study your name and address will be kept anonymous. Each participant will be only recorded and identified by a number. Disclosure of your name and participation in this study would only be done strictly with your written consent. The audio recordings and questionnaires gathered in this research will be kept in a locked filing cabinet in the Department of Clinical Psychology at the University of Hull. The questionnaires will be kept for five years after the study has finished and the audio recording will be destroyed after four months of recording . The filing cabinet can only be accessed by the primary researcher and the research supervisor.

What will happen to the results of this study?

It is hoped that this study will expand our knowledge and understanding of possible differences in illness perceptions between stroke survivors and their partners. It is the purpose of this study to publish the results in an academic psychology journal; however, no individual participants will be identified in any published work.

Who is conducting, supervising and funding this research?

This study will be conducted by Rachel Avison, primary researcher, as part of the academic requirements of the Clinical Psychology Doctorate course at The University of Hull. The research will be supervised by Dr Chris Clarke, Consultant Clinical Psychologist and Clinical Lecturer at the University of Hull. The research is funded by the Department of Clinical Psychology at The University of Hull and is sponsored by Humber Mental Health NHS Teaching Trust.

Who has reviewed this study?

This study has been reviewed and approved by the South Humber Research Ethics Committee.

Contact for further information.

If you would like any further information on the study then please do not hesitate to contact:

Rachel Avison, Trainee Clinical Psychologist & primary researcher
Department of Clinical Psychology
The University of Hull
Hull
HU6 7RX

Tel: 07709112241
Email: R.Avison@psy.hull.ac.uk

Thank you for taking the time to read through the participant information

Appendix 10. Consent Form for Stroke Survivors

Consent Form for Stroke Survivors

Title of Project: Perceptions of the causes and effects of stroke among stroke survivors and their partners

Name of Researcher: Rachel Avison, Trainee Clinical Psychologist

Please Tick

1. I confirm that I have read the Participant Information Sheet for the above study and understand the information provided. ☐

2. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that withdrawing will not affect any care I receive. ☐

4. I understand that I will be given a Participant Identification Number and that the responses I provide on the questionnaires will remain anonymous. ☐

5. I understand that the questionnaires gathered during the study will be kept in a locked filing cabinet at the University of Hull for five years after the study has finished. I am aware that the filing cabinet can only be accessed by the primary researcher and the research supervisor. ☐

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

______________________	____________	__________________
Name of Participant	Date	Signature
______________________	____________	__________________
Name of person obtaining consent	Date	Signature

Consent Form for Partners

Title of Project: Perceptions of the causes and effects of stroke among stroke survivors and their partners

Name of Researcher: Rachel Avison, Trainee Clinical Psychologist

Please Tick

1. I confirm that I have read the participant information sheet for the above study and understand the information provided. ☐

2. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐

3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason. I understand that withdrawing will not affect the care my partner receives. ☐

4. I understand that I will be given a Participant Identification Number and that the responses I provide on the questionnaires and the audio recording will remain anonymous. ☐

5. I understand that the questionnaires and audio recordings gathered during the study will be kept in a locked filing cabinet at the University of Hull, which can only be accessed by the primary researcher and the research supervisor. ☐

6. I understand that the questionnaires will be kept in a locked filing cabinet at the University of Hull for five years after the study has finished and that the taped session will be destroyed after three months of recording. ☐

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

______________________	____________	________________
Name of Participant	Date	Signature
______________________	____________	________________
Name of person obtaining consent	Date	Signature

Appendix 12. Demographic Information Sheet

Participant numbers:

Date:

Demographic Information Sheet

Questions to be completed with the partner

- Partner: Age_________ Gender_________
- Stroke Survivor: Age_________ Gender_________
- When did your partner have their stroke?_________
- How long has your partner been living at home since their stroke?_________
- Does your partner have any other health problems?___________
- Do you have any health problems?___________
- Does your partner receive any respite care? ________________
- If so, how much time do they spend in respite care each year?______________
- Does your partner receive any help from carers or a support agency?_______________
- If so, how many hours care do they receive each week/month? _________________

Appendix 13. Patient Competency Rating Scale for Stroke Survivors

Patient Competency Rating Scale for Stroke Survivors

This questionnaire asks you to judge your ability to do a variety of practical skills. Some of the questions may not apply to things you often do but you are asked to complete each question as if it were something you had to do. For each question, judge how easy or difficult a particular activity is for you and place a tick in the appropriate space in the table below and on the next page*.

