THE UNIVERSITY OF HULL

The effects of Expressed Emotion in adjustment to Long Term Health Conditions and its role in Post Stroke Depression

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

In the University of Hull

by

Naheed Rashid, BSc. (Hons) Psychology with Sociology, PG.Dip Psychology

June 2011
Acknowledgements

This research is dedicated to two special people who have forever been an inspiration and strength to me; my dear Dad who’s humility, optimism and love will never fade and who I wish with all my heart was here with me now. And to my courageous Mum, who understands only too well the challenges of life after a stroke, yet has always kept me positive and focused throughout my research.

I wish to thank my family, Abbas, Elaine, Tash and Harpreet, for their continuous support, both emotionally and financially. Without your endless help (loans and laughter!) I would not have been able to complete this course. A special thank you to the ‘sisterhood’; we walked together and have finally made it to the end. And to Snoozy for always making me smile.

I would like to express my gratitude to Dr Chris Clarke and Dr Miles Rogish for their valuable guidance, encouragement and patience throughout the research process; and Dr Eric Gardiner for his friendship, expertise and countless statistical support.

Also, thank you to all the staff in the stroke units, for their commitment in taking on so much more work to help in recruitment and for their countless e-mails of reassurance.

Finally, I am indebted to all the stroke survivors and partners who gave up their time and welcomed me into their homes, sharing such heartfelt and emotive experiences with me. Thank you for making this research possible.
Overview

This research portfolio is divided into three parts:

Part one is a systematic literature review of the literature titled ‘Expressed Emotion (EE) in long term health conditions including those with a neurological basis’. A great deal of research has been carried out looking at the role of EE in psychiatric conditions where EE is now seen as a well established strong predictor of relapse in schizophrenia. More recently, research has turned its focus onto the effects of EE within the domain of chronic health conditions, however, whether this maintains the same significance as shown in psychiatric illnesses remains unclear. This review examines the concept of EE in relation to adjustment, course of illness and functional outcomes in long term health conditions. Broadly it explores the individual components of EE (criticism, emotional over-involvement, hostility, warmth and positive remarks) to identify which have been most associated with outcome. Furthermore, this review has also focused upon how EE has been operationalized and measured in relation to long term health conditions. Clinical and research implications are discussed further in this review.

Part two is an empirical research study titled ‘Post stroke depression and expressed emotion’. The causes of PSD remain controversial, particularly regarding the location
of lesion that could be linked to depression. What remains clear, however, is that depression after a stroke injury is commonly experienced and has been evidenced as one of the key factors influencing adjustment and rehabilitation outcomes. Given the potential of the impact of EE in long term health conditions, particularly on psychological distress, understanding the causes of PSD in terms of how organic and psycho-social factors might relate to each other is vital for recovery. A cross-sectional design was used to investigate the extent to which EE might interact with lesion laterality to determine levels of post stroke depression (PSD) in stroke survivors. It was hypothesised that stroke survivors with a left lesion stroke injury living in a high EE climate would experience higher levels of PSD compared to those with a right lesion stroke injury living in a low EE climate. Secondary aims of this research explored the relationship between lesion laterality and levels of PSD; and levels of EE and PSD. Additional exploratory research was also carried out to examine the extent to which stroke survivors’ perceptions of EE may interact with lesion laterality to determine levels of PSD. Clinical implications and scope for further research are discussed further.

Part three contains the appendices which provide further information in relation to the systematic literature review, empirical paper and a reflective statement of the process on this research.
# Table of Contents

**Part One: Systematic Literature Review**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>12</td>
</tr>
<tr>
<td>Introduction</td>
<td>13</td>
</tr>
<tr>
<td>Method</td>
<td>18</td>
</tr>
<tr>
<td>Search strategy</td>
<td>18</td>
</tr>
<tr>
<td>Search terms</td>
<td>18</td>
</tr>
<tr>
<td>Search limits</td>
<td>20</td>
</tr>
<tr>
<td>Inclusion criteria</td>
<td>20</td>
</tr>
<tr>
<td>Exclusion criteria</td>
<td>21</td>
</tr>
<tr>
<td>Selection process</td>
<td>22</td>
</tr>
<tr>
<td>Assessment of methodological quality of studies</td>
<td>23</td>
</tr>
<tr>
<td>Review Findings</td>
<td>25</td>
</tr>
<tr>
<td>Depression and anxiety</td>
<td>31</td>
</tr>
<tr>
<td>Course of illness</td>
<td>34</td>
</tr>
<tr>
<td>Functional outcomes and adjustment</td>
<td>38</td>
</tr>
<tr>
<td>Individual components of EE most associated with adjustment to illness</td>
<td>41</td>
</tr>
<tr>
<td>Measures applied to assess expressed emotion (EE)</td>
<td>47</td>
</tr>
<tr>
<td>Construct of EE in relation to long term illness</td>
<td>48</td>
</tr>
<tr>
<td>Discussion</td>
<td>49</td>
</tr>
<tr>
<td>Key findings and methodological considerations</td>
<td>50</td>
</tr>
<tr>
<td>Other key methodological limitations in the studies accepted for review</td>
<td>56</td>
</tr>
<tr>
<td>Limitations of the present review</td>
<td>58</td>
</tr>
<tr>
<td>Clinical implications</td>
<td>59</td>
</tr>
<tr>
<td>Conclusions and future research</td>
<td>60</td>
</tr>
<tr>
<td>References</td>
<td>63</td>
</tr>
</tbody>
</table>

**Part Two: Empirical Paper**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>76</td>
</tr>
<tr>
<td>Introduction</td>
<td>77</td>
</tr>
</tbody>
</table>

5
Method.................................................................................................. 83
  Design.................................................................................................. 83
  Participants.......................................................................................... 83
  Inclusion and exclusion criteria for stroke survivors......................... 84
  Inclusion criteria for partners or spousal carers............................... 85
  Description of sample.......................................................................... 85
Procedure................................................................................................ 86
  Measures.............................................................................................. 90
  Nottingham Extended Activities of Daily Living Scale (EADL)........... 90
  Post Stroke Depression Rating Scale (PSDRS).................................... 91
  Level of Expressed Emotion Questionnaire (LEE)............................... 91
Statistical Analysis.................................................................................. 92
Results.................................................................................................... 94
  Descriptive statistics.......................................................................... 94
  Scores for EADL, PSDRS and LEE...................................................... 97
  Between group differences in measures............................................ 98
  Stroke survivor and spouse / partner differences in LEE scores.......... 99
  Main research question..................................................................... 100
  Secondary research questions.......................................................... 101
  Exploratory research question......................................................... 102
  Model checking................................................................................... 104
Discussion............................................................................................... 105
  Methodological issues....................................................................... 111
  Clinical implications.......................................................................... 112
  Future research................................................................................ 113
References............................................................................................... 115

Part Three: Appendices........................................................................... 131
  Appendix 1: Reflective Statement.......................................................... 132
  Appendix 2: Guidelines for submission to journals.............................. 137
    Appendix 2.1: Instructions for authors submitting to Clinical Psychology Review......................................................... 138
    Appendix 2.2: Instructions for authors submitting to Brain Injury........ 147
Appendix 3: Ethical Approval................................................................. 154
  Appendix 3.1: Ethical Approval Confirmation Letter..................... 155
  Appendix 3.2: Ethical Approval Confirmation Letter for Amendment... 158
Appendix 4: Humber NHS Foundation Trust Approval......................... 161
  Appendix 4.1: Research and Development (R & D) Sponsorship Letter. 162
  Appendix 4.2: R & D Approval Confirmation Letter.......................... 163
Appendix 5: Research Governance Approval for Recruitment Sites........ 164
  Appendix 5.1: Research Governance Approval for HEY Trust............. 165
  Appendix 5.2: Honorary Contract for HEY Trust............................... 168
  Appendix 5.3: Research Governance Approval for York Trust............. 173
  Appendix 5.4: Research Governance Approval for NLG Trust............. 174
  Appendix 5.5: Research Governance Approval for Calderdale and
    Huddersfield Trust........................................................................ 175
  Appendix 5.6: Research Governance Approval for Doncaster Trust...... 177
Appendix 6: Supplementary Information for Systematic Literature Review
  ........................................................................................................... 179
  Appendix 6.1: Adapted version of quality assessment checklist.......... 180
  Appendix 6.2: Quality assessment criteria by Rater A and Rater B...... 181
Appendix 7: Supplementary Information for Empirical Paper............... 183
  Appendix 7.1: Cover letter for stroke survivor and spouse / partner.... 184
  Appendix 7.2: Additional cover letter from Beverley Westwood........ 185
  Appendix 7.3: Participant Information Sheet for Stroke Survivor........ 186
  Appendix 7.4: Participant Information Sheet for Spouse / Partner....... 190
  Appendix 7.5: Consent form for stroke survivor............................... 194
  Appendix 7.6: Consent form for spouse / partner............................. 195
  Appendix 7.7: Demographic Information Sheet.................................. 196
Appendix 8: Measures Administered to Participants............................ 197
  Appendix 8.1: EADL....................................................................... 198
  Appendix 8.2: PSDRS.................................................................... 200
  Appendix 8.3: LEE for Client (stroke survivor)............................... 211
  Appendix 8.4: LEE for Relative (spouse / partner)......................... 216
Appendix 9: Data Analysis for Empirical Paper........................................ 221