*This table has been reduced in size compared to the version used with participants	**1** **Can't do**	**2** **Very difficult to do**	**3** **Can do with some difficulty**	**4** **Fairly easy to do**	**5** **Can do with ease**
1. How much of a problem do I have in preparing my own meals?					
2. How much of a problem do I have in dressing myself?					
3. How much of a problem do I have in taking care of my personal hygiene?					
4. How much of a problem do I have washing the dishes?					
5. How much of a problem do I have in doing the laundry?					
6. How much of a problem do I have in taking care of my finances?					
7. How much of a problem do I have in keeping appointments on time?					
8. How much of a problem do I have in starting a conversation in a group?					
9. How much of a problem do I have in staying involved in work activities even when bored or tired?					
10. How much of a problem do I have in remembering what I had for dinner last night?					
11. How much of a problem do I have in remembering names of people I see often?					
12. How much of a problem do I have in remembering my daily schedule?					

	1 **Can't do**	**2** **Very difficult to do**	**3** **Can do with some difficulty**	**4** **Fairly easy to do**	**5** **Can do with ease**
13. How much of a problem do I have in remembering important things?					
14. How much of a problem would I have driving a car if I had to?					
15. How much of a problem do I have in getting help when I'm confused?					
16. How much of a problem do I have in adjusting to unexpected changes?					
17. How much of a problem do I have in handling arguments with people I know well?					
18. How much of a problem do I have in accepting criticism from other people?					
19. How much of a problem do I have in controlling crying?					
20. How much of a problem do I have in acting appropriately when I'm around friends?					
21. How much of a problem do I have in showing affection to people?					
22. How much of a problem do I have in participating in group activities?					
23. How much of a problem do I have in recognising when something I say or do has upset someone else?					
24. How much of a problem do I have in scheduling daily activities?					
25. How much of a problem do I have in understanding new instructions?					
26. How much of a problem do I have in consistently meeting my daily responsibilities?					
27. How much of a problem do I have in controlling my temper when something upsets me?					
28. How much of a problem do I have in keeping from being depressed?					
29. How much of a problem do I have in keeping my emotions from affecting my ability to go on about the day's activities?					
30. How much of a problem do I have in controlling my laughter?					

Appendix 14. Patient Competency Rating Scale for Partners

Patient Competency Rating Scale for Partners

This questionnaire asks you to judge your partner's ability to do a variety of practical skills. Some of the questions may not apply to things they often do but you are asked to complete each question as if it were something they had to do. For each question, judge how easy or difficult a particular activity is for your partner and place a tick in the appropriate space in the table below and on the next pages*.

*This table has been reduced in size compared to the version used with participants	**1** **Can't do**	**2** **Very difficult to do**	**3** **Can do with some difficulty**	**4** **Fairly easy to do**	**5** **Can do with ease**
1. How much of a problem do they have in preparing their own meals?					
2. How much of a problem do they have in dressing them self?					
3. How much of a problem do they have in taking care of their personal hygiene?					
4. How much of a problem do they have washing the dishes?					
5. How much of a problem do they have in doing the laundry?					
6. How much of a problem do they have in taking care of their finances?					
7. How much of a problem do they have in keeping appointments on time?					
8. How much of a problem do they have in starting a conversation in a group?					
9. How much of a problem do they have in staying involved in work activities even when bored or tired?					
10. How much of a problem do they have remembering what they had for dinner last night?					

	1 Can't do	2 Very difficult to do	3 Can do with some difficulty	4 Fairly easy to do	5 Can do with ease
11. How much of a problem do they have in remembering names of people they see often?					
12. How much of a problem do they have in remembering their daily schedule?					
13. How much of a problem do they have in remembering important things they must do?					
14. How much of a problem would they have driving a car if I they had to?					
15. How much of a problem do they have in getting help when they're confused?					
16. How much of a problem do they have in adjusting to unexpected changes?					
17. How much of a problem do they have in handling arguments with people they know well?					
18. How much of a problem do they have in accepting criticism from other people?					
19. How much of a problem do they have in controlling crying?					
20. How much of a problem do they have in acting appropriately when they're around friends?					
21. How much of a problem do they have in showing affection to people?					
22. How much of a problem do they have in participating in group activities?					
23. How much of a problem do they have in recognising when something they say or do has upset someone else?					

	<u>1</u> **Can’t do**	**<u>2</u>** **Very difficult to do**	**<u>3</u>** **Can do with some difficulty**	**<u>4</u>** **Fairly easy to do**	**<u>5</u>** **Can do with ease**
24. How much of a problem do they have in scheduling daily activities?					
25. How much of a problem do they have in understanding new instructions?					
26. How much of a problem do they have in consistently meeting their daily responsibilities?					
27. How much of a problem do they have in controlling their temper when something upsets them?					
28. How much of a problem do they have in keeping from being depressed?					
29. How much of a problem do they have in keeping their emotions from affecting their ability to go on about the day’s activities?					
30. How much of a problem do they have in controlling their laughter?					

Appendix 15. Illness Perception Questionnaire-Revised for Stroke Survivors

Participant No:
Date:

Illness Perception Questionnaire-Revised for Stroke Survivors

Section 1

Listed in the table shown below are a number of symptoms that you may or may not have experienced since having the stroke. Please put a tick in either the 'Yes' or 'No' box next to the list of symptoms to indicate whether you have experienced any of these symptoms since having the stroke. Please also put a tick in either the 'Yes' or 'No' box in the next column of the table to indicate whether you believe these symptoms are related to having the stroke.

Symptom	**I have experienced this symptom since having the stroke**		**I believe this symptom is related to having the stroke**	
	Yes	**No**	**Yes**	**No**
Pain				
Sore Throat				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Wheeziness				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				

Section 2

I am interested to understand your own personal view of how you see the effects of the stroke. Please indicate how much you agree or disagree with the following statements about the effects of the stroke by putting a tick in the most appropriate box in the table below and on the next pages.

Views about the effects of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The effects of my stroke will last a short time					
The effects of my stroke are likely to be permanent rather than temporary					
The effects of my stroke will last for a long time					
The effects of my stroke will pass quickly					
I expect to have the effects of my stroke for the rest of my life					
The effect of my stroke is a serious condition					
The effect of my stroke has major consequences on my life					
The effect of my stroke does not have much effect on my life					

Views about the effects of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor**	**Agree**	**Strongly Agree**
The effect of my stroke affects the way others see me					
The effect of my stroke has serious financial consequences					
The effects of my stroke causes difficulties to those who are close to me					
There is a lot which I can do to control my symptoms					
What I do can determine whether my condition gets better or worse					
The course of my condition depends on me					
Nothing I do will affect my condition					
I have the power to influence my condition					
My actions will have no effect on the outcome of my condition					
My condition will improve in time					

Views about the effects of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor**	**Agree**	**Strongly Agree**
There is very little that can be done to improve my condition					
My treatment will be effective in curing the effects of the stroke					
The negative effects of my stroke can be prevented by my treatment					
My treatment can control the effects of the stroke					
There is nothing that can help my condition					
The symptoms of my stroke are puzzling to me					
The effects of my stroke are a mystery to me					
I don’t understand my condition					
My condition doesn’t make any sense to me					
I have a clear picture or understanding of my condition					
The symptoms of my stroke change a great deal from day to day					

Views about the effects of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My symptoms come and go in cycles					
My condition is very unpredictable					
I go through cycles in which my condition gets better and worse					
I get depressed when I think about the effects of my stroke					
When I think about the effects of my stroke I get upset					
The effects of my stroke makes me feel angry					
The effects of my stroke do not worry me					
Having this condition makes me feel anxious					
My condition makes me feel afraid					

Please continue on next page...