Appendix 9.1: Main research question 1................................................. 222
Appendix 9.2: Secondary research questions (2 + 3)............................ 225
Appendix 9.3: Exploratory research question........................................ 228
List of Tables

Systematic Literature Review
Table 1. List of long term health conditions searched for review.................. 19
Table 2. Overview of studies included in review........................................... 26
Table 3. Summary of measures applied and adapted in review studies...... 47

Empirical Paper
Table 1. Participant demographic information............................................ 86
Table 2. Stroke survivor between group differences in significant health problems.................................................................................................................. 95
Table 3. Stroke survivor between group differences in prior history of depression......................................................................................................................... 95
Table 4. Spouse / partner between group differences in significant health problems.................................................................................................................. 96
Table 5. Stroke survivor EADL, PSDRS & LEE scores.............................. 97
Table 6. Spouse / partner LEE scores........................................................... 98

List of Figures

Systematic Literature Review
Figure 1. Flow Chart Illustrating Systematic Review Process....................... 24

Empirical Paper
Figure 1. PSDRS and relative EE LEE scores for left (LHS) and right (RHS) lesion stroke survivors.......................................................... 100
Figure 2. Interaction between left and right lesion stroke survivors........... 103
Part One: Systematic Literature Review

This paper is written in the format ready for submission to Clinical Psychology Review.

Please see appendix 2.1 for the guidelines for authors.

Word count (including tables and references): 13,792
Expressed Emotion in long term health conditions including those with a neurological basis: A Systematic Review of the Literature

Naheed Rashid, Chris Clarke & Miles Rogish

Correspondence should be addressed to:
Department of Clinical Psychology and Psychological Therapies, The University of Hull, HU6 7RX, England
Telephone contact number: +44 1482 464106 Fax number: +44 1482 464093
E-mail correspondence: n.rashid@2008.hull.ac.uk
Expressed Emotion in long term health conditions including those with a neurological basis; a systematic literature review.

Abstract

This review examines the role of Expressed Emotion (EE) in adjustment, course of illness and functional outcomes in long term health conditions. The effect of the family environment on outcome and course of physical illness has yet to be fully understood. Although a number of inconsistencies were highlighted in the literature, high EE was predominantly found to negatively influence illness outcomes and adjustment. High criticism was seen as the key EE component in predicting a poor course of illness. While most studies indicate a link between EE and illness outcomes in long term health related conditions, the causal relationship of this interaction remains unclear. EE measures were adapted in most of the research studies reviewed to suit the cohort sample investigated. However, the actual concept of EE was not adapted and this raises questions about whether this needs to evolve to better fit with the complexities of health related conditions. Future longitudinal studies may offer a better understanding of the interactional patterns of EE, adjustment and outcomes in long term health conditions.

Keywords: Long term physical health, chronic illness, neurological conditions, expressed emotion.
Introduction

The concept of expressed emotion (EE) was originally developed to describe and assess the emotional climate of households, in particular the interpersonal relationships between a person diagnosed with schizophrenia and their relatives or partner (Brown & Rutter, 1966). Over the past four decades, EE has been extensively researched within the domain of schizophrenia, where studies have consistently highlighted that living with a high EE relative or partner is linked with early relapse and poor clinical outcomes for this disorder (Vaughn & Leff, 1976b; Kavanagh, 1992; Butzlaff & Hooley, 1998); Hooley & Hiller, 1998; Hooley & Campbell, 2002; Chan, 2010). The model of EE proposed in most of the literature conceptualizes it as a trait-like measure of relatives’ or carers’ levels of criticism, hostility, emotional over-involvement, warmth and positive comments. A family member is classified as high in EE according to the number of critical comments, hostile attitude and emotional over-involvement shown towards their relative. Hooley and Campbell (2002) state the measurement of ‘criticism’ to be the most important component of EE, where six or more critical comments made by a relative establish a high EE category.

The concept of EE, now evidenced as a well validated predictor of relapse in schizophrenia, has also been applied to chronic physical illnesses. Due to the enduring nature of a chronic health condition, extant studies have generally regarded EE as a predictor of the course of illness, adjustment and other psycho-social related outcomes, rather than relapse. Chronic physical health illnesses have been
categorised in a number of different ways; for instance the Department of Health (DH) defines them as ‘long term’ health conditions, that is, “any condition that cannot be cured but can be controlled by medication and / or therapy”. The World Health Organization (WHO) applies the term ‘chronic diseases’ and defines this as “diseases of long duration and generally slow progression” (personal communication: Johnson, 14 April 2011). For the purposes of this review the term ‘long term health conditions’ was used to capture these kinds of physical health conditions including chronic illness with a neurological basis.

Social support is widely regarded as a vital factor in adjustment outcomes in long term health conditions and the social support literature provides compelling evidence of the beneficial effects of family relationships on patient’s response to illness (Primomo, Yates & Woods, 1990; Ell, 1996; Hatchett, Friend, Symister & Wadhwa, 1997; Symister & Friend, 2003; Curtis, Groarke, Coughlan & Gsel, 2004). Increasing evidence from studies of long term health conditions leaves little doubt that families tend to be the primary source of support for the patient (Coyne, Ellard & Smith, 1990; Ell & Northern, 1990; Melamed & Brenner, 1990; Charyton, Elliott, Lu & Moore, 2009). Such support could determine how well the patient continues with their treatment or adjusts to and manages their illness. EE provides one framework for conceptualising and investigating the support given to a person with a health condition by their close family members.
Taking a narrative approach in their review of EE in health care, Wearden, Tarrier and Barrowclough (2000) provided a detailed account on the origins of EE and the contribution this concept has made towards understanding the relational impact on relapse in schizophrenia. In addition, they also reviewed the few initial studies indicating a link between EE and health related conditions. Wearden et al. (2000) report that although evidence from psychiatric studies shows a strong predictive link between EE and relapse; this was difficult to conclude in relation to illness outcomes within health related conditions. Among the limitations of this review, however, was the general lack of research within an EE-health related framework available at the time and the cross-sectional nature of most studies, which made it difficult to assess the actual impact of EE within health conditions. Therefore, future research is clearly warranted to enhance our understanding of the relationship between psycho-social factors, such as, EE and illness outcomes. Clinically, such research would highlight factors that may impede rehabilitation or illness management.

One of the inconsistencies present in the available EE literature as a whole relates to the various measures designed to assess EE and this issue is relevant to the investigation of EE in long term health conditions. For instance, the Camberwell Family Interview (CFI: Vaughn & Leff, 1976a) has commonly been the instrument of choice used for assessing EE in relatives and is administered using a semi-structured interview. However, the lengthy process taken to administer and subsequently score the CFI has led to other researchers producing a shorter version which reduces the time by half whilst maintaining predictive power and classification accuracy (Mueser,
Bellack & Wade, 1992). A number of further questionnaire based measures have since been developed, enabling researchers to assess EE in a less intrusive and more efficient way (Moos & Moos, 1981; Magna, Goldstein, Karmo, Miklowitz & Jenkins, 1986; Cole & Kazarian, 1988; Shields, Franks, Harp, McDaniel & Campbell, 1992; Moore & Kuipers, 1999). The extent to which variation in the measurement of EE might influence the conclusions that can be drawn about its relationship with outcomes and adjustment in long term health conditions has not been explored in any previous review.

A further difficulty often highlighted in relation to long term health conditions is how ‘adjustment’ is defined across studies. Adjustment in health conditions has been conceptualized and measured in many different ways. For example, whilst some studies have looked simply at the course of an illness, others have investigated the presence or absence of anxiety and depression as a marker of adjustment. More recently, researchers have defined the positive and negative aspects of adjustment whilst incorporating the experiences of an individual’s social context (Brennan, 2001). The extent to which EE might only be related to certain kinds of adjustment in long term health conditions is currently unclear.