Section 3

I am interested to understand what you think may have caused your stroke. There is no correct answer, I would like to know your own views about the factors that caused your stroke rather than what other people such as doctors or family may have suggested.

Below is a list of possible causes. Please indicate how much you agree or disagree that they were causes for your stroke by putting a tick in the most appropriate box.

Possible causes of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
Stress or worry					
Hereditary – it runs in the family					
A germ or virus					
Diet or eating habits					
Chance or bad luck					
Poor medical care in my past					
Pollution in the environment					
My own behaviour					
My mental attitude					
Family problems or worries					
Overwork					
My emotional state e.g. feeling down, lonely, anxious, empty					
Ageing					
Alcohol					
Smoking					
Accident or injury					
My personality					
Altered immunity					

Please list the three most important factors that you believe caused your stroke in rank order below (ie. 1 = most important cause). You may use any of the items from the box above or you may have additional ideas of your own.

The most important causes for my stroke are:

1.____

2.____

3.____

Thank you very much for taking the time to complete the questionnaire

Appendix16. Illness Perception Questionnaire-Revised for Partners

Participant No:
Date:

Illness Perception Questionnaire-Revised for Partners

Section 1

Listed in the table shown below are a number of symptoms that your partner may or may not have experienced since having the stroke. Please put a tick in either the 'Yes' or 'No' box next to the list of symptoms to indicate whether your partner has experienced any of these symptoms since having the stroke. Please also put a tick in either the 'Yes' or 'No' box in the next column of the table to indicate whether you believe your partners symptoms are related to having the stroke.

Symptom	**My partner has experienced this symptom since having the stroke**		**I believe this symptom is related to my partner having the stroke**	
	Yes	**No**	**Yes**	**No**
Pain				
Sore Throat				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Wheeziness				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				

Section 2

I am interested to understand your own personal view of how you see the effects of your partners' stroke. Please indicate how much you agree or disagree with the following statements about the effects of the stroke by putting a tick in the most appropriate box in the table below and on the next pages.

Views about the effects of your partners stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The effects of my partner's stroke will last a short time					
The effects of my partner's stroke are likely to be permanent rather than temporary					
The effects of my partner's stroke will last for a long time					
The effects of my partner's stroke will pass quickly					
I expect my partner to have the effects of their stroke for the rest of their life					
The effect of my partner's stroke is a serious condition					
The effect of my partner's stroke has major consequences on their life					

Views about the effects of your partners stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The effect of my partner’s stroke does not have much effect on their life					
The effect of my partner’s stroke affects the way others see them					
The effect of my partner’s stroke has serious financial consequences					
The effects of my partners stroke causes difficulties to those who are close to them					
There is a lot my partner can do to control their symptoms					
What my partner does can determine whether their condition gets better or worse					
The course of my partner’s condition depends on them					
Nothing my partner does will affect their condition					
My partner has the power to influence their condition					

Views about the effects of your partners stroke	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My partner’s actions will have no affect on the outcome of their condition					
My partner’s condition will improve in time					
There is very little that can be done to improve my partner’s condition					
My partner’s treatment will be effective in curing the effects of their stroke					
The negative effects of my partner’s stroke can be prevented by their treatment					
My partner’s treatment can control the effects of their stroke					
There is nothing that can help my partner’s condition					
The symptoms of my partner’s stroke are puzzling to them					
The effects of my partner’s stroke are a mystery to them					
My partner does not understand their condition					

Views about the effects of your partners stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My partner’s condition doesn’t make any sense to them					
My partner has a clear picture or understanding of their condition					
The symptoms of my partner’s stroke change a great deal from day to day					
My partner’s symptoms come and go in cycles					
My partner’s condition is very unpredictable					
There are cycles in which my partner’s condition gets better and worse					
My partner gets depressed when they think about the effects of their stroke					
When my partner thinks about the effects of their stroke they get upset					
The effects of my partner’s stroke make them angry					
The effects of my partner’s stroke do not worry them					

My partner’s condition makes them feel anxious					
My partner’s condition makes them feel afraid					

Please continue on next page...

Section 3

I am interested to understand what you think may have caused your partners stroke. There is no correct answer, I would like to know your own views about the factors that caused your partner's stroke rather than what other people such as doctors or family may have suggested.

Below is a list of possible causes. Please indicate how much you agree or disagree that they were causes for your partner's stroke by putting a tick in the most appropriate box.

Possible causes of my stroke	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
Stress or worry					
Hereditary – it runs in the family					
A germ or virus					
Diet or eating habits					
Chance or bad luck					
Poor medical care in my past					
Pollution in the environment					
My own behaviour					
My mental attitude					
Family problems or worries					
Overwork					
My emotional state e.g. feeling down, lonely, anxious, empty					
Ageing					
Alcohol					
Smoking					
Accident or injury					
My personality					
Altered immunity					

Please list the three most important factors that you believe caused your partner’s stroke in rank order below (ie. 1 = most important cause). You may use any of the items from the box above or you may have additional ideas of your own.

The most important causes for my partners stroke are:

1.____

2.____

3.____

Thank you very much for taking the time to complete the questionnaire

Appendix 17. Hospital Anxiety and Depression Scale for Stroke Survivors

(Removed for hard binding due to copyright restrictions)

Appendix 18. Instructions for Administering and Scoring the Five Minute Speech Sample

(Removed for hard binding due to copyright restrictions)

Appendix 19a. Example FMSS transcript: High EE

“Erm well things have changed so much since he’s had the stroke it was so sudden erm with no symptoms erm until it actually did happen from being er quite an easy person to get on with he’s now changed he on sometimes he’s very easy other times he’s very very difficult erm he won’t accept anything that’s told to him told to him he can’t accept that he’s had a severe stroke he erm seems to enjoy an argument and erm he can be absolutely vitriolic at times and that’s the only way to describe it if I ask him to not shout or tell him not to shout and remind him that I’m his wife he’ll say I will talk to you how I want to when I want to and I will shout if I want to so it doesn’t make very good relationships really (cough) umm he tries very hard to do things he’s wanting to walk so he goes to physio an tries walking but he has a person either side and a wheelchair at the back of him and then he’s trying to persuade them to let him come home with a quad stick and walk on his own which is quite scary really er cause I know he won’t be able to do it he can’t manage to do anything on his own apart from eat I cut up the food for him he enjoys his food still which is good he enjoys his alcohol which he shouldn’t have according to his tablets but I think well to hell with it you know we don’t know how long he’s got to live anyway he’s got a very restricted lifestyle now so he may as well do something that he can enjoy he has been unable to get into a car ah getting into a car but I couldn’t get him out of it so we’ve had to er we’re changing the car this week erm we had a bath he couldn’t get in into that without one of these up and down appliances and erm which was very painful cos I had to lift his painful leg in for him and then try and get him out on the stroke side which was pretty impossible he didn’t like carers to come in and help him he wanted to me to do it all because he didn’t want any strangers around erm we’ve now had it altered into a wet room which makes it a lot easier so he can be on a commode and be pushed into the shower have a shower and out again to bed erm he’s not keen on going out erm I have got a car as I say with a higher seat and I’m hoping to make him get in that so he can have a ride out and do something that’s different (yeah) on a Tuesday we have a post office that comes to the village hall and one of our neighbours has very kindly started up a coffee morning so that the older people can all get together and have a chat about different things and so I’m bullying him into going down there so I wheel him down there and I say when you go in just smile I can’t smile so I said well just wave to them make make them think that you are interested in them but he sits there and doesn’t say very much at all but if X who lives next door comes and talks to him he’ll chat because X’s ex seaman and he was ex marines so they get on quite well together if he can find somebody to talk to about sailing he’ll talk about sailing erm that’s his only real hobby and for many many years I said to him you’ve got to get another hobby he was interested in model making but with one hand you can’t do that erm he can’t manage to do anything in the kitchen at all he used to do cooking and all sorts of things but not anymore er not quite sure what else well he uh he thinks that he can do all the things that he used to do in his mind and strangely enough my mother was like that following many many TIA’S she was convinced or he’s convinced that he can go up into the loft walk up the ladder and into the loft erm that he can climb onto a boat if I say to him well think logically X about it how would you do it watch me I’ll do it.”