Overall, the role that aspects of EE might play in predicting adjustment and outcomes in long term health conditions has yet to be fully understood. Accordingly, the main aim of the present review was to explore how EE may impact on adjustment
outcomes in various long term health conditions. As research has widely documented the effects of social support and family relationships in adjustment and illness outcomes within children (Wallander & Varni, 1989; Ellerton, Stewart, Ritchie & Hirth, 1996; Sheppard, 2009; Dingfelder, Jaffee & Mandell, 2010), this present review focused on an adult population. The burden of long term health problems can appear to be the norm and a common feature of an ageing population where spouses, partners or older children tend to be the main source of support in its management. A family carer often shares a reciprocal interactive relationship with a chronic illness which can positively or negatively impact on the course of an illness and successful adjustment to it.

The research questions addressed by this review were:

1. What is the role of EE in adjustment, course of illness and functional outcomes in long term health conditions?
2. Which components of EE are most associated with adjustment and outcomes?
3. How has EE been defined, measured and operationalized in relation to long term health conditions?

By providing an up-to-date and systematic review of the literature concerning EE in long term health conditions, it is hoped that clinicians and researchers can be aided in developing and applying family based psycho-social interventions that promote positive adjustment and improve illness-related outcomes.
Method

Search strategy

Searches were initially carried out using a number of health review databases, namely, the Cochrane Database of Systematic Reviews, SCOPUS, Web of Science, INTUTE and NHS health information resources, in order to establish that this present review would not replicate existing reviews. Prominent researchers in the field of EE were also contacted to confirm that similar reviews with this particular focus had not been under-taken recently or were on-going. Subsequently, a systematic literature search was conducted on the 3rd April 2011 using the following online electronic databases: PsycINFO, MEDLINE, PsycARTICLES and CINAHL.

Search terms

Search terms used for EE included ‘expressed emotion*’, ‘EE’ or ‘criticism’. Other key components of EE – ‘emotional over involvement’, ‘EOI’, ‘hostility’ and ‘warmth’ - did not generate relevant papers and were therefore excluded from the search terms. Journal articles and abstracts were searched initially using terms relating to the concept of long term health conditions; these included ‘long term health condition*’, ‘long term health illness*’, ‘chronic health condition*’, ‘chronic disease’, ‘chronic illness*’, ‘physical health condition*’, ‘physical health’, ‘physical illness’. A list of particular long term health conditions including those with a neurological basis was then created on the basis of information derived from the DH, WHO and the review conducted by Wearden et al. (2000) and these were individually searched. Table 1
details a list of the health conditions and search terms applied for this review. As noted, acronyms and the asterisk (*) truncation was applied where required.

<table>
<thead>
<tr>
<th>Long term Physical Health Conditions</th>
<th>Search terms applied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>‘cancer’</td>
</tr>
<tr>
<td>Chronic Heart Failure (CHF)</td>
<td>‘chronic heart’ or ‘CHF’</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>‘epilep*’</td>
</tr>
<tr>
<td>Asthma</td>
<td>‘asthma*’</td>
</tr>
<tr>
<td>Diabetes</td>
<td>‘diabet*’</td>
</tr>
<tr>
<td>Acute Myocardial Infarction (AMI)</td>
<td>‘acute myocardial infarction’ or ‘AMI’</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>‘rheumatoid arthritis or ‘arthritis’</td>
</tr>
<tr>
<td>Bowel disease</td>
<td>‘bowel disease*’</td>
</tr>
<tr>
<td>Kidney disease / transplant recipient</td>
<td>‘kidney disease*’ or ‘transplant recipient*’</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease (COPD)</td>
<td>‘chronic obstructive pulmonary disease*’ or ‘COPD*’</td>
</tr>
<tr>
<td>Coronary Heart Disease</td>
<td>‘coronary heart disease*’</td>
</tr>
<tr>
<td>ME - Myalgic Encephalomyelitis</td>
<td>‘myalgic encephal*’ or ‘ME’</td>
</tr>
<tr>
<td>CFS - Chronic Fatigue Syndrome</td>
<td>‘chronic fatigue syndrome*’ or ‘CFS’</td>
</tr>
<tr>
<td>PVRS - Post Viral Fatigue Syndrome</td>
<td>‘post viral fatigue syndrome’ or ‘PVRS’</td>
</tr>
<tr>
<td>HIV - Human Immunodeficiency Virus</td>
<td>‘human immunodeficiency virus’ or ‘HIV’</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>‘fibromyalgia’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neurological Conditions</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>‘stroke’</td>
</tr>
<tr>
<td>Dementia</td>
<td>‘dementia’</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>‘Alzheimer*’ or ‘AD’</td>
</tr>
<tr>
<td>Acquired brain injury (ABI)</td>
<td>‘brain injur*’, ‘neurological condition*’,</td>
</tr>
<tr>
<td></td>
<td>‘acquired brain injur*’ or ‘ABI’</td>
</tr>
<tr>
<td>Traumatic brain injury (TBI)</td>
<td>‘traumatic brain injur*’ or ‘TBI’</td>
</tr>
</tbody>
</table>

Table 1: Long term health conditions searched for review
Search limiters applied

Based upon the eligibility criteria, specific search limits were applied in order to restrict results to reflect the focus and research questions of this review. The limits set included only articles written in English, involving human subjects, articles published from 1966 onwards, adult participants aged 16 years or older and articles that had been published in peer-reviewed journals.

Inclusion criteria

This review included studies which met the following criteria:

- Studies involving patients who have a long term health condition, such as cancer, chronic heart failure, epilepsy, asthma, diabetes, acute myocardial infarction, rheumatoid arthritis, bowel disease, kidney disease, transplant recipient, chronic obstructive pulmonary disease, coronary heart disease, myalgic encephalomyelitis, chronic fatigue syndrome, post viral fatigue syndrome, human immunodeficiency virus and fibromyalgia.

- Studies involving patients who have a long term neurological condition, such as, dementia, Alzheimer’s disease, stroke, traumatic or acquired brain injury.

- Studies that explicitly focused on the relationship between EE and psychological distress, adjustment outcomes or frequency and intensity of symptoms in patients experiencing these conditions.
Studies that included a valid EE measure for relatives, such as, the CFI (Vaughn & Leff, 1976a), Five Minute Speech Sample (FMSS: Magna et al, 1986) and Level of Expressed Emotion scale (LEE: Cole & Kazarian, 1988).

Studies that included patient measures of psychological distress, adjustment or illness outcome that have previously been shown to have good psychometric properties, i.e. acceptable reliability and validity.

Studies published after 1966, when the concept of EE was originally coined by Brown & Rutter (1966).

Studies utilising quantitative and mixed design methods in order to maximise the number of studies for selection.

Exclusion criteria

This review excluded studies which met the following criteria:

- Studies that focused on mental health problems and non-chronic physical health problems, for example, depression, schizophrenia, eating disorders, bipolar disorder and any other psychiatric conditions.
- Studies that involved children (under 16 years old).
- Studies that were unpublished, e.g. dissertation manuscripts, case reports, systematic literature reviews or discussion papers.
- Studies not published in peer reviewed journals.
- Studies published in a language other than English.
Selection Process

After the wide range of search terms had been established they were entered into the following database search engines - PsycINFO, MEDLINE, PsycARTICLES and CINAHL. This generated 212 articles, which was reduced to 66 after limits were applied to reflect eligibility criteria. Abstracts were initially searched to check for relevant studies and, on the basis of this, 34 were rejected due to their content being unrelated to the focus of this review (i.e. psychiatric or medical based). A further 6 studies were removed due to duplications in searches. A total of 26 articles were read fully to ascertain suitability for the review, however, 16 were rejected because they did not meet the inclusion criteria outlined above (for example, studies where no valid assessment measure of EE was used, or where carer burden and stress were noted as outcomes rather than patient outcomes and where the age of participants was under 16 years. No further studies were sourced after a hand search of reference lists, or as a result of corresponding with researchers in the field. In total, 10 studies were included for review; details of each study are shown in table 2. Figure 1 outlines the systematic review process and final number of studies accepted for this review.
Assessment of methodological quality of studies

The methodological quality of the accepted articles was assessed using a 13-item adapted version of the Downs and Black (1998) checklist. A total of 10 studies accepted for review were rated using this adapted checklist with a total point score of 13. No studies were excluded from this review based on methodological quality. In addition, the studies were rated by one independent rater to ensure reliability of ratings. There was a 91.9% agreement overall between raters which shows a good level of reliability. The adapted checklist, researcher (rater A) and independent rater (rater B) scores can be found in appendix 6 of this review.
Electronic databases searched

PsycINFO  
\( n = 85 \)

MEDLINE  
\( n = 111 \)

PsycARTICLES  
\( n = 7 \)

CINAHL  
\( n = 9 \)

Total  \( n = 212 \)

Refined results: limits applied to publication date, age and publication type

PsycINFO  
\( n = 24 \)