Appendix 19b. Example FMSS transcript: Low EE

How we get on? (yeah) absolutely great we've been married 47 years and I can honestly say were still sweethearts all the things we've been through and we've been through a lot but we're still er friends as well as sweethearts you know er were always laughing winding each other up in a nice way um we just get on really great we've got five kids and numerous grandkids and greatgrandkids I know it sounds really tripe but were happy people who know us well you know just really really know us well the young ones say well I hope when I get married I'm like that after all you've been through and everything and I say well you don't know what we've been through and they said no but you know it's nice to see it after you've been married all these years yeah we got married when I was 20 and X was 22 yeah and I've never wanted anybody else since before I did we've both had numerous er romantic liaisons you know I don't mean like they get too heavy nowadays but we didn't go in for that sort of thing ourselves you know and I've never regretted it what else do you want to know? I was just going to say if you wanted to know how X's stroke affects him sometimes he'll get upset or annoyed over things he would never have done before erm but I've found the best thing to do is just to keep quiet and invariably he apologises er he's er sometimes just now and again but I don't know if this is the drugs he's taking or whether it's or whether it's the effects of the stroke but sometimes he gets mixed up sometimes he'll get things wrong but I find it very difficult to separate the two because he's on so much medication now and medication can make you be like that so whether it's the effects of the stroke but he doesn't realise he's done it but we as family and friends all know what it means anyway but he's a really warm person loving kind happy most of the time except when he gets a bit fed up thinking he's going to have another stroke if anything goes wrong you know his eyes I can't blame him yeah what you see today is what I get 90% of the time even when he's ill and he's in bed which quite often he is he's still nice and warm and kind some people don't like hugging were the kind of people who hug people if you know and if you don't like hugging and you want to be our friend you can find life very difficult we've got five children I would have liked more."

Appendix 20. Instructions for Scoring the Patient Competency Rating Scale

According to Prigatano et al. (1986), the 30 items on the patient and partner measures of the Patient Competency Rating Scale are scored from 1 to 5, depending on the option chosen by the respondent.

Please see the example below:

Question 1: How much of a problem do I have (or does my partner have) preparing meals?

Responses: Can’t do = 1 point

Very difficult to do = 2 points

Can do with some difficulty = 3 points

Fairly easy to do = 4 points

Can do with ease = 5 points

If a respondent selected ‘can do with some difficulty’ they would receive a score of 3 points. Total scores range from 30 to a maximum of 150. Discrepancy scores are calculated by taking away the patients total score from the partner’s total score.

Impaired self-awareness may be inferred from the discrepancy score by examining the degree of over or underestimation on the part of the patient. Positive discrepancy scores represent overestimation of abilities and negative discrepancy scores represent underestimation of abilities.

Appendix 21. Instructions for Scoring the Illness Perception Questionnaire-Revised

(Removed for hard binding due to copyright restrictions)

Appendix 22. Instructions for Scoring the Hospital Anxiety and Depression Scale

According to Zigmond and Snaith (1983), each of the 14 items (7 anxiety and 7 depression items) are scored from 0 to 3, with higher scores indicating greater anxiety or depression.