MEDLINE  
\( n = 26 \)

PsycARTICLES  
\( n = 7 \)

CINAHL  
\( n = 9 \)

Total  \( n = 66 \)

Abstracts searched against inclusion / exclusion criteria

Rejected  
\( N = 34 \)

Duplicates removed  
Rejected  
\( N = 6 \)

Full studies read to determine suitability

Rejected  
\( N = 16 \)

Total accepted  
\( n = 10 \)

Hand searching of reference lists  
\( n = 0 \)

Information from key authors  
\( n = 0 \)

Total studies identified for review  
\( n = 10 \)

Figure 1: Flow chart illustrating systematic review process
**Review findings**

The studies reviewed indicate broadly that EE is associated with various aspects of adjustment and illness outcomes in long term health conditions. Each of the ten studies reviewed investigated distinct chronic conditions, including: inflammatory bowel disease (IBD), acute myocardial infarction (AMI), chronic heart failure (CHF), heart operated patients, rheumatoid arthritis, diabetes, epilepsy, non-epilepsy seizures (NES), Alzheimer’s disease and traumatic brain injury (TBI). A range of designs were used in the studies; while the majority used a cross-sectional design (Manne & Zautra., 1989; Wearden, Tarrier & Davies., 2002; Stanhope, Goldstein & Kuipers., 2003; Bressi, Cornaggia, Beghi, Porcellana, Landoli & Invernizzi., 2007; Weddell, 2010), 3 studies used a longitudinal design (Vaughn, Leff & Sarner., 1999; Invernizzi, Bressi, Bertrando, Passerini, Giannelli, Clerici, Biglioli & Cazzullo., 1991; Vitaliano, Young, Russo & Romano., 1993) and 2 used an exploratory design (Bressi, Porcellana, Pedrinazzi, Manoussakis, Marinaccio, Magri & Inama., 2009). Table 2 presents an overview of the studies included in this review.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Design</th>
<th>Participants</th>
<th>Aim of study</th>
<th>EE Measures</th>
<th>Outcome Measures</th>
<th>Key findings</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaughn, Leff &amp; Sarne (1999)</td>
<td>Longitudinal cohort study</td>
<td>31 patients with a recent onset or relapse of inflammatory bowel disease (IBD) and 31 key relatives. Majority of participants were spouses / partners (n=25); remainder included 3 mothers, 2 fathers, 1 daughter.</td>
<td>To explore the relationship between relative EE status and course of IBD illness over a 12-month period, to report on the adapted version of the CFI (adapted for use with relatives of IBD patients) and to analyse the relatives responses.</td>
<td>Spouse / partner / key relative – modified version of CFI, additional questions re: bowel functions were added.</td>
<td>Patient – Present State Examination (PSE), physical status monitored throughout 12-month period by a Consultant Gastroenterologist and data recorded.</td>
<td>9 relatives were rated as high EE and 22 as low EE. Low EE was not associated with a better course of illness over a 12-month follow-up period. Patients with high EE did not show a tendency to experiencing a worse outcome in IBD. Contrary, low EE relatives exhibited the highest number of patients requiring major surgery. Critical comments were reported as highest from the EE category.</td>
<td>10/13</td>
</tr>
<tr>
<td>Bressi, Porcellana, Pedrinazzi, Manoussakis, Marinaccio, Magri &amp; Inama (2009)</td>
<td>Exploratory prospective cohort study</td>
<td>50 consecutive male in-patients with a diagnosis of acute myocardial infarction (AMI) and their wives.</td>
<td>To examine EE in the wives of patients who were at the first episode of AMI and to explore its possible influence on illness course over a 12-month follow-up period.</td>
<td>Wife – CFI</td>
<td>Patient – Stait-Trait Anxiety Inventory (STAI-X1, STAI-X2), Beck Depression Inventory (BDI) and medical evaluation by Cardiologist 1 yr after illness.</td>
<td>34 wives were categorized as high EE and 16 were low EE. 14 wives expressed high criticism and 41 expressed low warmth during the critical period of their husband’s illness. Patients within the high EOI relative group significantly scored higher on the BDI and exhibited worse illness course if their wives were high EOI. Results of the remainder EE components are discussed in this review.</td>
<td>10/13</td>
</tr>
<tr>
<td>Benazon, Foster &amp; Coyne (2006)</td>
<td>Exploratory study</td>
<td>184 couples with a spouse who had a confirmed diagnosis of chronic heart failure (CHF).</td>
<td>To investigate EE levels among CHF patients and their spouses. To examine links between patient and spouse EE and adaptation to CHF. Association of gender and role with negative family attitudes. Moderating role of gender if EE predicted mortality were assessed as secondary research questions.</td>
<td>Patient &amp; spouse – FMSS</td>
<td>Patient – CHF severity measure Patient &amp; spouse – Hopkins Symptom Checklist (HSCL), 11-patient-efficacy item measure &amp; marital quality scale (no specific measure detailed).</td>
<td>Rates of EE were low among couples and patient spouse EE were unrelated. No clear support for EE predicting earlier mortality or poorer adaptation was found. Contrary to hypothesis, patient high EE predicted survival. Relationship between EE and self-report measures were inconsistent. EE was not significant in predicting adaptation to CHF.</td>
<td>12/13</td>
</tr>
<tr>
<td>Authors</td>
<td>Design</td>
<td>Participants</td>
<td>Aim of study</td>
<td>EE Measures</td>
<td>Outcome Measures</td>
<td>Key findings</td>
<td>Quality rating</td>
</tr>
<tr>
<td>---------</td>
<td>--------</td>
<td>--------------</td>
<td>--------------</td>
<td>-------------</td>
<td>-----------------</td>
<td>--------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Invernizzi, Bressi, Bertrando, Passerini, Giannelli, Clerici, Biglioli &amp; Cazzullo (1991)</td>
<td>Longitudinal cohort study</td>
<td>10 relatives and patients who had undergone a surgical heart operation.</td>
<td>To explore emotional attitudes in the relatives of surgically heart-operated patients.</td>
<td>Relative – CFI</td>
<td>Patient – Hamburg Rating Psychiatric Scale (HRPD), Hamilton Anxiety Scale, Hamilton Depression Scale, State-Trait and Anxiety Inventory (STAI), detailed neurological examination, cardiology symptom assessment.</td>
<td>High EE was found in 3 relatives and 7 relatives were low in EE. Overall findings indicated specific components of EE, namely, EOI and warmth were associated with lower anxiety and depression. Generally, a better course of illness was found after a 12-month period.</td>
<td>9/13</td>
</tr>
<tr>
<td>Manne &amp; Zautra (1989)</td>
<td>Cross-sectional study</td>
<td>103 women with rheumatoid arthritis and their husbands.</td>
<td>To explore the association between social interaction, coping and adjustment in patients with a chronic and progressive illness. A number of factors were investigated; personal vulnerability to illness, relative burden, relational aspects and its impact on coping and psychological adjustment and the association between types of coping with psychological symptomatology.</td>
<td>Husbands – modified version of CFI adapted for relatives coping with arthritis.</td>
<td>Wives – Illness Severity, Activities of Daily Living (ADL) Measure, Ways of Coping Scale, The Cognitive Restructuring Scale, The Information-Seeking Scale, The Wishful Thinking Scale, Inventory of Socially Supportive Behaviours and Mental Health Inventory. Husbands – Vulnerability measure and Relative Burden measure.</td>
<td>The main finding suggested that a patient’s family environment does play a key role in their adaptation to the illness. While EE as a whole concept was not explored, the component of criticism derived from the EE scale was found to be associated negatively with wives’ coping behaviours and poor adjustment to illness.</td>
<td>11/13</td>
</tr>
<tr>
<td>Authors</td>
<td>Design</td>
<td>Participants</td>
<td>Aim of study</td>
<td>EE Measures</td>
<td>Outcome Measures</td>
<td>Key findings</td>
<td>Quality rating</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Wearden, Tarrier &amp; Davies (2002)</td>
<td>Cross-sectional study</td>
<td>60 patients with type 1 diabetes and their spouse / partner.</td>
<td>To replicate Koenigsberg, Klausner, Pelino &amp; Rosnick (1993) study by investigating the association between criticism and glucose control. To explore the role of EE in partners of patients with diabetes and its association with poorer glucose control, management and adaptation to diabetes.</td>
<td>Partner - modified version of CFI adapted for relatives of patients with diabetes.</td>
<td>Patient – Psychosocial aspects of diabetes schedule, Appraisal of diabetes scale (ADS). Partners – General Health Questionnaire (GHQ). Patient &amp; partners – Hospital Anxiety &amp; Depression Scale (HADS), Spanier dyadic adjustment scale (DAS).</td>
<td>The majority of relatives were found to be in the low EE category. No association was found between partners’ EE and blood glucose control, however, associations were found between partners’ EE with management and adaptation to diabetes. Patients with high EE partners had poorer levels of dyadic adjustment, negatively appraised their diabetes and had higher levels of depression.</td>
<td>13/13</td>
</tr>
<tr>
<td>Stanhope, Goldstein &amp; Kuipers (2003)</td>
<td>Cross-sectional study</td>
<td>36 people with a confirmed diagnosis of epilepsy and their relatives. 21 people confirmed in non-epilepsy seizures (NES) group and relatives. Relatives included spouse, partner, parent, child, and sibling.</td>
<td>To explore EE in relatives of people with epileptic seizures or NES.</td>
<td>Relative - The Five Minute Speech Sample (FMSS).</td>
<td>Patient – semi-structured interview to gather socio-demographic and seizure-related information; if patient was unsure then relative provided this or medical records were accessed. HADS &amp; Coping questionnaire. Relative – HADS, COPE scale.</td>
<td>A high proportion of relatives of NES patients than epilepsy patients were rated as high EE. Hostility was evident in high EE epilepsy than high EE NES relatives and emotional over-involvement and positive relationship ratings were more common in high EE NES relatives. Both high / low EE epilepsy relatives used problem-focused instead of emotion-focused coping strategies. High EE and seizure frequency were not associated.</td>
<td>12/13</td>
</tr>
<tr>
<td>Authors</td>
<td>Design</td>
<td>Participants</td>
<td>Aim of study</td>
<td>EE Measures</td>
<td>Outcome Measures</td>
<td>Key findings</td>
<td>Quality rating</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Bressi, Cornaggia, Beghi,</td>
<td>Cross-sectional design</td>
<td>43 outpatients suffering from epilepsy and their key relatives</td>
<td>To explore EE in relatives of adult patients diagnosed with epilepsy, and whether this is related to adjustment and the course of illness over time.</td>
<td>Relatives - modified version of CFI adapted for relatives of epileptic patients.</td>
<td>Patient – medical and neurological examination; evaluated on their EEG findings and plasma levels of anti-epileptic drugs. Information gathered from Epileptologist and relative about presence/absence of epileptic seizures. Epileptologist assessment of patients each month – standardised questionnaire covering EEG, plasma drug levels, seizure frequency and treatment compliance. STAI-XI, STAI-X2 and BDI also administered.</td>
<td>26 relatives of patients with epilepsy were rated as high in EE and 17 relatives were rated as low EE. After a 12 month follow up, patients within the high EE and high EOI relatives group significantly showed a greater frequency of seizures than that of the low EE relatives group. High warmth expressed by relatives was statistically significant with better compliance with medication; however, poor compliance was shown in patients from high EE relationships, particularly, highly critical households. Higher depression and anxiety scores were associated with high criticism in relatives. Mothers were reported as showing the highest EOI than fathers or spouses.</td>
<td>10/13</td>
</tr>
<tr>
<td>Porcellana, Iandoli &amp;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invernizzi (2007)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitaliano, Young, Russo &amp;</td>
<td>Longitudinal cohort study</td>
<td>79 patients with a confirmed diagnosis of Alzheimer’s Disease and spousal caregivers.</td>
<td>To examine whether EE in spouses predict subsequent problems among patients with AD.</td>
<td>Spouse - The Five Minute Speech Sample (FMSS).</td>
<td>Patient – The Mini Mental Status (MMS), The Record of Independent Living scale (RIS), The Hamilton Depression Rating Scale (HDRS), and Negative Care Recipient Behaviours Scale. Spouse – BDI, The Spielberger Anger Expression Scale, Satisfaction with Life Scale.</td>
<td>High EE was found in 22% of caregivers. Higher negative behaviours, which increased over time, were found in AD patients living in a high EE household than those living in a low EE household. No association was found between caregiver EE and patient cognitive or ADL decline, and any decline was seen as expected with the degenerative nature of this disease. Caregivers who were classified as high EE were significantly more depressed, had lower life satisfaction and greater anger suppression than those in low EE group.</td>
<td>12/13</td>
</tr>
<tr>
<td>Romano (1993)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 2: Overview of studies included in review

<table>
<thead>
<tr>
<th>Authors</th>
<th>Design</th>
<th>Participants</th>
<th>Aim of study</th>
<th>EE Measures</th>
<th>Outcome Measures</th>
<th>Key findings</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weddell (2010)</td>
<td>Cross-sectional study</td>
<td>78 participants with traumatic brain injury (TBI) and their relatives.</td>
<td>To explore the effects of relatives’ EE, particularly, criticism, on patient outcome and emotional distress after TBI.</td>
<td>Relatives - modified version of CFI adapted for relatives of TBI patients.</td>
<td>Patient - The Zung Depression Scale, Spielberger Trait Anxiety Inventory (STAXI), Anger Towards Relative (ATR) questionnaire, the WAIS-R Full Scale IQ was scored from 6 sub-tests, the Wechsler Memory Scale Logical Memory and Visual Reproduction sub-test, and the B-SIT 12 item version of the Smell Identification Test.</td>
<td>As hypothesized, relatives’ critical comments were negatively associated with patient reactions and outcome after controlling for social class and injury severity. Furthermore, patients with highly critical relatives were found to be more depressed which increased over time than those with less or absent critical relatives.</td>
<td>12/13</td>
</tr>
</tbody>
</table>
The following areas were highlighted from the 10 studies accepted for this review:

- **Depression and Anxiety**

  Several studies indicate that there is an association between EE and depression or anxiety in various health conditions. However, not all studies have verified this association and most have not closely examined the possible direction of causality. Out of the 10 studies reviewed the majority (n=8) reported findings of an association between EE and depression or anxiety. Bressi et al. (2009), for example, carried out the first exploratory study looking at the association of EE in wives of myocardial infarction patients. EE, specifically wives who expressed high emotional over involvement (EOI), was found to be related to higher depression in patients after a 4 month and 12 month assessment.

  Wearden et al. (2002) investigated the association of familial relationships in patients with diabetes and adjustment. Despite exploring a different illness condition to the Bressi et al. (2009) study, Wearden et al. (2002) similarly found EE to be positively correlated with depression. They reported that patients with partners who were categorised as high in EE negatively appraised their diabetes, scored higher in depression and showed poorer outcomes of adjustment within their relationship. Manne & Zautra’s (1989) study explored the impact of spouse criticism and support among women with
rheumatoid arthritis. A point to note however is that although this study did not focus upon EE as a whole concept, components of EE, specifically, criticism, derived from the adapted version of the CFI was reported. Poor psychological distress was found to be associated with highly critical spouses, as well as, the patient’s perception of the amount of their spouse’s supportive interaction with them.

In a further study looking at the role of family EE in epilepsy, Bressi et al. (2007) found patients whose relatives expressed more critical comments scored higher depression and anxiety. Surprisingly, higher depression scores were also found to be correlated with patients living within a high warmth household. One explanation for this could be that the sample consisted of mothers, fathers and spouses and it could be argued that high warmth may generate a different response in patients depending upon whether it is expressed by a parent or a spouse. Dyadic differences within EE are explored further in the later part of this review.

Whilst extensive research has looked at the broad impact of the family environment in long term health conditions with a neurological basis, literature has been scarce regarding the specific influence of EE in this group. Only two relevant studies were found that met the criteria for this review paper. Firstly, Weddell (2010) investigated the influence of relative’s criticism in adjustment and outcome with patients who had suffered
a traumatic brain injury. Weddell (2000) found that the number of critical comments expressed by relatives was significantly associated with depression in brain injured patients. Patients with highly critical relatives were found to be more depressed which increased over time, compared to those with less or absent critical relatives.

Secondly, Vitaliano et al. (1993) carried out a longitudinal study in people with Alzheimer’s disease (AD) and explored the impact of spousal EE in relation to cognition, activities of daily living (ADL) and negative behaviours. At baseline, patients in the high EE spousal group had higher depressive symptoms than those in the low EE spousal group. Furthermore, after an 18 month period, patients showed slightly elevated signs of depression amongst the high EE spousal group and a small reduction of depression was noted in patients in the low EE spousal group.