Please see the example below:

Anxiety Item: ‘I feel tense or wound up’

Responses: Most of the time (score of 3)
A lot of the time (score of 2)
From time to time, occasionally (score of 1)
Not at all (score of 0)

If a respondent circled the option ‘most of the time’ they would receive a score of 3.

Total scores range from 0 to 21 for the anxiety subscale and 0 to 21 for the depression subscale. According to Zigmond and Snaith (1983), scores ranging from 8 to 10 on each scale indicate possible clinical disorder and from 11 to 21 indicate probable clinical disorder.

Reflective Statement

Introduction

This statement provides reflections on the process of planning and carrying out a research project. I will consider all aspects of the research, from the initial ideas to meeting with participants to analysing and reporting the data. I will also consider what I have learned at each stage of the project and the areas that I can build on or develop in any future research.

Initial ideas

During my Undergraduate Psychology training, I worked at a specialist day care centre for people with acquired brain injury. The majority of day guests had suffered a stroke and each person had their own unique physical and/or psychological difficulties. The ages of survivors ranged from approximately 30 to 80 years old and most of the younger stroke survivors lived at home with family. At one of the end of year events, family members were invited to attend and it was observations of the interactions between survivors and their family that stimulated my interests in this area. I noticed that some people were very protective over their family member and tended to do lots for them, yet others people did not appear to be so concerned. Although I had initially thought it was due to the extent of stroke survivors' physical or psychological difficulties, it became clear that family members had very different ideas about stroke and its effects in comparison with those who had suffered the brain injury. When I began developing ideas for the research project I knew I wanted to focus on stroke and was also interested in systemic models and ideas. When reviewing the existing literature in brain injury and rehabilitation journals, I noticed how very few studies collected information or took the views of both the people who had suffered a brain injury and their partners or family members. The available research appeared to be dominated by studies that either focused on carer distress or survivor distress. I knew that I did not want to carry out a piece of research that would add to an area that was already heavily investigated and was keen to explore what might contribute to such high levels of distress, particularly after stroke as well as to think about my experiences of working with survivors and their family members. To ensure my research ideas were not based purely on assumptions about people and their behaviour, I ensured that I spent time examining existing research literature in the area and discussing my own experiences and interests with my research supervisor.

The ethics and research and development process

Once I had developed my research ideas and refined my proposal ready for submission to ethics and R&D, I felt excited about the prospect of starting data collection. A favourable opinion was received from the South Humber Research Ethic Committee on the 13th August stating that the research project could proceed on condition that management permission or approval was obtained from the host organisation. The R&D department for also required confirmation and requested an honorary contract from the human resources department. Unfortunately, it took two months and a lot of time spent phoning and writing to the department before I received the contract. I then had to send a signed copy of the contract back to R&D, so I did not receive confirmation that I could begin the research until the 1st of November 2008. I had not anticipated that it would take that long to obtain a contract and feel that the process really held up the whole study. This is definitely something to be mindful of in future projects.

Choice of journal

When I was developing ideas for the project and examining previous research in the area, the majority of studies were obtained from ‘Brain Injury’. This journal was the most relevant to my research project as it covers all aspects of brain injury and the guidelines state that it embraces issues such as family relationships and welcomes psychological research.

Chosen design

As this research had not been carried out before, it was necessary that the study took an exploratory-descriptive design in order to explore possible links and associations between variables rather than finding a definitive answer.

Participants

I feel I have gained a real insight into peoples’ experience of stroke and the different ways people have adjusted to the life changes encountered. It was apparent when meeting with couples that talking about stroke was something that was very new for them. Quite a few people mentioned at the end of data collection that going through the answers on the illness perception questionnaire was like a ‘reality check’ and I wonder whether questions such ‘I expect to have the effects of the stroke for the rest of my life’ were rather daunting for some people who might have held a belief that one day they would be ‘back to normal’ as one gentleman described. I feel that sometimes clinicians may over-look just how powerful it can be to ask people to complete a questionnaire that requires an assessment of one’s life. In any future research project I will very carefully consider the measures to be included and the questions people have to contemplate.