In contrast to the above findings, two existing studies report no association between EE and depression and anxiety. For instance, Stanhope et al. (2003) found that patient’s depression and anxiety levels did not differ between the epilepsy and non epileptic seizure (NES) patient groups whilst living with a high EE relative. Inconsistency in findings from other EE-epilepsy research could be explained by the different measures used in assessing EE and depression. For instance, while Bressi et al. (2007) used the CFI and the BDI in their sample, Stanhope et al. (2003) used the FMSS measure and HADS scale.
The second contradictory finding was reported in a pilot study exploring the emotional profiles of families who had undergone heart operations. Invernizzi et al. (1991) noted that higher levels of anxiety and depression were found in patients of relatives who belonged to the low EE relative group rather than those within the high EE group. This finding disputes the traditional belief that relatives categorised as low EE tend to contribute to a more positive outcome in illness. However, a small sample size and the nature of the cohort studied could account for these opposing results.

- **Course of illness**

The impact of EE on the course of illness was reported in 7 studies (Bressi et al, 2009; Stanhope et al, 2003; Bressi et al, 2007; Vitaliano et al, 1993; Benazon et al, 2006; Vaughn et al, 1999; Invernizzi et al, 1991). Some studies have reported an association between EE and the actual course of a long term health condition; however, again, there appear to be inconsistencies in this limited literature base. While 4 studies report that high EE is associated with a poorer course of illness (Bressi et al, 2009; Stanhope et al, 2003; Bressi et al, 2007; Vitaliano et al, 1993), 3 studies present conflicting findings, where high EE was actually seen to improve illness outcome (Benazon et al, 2006; Vaughn et al, 1999; Invernizzi et al, 1991).
Stanhope et al. (2003) investigated the number of seizures patients had within each category (epileptic and non-epileptic seizures (NES) and high / low EE relative group). Seizure related injuries were reported to be higher within the past year in NES patients living with a high EE relative as opposed to epilepsy patients living with a high EE relative. Although it was predicted that epilepsy patients in the high EE relative group would have a higher frequency of seizures, surprisingly, no significant association was found between EE levels and seizure frequency in both epilepsy and NES group.

Specifically exploring an epilepsy diagnosed cohort, Bressi et al. (2007) found that, at baseline, no statistically significant differences were reported in the socio-demographic or clinical variables of patients of both high and low EE relative groups. However, after a 12-month follow-up high EE and EOI were both associated with significantly higher seizure frequency than that recorded for the patients living in low EE households. Furthermore, patients in high criticism households showed poorer drug compliance, whereas those living with relatives with high warmth showed better clinical and pharmacological compliance.

Only one study within the neurological based long term health condition reported findings on course of illness. Vitaliano et al. (1993) established that at onset people with AD had a greater number of negative behaviours living in high EE households than those
living in a low EE household. After an 18 month follow up, however, high EE caregivers reported that negative behaviours in the AD sufferer had almost doubled since baseline, in comparison with low EE caregivers. As caregiver affect was seen to be related to caregiver EE in this study, it was perhaps likely that those in the high EE group reported higher behavioural problems than those in the low EE group. Furthermore, although the mini mental state examination (MMSE: Folstein, Folstein & McHugh, 1975) showed mild to moderate levels of cognitive impairment at baseline, this had significantly worsened after 18 months for both high and low EE relative groups. However, the authors report that people with dementia who also showed agitation exhibited an accelerated decline in cognitive functioning and they argue that patient agitation may be a function of carer EE. Finally, Bressi et al. (2009) noted the most important finding in their study of patients with AMI was the effects of high EOI, which was seen to be the most significant predictor of illness outcome; when the patients’ wives in this study scored high on EOI, the patients exhibited a poorer illness course. Wives also showed high criticism and low warmth during the most critical period of their husband’s illness.

Benazon et al. (2006) carried out the first exploratory study looking at EE within adaptation and patient survival among couples with chronic heart failure. Contrary to the common prediction of high EE being associated with a negative outcome, patient survival was associated with high EE. Patients who were rated among the high EE category were shown to survive longer, increasing their survival rate by 68%. Increased survival rates in
patients were still found after patient adaptations, such as, illness severity and marital functioning, were controlled for. In terms of spouses who scored high in EE, patients were found to have a lower survival rate.

Vaughn et al. (1999) similarly reported a lack of association with high EE in their first study of EE in families of patients diagnosed with inflammatory bowel disease (IBD). Four clinical groups were allocated, according to the severity of symptoms and needs for clinical interventions; (i) Well/asymptomatic, (ii) No major disabling symptoms, (iii) major relapses and (iv) major surgery (colostomy, ileostomy or bowel resection) which enabled researchers to record outcomes over the 12 month period of their study. However, irrespective of EE status, no significant differences were found between high and low EE groups, suggesting that patients from high EE groups were similar in symptomology count to those from the low EE group.

Interestingly, Vaughn et al. (1999) also found no association between low EE key relatives and a more positive course of illness. Instead, contrary to other research findings where low EE is predicted to show a better illness outcome, after a 12 month follow up, those patients requiring major surgery tended to come from low EE households. As at least 71% of their participants had been categorised as low EE that may have contributed to this higher number requiring surgery. Also, the very nature of this complex physical
illness means that increased risk inevitably leads to treatment strategies or surgery which may not be seen as a consequence of the environment. Similarly, Invernizzi et al. (1991) found that patients who had undergone a surgical heart operation living with relatives from the low EE category showed a higher number of neurological deficits and tended to demonstrate greater problems in emotional and relational care, thus, drawing into question the notion that high EE has a negative effect on illness outcomes and patient care. Again, the small sample of 10 couples used in this study may have accounted for this finding.

- **Functional outcomes and adjustment**

  In respect of functional outcomes and adjustment, only half (n=5) of the studies described the impact of EE status (Vaughn et al, 1999; Benazon et al, 2006; Mann & Zautra, 1989; Wearden et al, 2002; Bressi et al, 2007). In their study of people diagnosed with IBD, Vaughn et al. (1999) reported a small difference between the number of patients from the high EE group in the ‘major disabling symptoms’ category as compared to that of the low EE group. However, the most interesting finding in this study was that the majority of IBD patients from the low EE group required surgery which contradicted the role high EE traditionally plays in illness outcome. However, it could be argued that the dominant biological aspect of IBD may account for the high number of people requiring surgery in the low EE group.
In their study of women with rheumatoid arthritis, Manne and Zautra (1989) noted that husbands’ critical remarks tended to be most associated with their wives’ poor coping behaviours which in turn directly affected their adjustment outcome. A point to consider was that criticism was the only component of EE that was reported. The main key finding in this study suggested that a patient’s family environment, particularly spousal criticism, does play a key role in adjustment and adaptation to a chronic illness.

In the study conducted by Wearden et al. (2002) of people with diabetes, although none of the individual EE components were associated with poorer glucose control, a correlation between partners’ EE and management of and adaptation to diabetes was found. In particular, patients who poorly managed their diabetes were likely to have partners who scored high in EE, particularly those high in critical comments, as compared to those who scored low in EE or critical comments. These patients also tended to report lesser marital satisfaction and a greater number of negative appraisals of diabetes. Furthermore, higher warmth was found in partners of patients in the poor control group (categorised in the study as one diabetes related hospitalization in the past year) than those in the good control group (no diabetes related hospitalisations in the past year), suggesting that patients who scored lower on overall control of their diabetes were likely to be associated with partners who presented higher warmth.
However, contrary to this finding, Bressi et al. (2007) reported that high warmth expressed by relatives was significantly associated with successful medication compliance in patients diagnosed with epilepsy. Poor compliance was more prominent in patients from high EE households, particularly those who scored higher in critical comments. Studies frequently highlight the importance of medication compliance in this group; particularly as poor management can lead to an increase in the frequency of seizures and associated risk of other seizure related injuries. The inconsistencies in findings, particularly in the warmth component of EE could be seen as a result of the different dyadic relationships used in the studies. For instance, while the study conducted by Wearden et al. (2002) consisted of partners of people with diabetes, Bressi et al. (2007) used a mixed sample of parents and spouses.

Finally, only one study found no association with EE and other measures of adjustment; Benazon et al. (2006) reported that patient adaptation variables in heart failure, such as, illness severity, survival, distress and self-efficacy were not found to be related to spousal composite EE score or criticism specifically. However, a number of methodological reasons could account for the lack of association found in this study. For instance, an unrepresentative sample recruited, limitations of the FMSS measure and the nature of the CHF condition, could perhaps account for the lack of association in this study.
- **Individual components of EE most associated with adjustment to illness**

**Criticism**

Some studies indicate that certain aspects of EE might be most associated with adjustment and outcomes in long term physical health conditions, though again, findings in this area are not consistent across conditions. For instance, several studies indicate that criticism is a key component of EE with regard to predicting aspects of adjustment to illness. Vaughn et al. (1999) reported a total of 76 critical comments made by 19 relatives of IBD patients; critical comments were predominantly about patient’s behaviours unrelated to their illness and the patient’s personality traits. Approximately a third of these critical comments made were related to the patient’s illness, specifically in areas of irritability, mood, failure to communicate their symptoms and seeking appropriate support when necessary. Out of their small sample of 31 couples, 12 relatives made no critical comments at all. Interestingly, relatives from the high EE ‘major disabling symptoms’ group were significantly more critical than relatives of the ‘well, minor symptoms and surgery’ clinical groups. Relatives of the high number of patients requiring surgery were found to be the lowest in criticism suggesting that patients’ genuine lack of control over their illness may factor into the amount of criticism in relatives.

Wearden et al. (2002) found almost half of their sample made no critical comments; however, from those that did, criticism was negatively associated with medication compliance and higher depression scores. In the Bressi et al. (2009) study of husbands with AMI, critical comments was seen to be the most influential component of
EE. Although the majority of wives scored low in criticism, those who did score high on the criticism scale made more than 6 critical comments during the CFI. It could be argued that as Bressi et al. (2009) only measured wives’ EE, this may have influenced the number of critical comments reported. A mixed gender sample may have been provided an unbiased reflection of criticism.

In a study similarly looking at patients with heart related problems, Benazon et al. (2006) found that spouses were rated higher in criticism than patients. Although, the Bressi et al. (2009) study overall reported wives to be lower in criticism, Benazon et al. (2006) recruited a much larger mixed sample including husbands and wives. Furthermore, they measured both spouses and patients using the FMSS which provided an indication of how much criticism the patient perceived from their spouse. The only limitation of this study, however, is that past research has frequently reported differences found in scoring of the FMSS compared to the CFI (Halford, 1992). The Invernizzi et al. (1991) study on patients who had undergone heart operations found only a small number of critical comments in relatives. Interestingly, this was found to have an opposite effect to what is traditionally reported in the literature. For instance, relatives who expressed less criticism towards the patient were seen as unresponsive and detached.

*Emotional Over-involvement (EOI)*

EOI tends to be reflected in a relative’s intrusiveness, overprotective nature or exaggerated response towards the patient or their illness. With the exception of one
study (Invernizzi et al, 1991), most of the other studies in this review have shown EOI to be negatively associated with adjustment and outcomes in long term physical health conditions. Broadly exploring the individual components of EE, Bressi et al. (2009) found that out of a sample of 50 couples where husbands had AMI, 29 wives conveyed high EOI and 21 low EOI. Patients within the high EOI relative group scored significantly higher in depression and negative illness outcomes. The effect of EOI as the most significant predictor of illness outcomes was the most important finding in the study of Bressi et al. (2009). However a point to note is that this sample consisted of male patients and their wives and a mixed sample may have yielded different EOI scores.

Benazon et al. (2006) found that both spouses and patients with a diagnosis of CHF expressed the same amount of EOI towards each other. While no association was found between spouses EOI and patient self-efficacy, spouses EOI was positively related to patient distress. This indicated that patients were more distressed living with spouses who exhibited high EOI. Furthermore, female patients scored higher in the EOI component than male patients. Wearden et al. (2002) found a larger proportion of partners were rated as high on EOI, which was in turn positively correlated with patients’ number of complications of diabetes. Similarly, in relation to the study of patients diagnosed with epilepsy, Bressi et al. (2007) found that patients whose relatives scored higher on the EOI scale were more likely to report a greater number of seizures. EOI was only found in the majority of parents in the Vaughn et al. (1999) study; however, no specific EOI related to illness outcome were reported. As their study consisted of a mixed
sample group, the high EOI in parents perhaps indicates the over-protective nature of a parental-child relationship.

Contrary to the studies mentioned where high EOI correlates with a worse illness outcome, Invernizzi et al. (1991) found that EOI contributed to a more positive illness outcome in surgically heart operated patients, particularly, when associated with high warmth. Symptoms of anxiety and depression were lower in patients who lived with high EOI relatives. Furthermore, Invernizzi et al. (1991) concluded a rating of high EE was purely made on the basis of high EOI rather than the traditional criticism component which usually determines whether a relative is rated high in EE. One explanation for this finding could be that heart disease patients perhaps require a great deal of attention and containment surrounding their illness, therefore, a highly intrusive relative could be seen as a positive influence.

Hostility

The EE component of hostility has been seen closely related to the criticism component (Wearden et al, 2000). In the 4 studies that reported scores on hostility, all were consistent in their findings of low scores on hostility. Bressi et al. (2009) found hostility was only present in a small number of wives in their study of patients with AMI. Similarly, Invernizzi et al. (1991) found very little expressions of hostility or low levels of
criticism within relatives of people who had undergone heart operations. In their sample of patients with diabetes, Wearden et al. (2002) found and a very small number of partners were rated as hostile. Finally, out of their sample of 31 couples looking after a patient with IBD, Vaughn et al. (1999) found that only 4 relatives showed remarks of hostility which tended to be rejecting or critical. Symptoms of long term health conditions may be beyond the patients’ control, therefore, attitudes of relatives tend to be less blame-worthy towards the patient. As hostile attitudes are directly negative towards the patient and their illness, this can perhaps explain the consistency in findings of low hostility exhibited in relatives.

*Warmth and Positive Remarks*

The positive components of EE, such as, warmth and positive remarks, are often overlooked in the EE literature. From the 4 studies that reported the warmth component (Invernizzi et al, 1991; Bressi et al, 2007; Wearden et al, 2002; Bressi et al, 2009), inconsistencies in findings were apparent. For example, Invernizzi et al. (1991) found high warmth to be significantly greater in relatives who were also rated high on EOI. Their main finding in relation to the warmth scale was that patients who had undergone a heart operation showed fewer symptoms of anxiety and depression when they had relatives high in warmth.
Bressi et al. (2007) study of patients with epilepsy found 12 relatives scored high on the warmth scale while 31 relatives were reported as showing low warmth. While high warmth expressed by relatives was significantly associated with patients’ medication compliance, high warmth was also found to be correlated with higher depression scores which was contrary to the findings reported by Invernizzi et al. (1991). One of the limitations of this study was that the sample included a mixture of mothers, fathers and spouses and differences in these relationships itself could yield a different set of responses.

Again, findings in the warmth component of EE were surprising in Wearden et al. (2002) study of patients with diabetes. Relatives who scored higher in warmth in this study were found to be associated with patients’ lower overall control for diabetes. However, similar to the findings of Bressi et al. (2007) study, a positive outcome for medication compliance was shown for patients whose relatives expressed higher warmth. In a different study by Bressi et al. (2009) high warmth was present in 9 wives of patients with AMI and was low in 41 wives while the number of spouses positive comments reported was a mean of 1.64 (sd = 1.72). However, implications for these positive components were not reported other than the majority of this sample expressed low warmth particularly during the critical period of their husband’s illness.
- **Measures applied to assess EE**

  Studies have measured EE in slightly different ways and most measures have been adapted to suit the cohorts studied. Out of the 10 studies reviewed, 7 used the CFI measure to assess EE. 6 of those studies reported, adapted the CFI to suit the cohort studied, however, 1 study did not state whether this had been modified (Bressi et al, 2009). The FMSS was used in 3 studies and was not reported as having been adapted. From the 6 studies that adapted the CFI, 3 reported the majority of their sample to be in the low EE category (Invernizzi et al, 1991; Wearden et al, 2002; Vaughn et al, 1999) while 1 had the opposite effect and high EE was found to be greater in their sample (Bressi et al, 2007). 2 of the studies did not report composite scores of EE [Weddell, 2010; Manne & Zautra, 1989). Table 3 details a summary of the measures used in each study and whether adaptations were made.

<table>
<thead>
<tr>
<th>Study</th>
<th>Cohort studied</th>
<th>EE measures used</th>
<th>EE measures adapted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitaliano et al. (1993)</td>
<td>AD</td>
<td>FMSS</td>
<td></td>
</tr>
<tr>
<td>Benazon et al. (2006)</td>
<td>CHF</td>
<td>FMSS</td>
<td></td>
</tr>
<tr>
<td>Invernizzi et al. (1991)</td>
<td>Heart operation</td>
<td>CFI</td>
<td>✓</td>
</tr>
<tr>
<td>Wearden et al. (2002)</td>
<td>Diabetes</td>
<td>CFI</td>
<td>✓</td>
</tr>
<tr>
<td>Vaughn et al. (1999)</td>
<td>IBD</td>
<td>CFI</td>
<td>✓</td>
</tr>
<tr>
<td>Bressi et al. (2009)</td>
<td>AMI</td>
<td>CFI</td>
<td></td>
</tr>
<tr>
<td>Stanhope et al. (2003)</td>
<td>Epilepsy &amp; NES</td>
<td>FMSS</td>
<td></td>
</tr>
<tr>
<td>Bressi et al. (2007)</td>
<td>Epilepsy</td>
<td>CFI</td>
<td>✓</td>
</tr>
<tr>
<td>Weddell (2010)</td>
<td>TBI</td>
<td>CFI</td>
<td>✓</td>
</tr>
<tr>
<td>Manne &amp; Zautra (1989)</td>
<td>Arthritis</td>
<td>CFI</td>
<td>✓</td>
</tr>
</tbody>
</table>

*Table 3: Summary of measures applied and adapted in review studies*
• **Construct of EE in relation to long term illness**

Studies explored in this review raise questions about the complexities of EE and how this has been operationalized in relation to chronic illness. Bressi et al. (2009) point out the difficulties in understanding whether the role of high EOI triggered higher depression in patients or alternatively a higher depressive state elicited a higher EOI response. Furthermore, Benazon et al. (2006) questioned whether EE should be seen as a unitary concept based on their findings that separate components of EE were not related to each other. They suggested that the lack of association found between spouse and patient EE indicates that EE may be more about the person’s individual processes rather than a reciprocal relational process, as it usually understood in EE literature. While there is some evidence of the relational impact on long term health conditions, the conceptual underpinning of EE remains unclear in this area and calls for further investigation.
Discussion

This review highlights a number of key findings relating to the impact of familial EE on adjustment outcomes in long term health conditions. Studies differed markedly in the extent to which relatives were classified as displaying high EE. Whilst low EE scores were more prominent in the majority of the studies reviewed (Vaughn et al, 1999; Benazon et al, 2006; Invernizzi et al, 1991; Wearden et al, 2002; Vitaliano et al, 1993), three studies found high EE to be greater in their samples (Bressi et al, 2009; Stanhope et al, 2003; Bressi et al, 2007). Two studies did not report full composite EE scores but illustrated the negative impact of criticism on illness outcomes (Mann & Zautra, 1989; Weddell, 2010).

The most consistent and significant result from this review is that the EE component of criticism is most likely to be the key factor in predicting a poor course of physical illness. This echoes the findings of a previous narrative review of EE in health care (Wearden et al, 2000). Whilst not all of the studies reviewed here reported individual components of EE, the majority described findings for criticism the most, followed by EOI and warmth. Hostility was mentioned briefly in three studies and positive remarks was mostly absent in all.
Key findings and methodological considerations

A number of studies in this review have clearly shown that relatives’ EE status plays a role in adjustment, course of illness and functional outcomes in long term health conditions. For instance, high EE in relatives consistently predicts depression and anxiety symptoms in long term health conditions [Bressi et al, 2009; Manne & Zautra, 1989; Wearden et al, 2002; Bressi et al, 2007; Weddell, 2010]. These findings concur with previous research looking at EE and mental health problems such as bipolar disorder, where higher rates of relapse were found in patients who lived with high EE relatives, particularly, those who scored higher on critical comments (Hooley & Teasdale, 1989; Miklowitz, Goldstein, Neuchterlein, Snyder & Mintz, 1988). Similarly, in this review, patients living with a high EE relative generally showed a poorer course of illness than those living with low EE relatives (Bressi et al, 2009; Stanhope et al, 2003; Bressi et al, 2007; Vitaliano et al, 1993). From the studies that reported individual components of EE, high EOI was seen as the most significant predictor of poorer illness outcomes (Bressi et al, 2009; Bressi et al, 2007). This is supported by similar findings from the EE-psychiatric literature suggesting high EOI correlates with measures of poor outcome and psychosocial functioning (Miklowitz, Goldstein & Fallon, 1983; Vaughn, 1984).

A common pattern emerging from studies reporting a negative impact of EE on depression and anxiety was that most illustrated high criticism as the key factor (Manne &
Zautra, 1989; Wearden et al, 2002; Bressi et al, 2007; Weddell, 2002]. One methodological point to consider, however, is the lack of agreement between researchers regarding which cut-off points to apply to the criticism scale which in turn would lead to a rating of high EE. Where some studies have reduced the traditional 6 critical comments cut-off to 2 (Vaughn & Leff, 1976a; Hooley et al, 1986), others have kept the original cut-off point of 6 (Miklowitz et al, 1988). Only some studies in this review reported cut-off points for criticism; 6 or more critical comments were consistent in 4 studies (Bressi et al, 2009; Invernizzi et al, 1991; Wearden et al, 2002; Bressi et al, 2007) and 1 or more critical comments were reported in 2 studies (Stanhope et al, 2003; Vitaliano et al, 1993). The remainder of the studies (Vaughn et al, 1999; Benazon et al, 2006; Manne & Zautra, 1989; Weddell, 2010) reported no cut off points for critical comments. Having said that, clearly the criticism component of EE appears to be a robust factor capable of moderating depression or anxiety symptoms. However, it is important not to overlook other possible factors that could interplay with negative outcomes, including phase or severity of the chronic illness or the coping styles family members or patients adopt.

Similar to course of illness, functional outcomes varied across health conditions, however, a number of studies were consistent in reporting high criticism as the main factor of EE to be negatively associated with lower functional outcomes (Bressi et al, 2009; Wearden et al, 2010; Vaughn et al, 1999). Past research on EE and long term health related conditions also supports these findings; for example, Koenigsberg et al. (1993)
found the number of critical comments expressed by a relative was associated with poor glucose control in patients with diabetes. The EE component, EOI, was also found to have a negative impact on course of illness in one study of patients with chronic heart failure where a negative association of spouse high EOI was related to poor self-efficacy in patients (Benazon et al, 2006). Again, the negative impact of high EOI on diverse measures of illness outcomes has been widely supported in the literature (Miklowitz et al 1983; Vaughn, 1984).

While there has been a general consensus across studies regarding the negative impact high EE has shown in relation to adjustment, course of illness and functional outcomes, there are a number of inconsistent findings to be noted. For instance, Invernizzi et al. (1991) surprisingly reported that patients with higher depression and anxiety symptoms were found in relatives who scored low in EE. This pilot study was the first of its kind to investigate EE in surgically heart operated patients; therefore, it was difficult to compare these contradictory findings with other similar research. However, drawing upon the wide body of research into heart operated patients, it is commonly believed that patients who undergo heart operations tend to present with higher anxiety and depressive symptoms, particularly during the post operative period (Wang, Gao & Li, 2009; Rymaszewska, Kiejna & Hadrys, 2003).
Another interesting finding came from the Bressi et al. (2009) study where the EE components of EOI and warmth were found associated with a negative course of depression and anxiety. Similarly, Wearden et al. (2002) found spousal high warmth to be related to poorer control in diabetes. In addition, Stanhope et al. (2003) and Vitaliano et al. (1993) found no association between EE and depression or anxiety in their sample. Interestingly, contrary to the traditional belief of high EE being negatively associated with outcome, the reverse effect was seen in 3 studies (Benazon et al, 2006; Vaughn et al, 1999; Invernizzi et al, 1991) where high EE was reported to be associated with more positive illness outcomes. Again, as these findings were drawn from first ever studies conducted in this illness cohort (CHF, IBD and surgically heart operated patients), it is difficult to corroborate the results.

As noted above, inconsistencies in the literature make it difficult to draw clear conclusions about the role of EE in relation to long term health conditions. Methodological limitations in the studies are one factor that may have added to the differences in findings reported. For instance, a number of different measures have been used to assess depression, anxiety, illness and functional outcomes. For example, whilst some studies have used validated scales, such as, the CHF Severity Measure (Benazon et al, 2006), Mini Mental Status Examination (Vitaliano et al, 1993) and Present State Examination Scale (Vaughn et al 1999), others have applied a less structured and

Another factor that may explain the relatively inconclusive findings of this review is heterogeneity among the wide variety of long term health conditions explored in the included studies. For instance the diverse symptomological profile that exists between different health related conditions could have a role to play in moderating the effect of EE. Future replication studies involving larger more representative samples may enhance the evidence as to why some chronic health conditions apparently yield opposing findings regarding the role of EE as compared to others.

The concept of EE has evolved since its original theory was introduced in 1962 (Brown, Monck, Carstairs & Wing, 1962). Since then the individual components of EE have been refined to reflect both positive and negative attitudes expressed by relatives (Brown, Birley & Wing, 1972; Vaughn & Leff, 1976a). In understanding whether the concept of EE should be adapted in relation to long term health conditions, it would be important to explore these separate components independently. For instance, in the psychiatric literature, the role of warmth is seen as having a positive effect and is correlated with less relapse rates (López, Nelson-Hipke, Polo, Jenkins, Karno, Vaughn, & Snyder, 2004). However, viewing this component from a chronic illness standpoint may suggest that
regardless of relatives expressing high warmth, patients may only see themselves in light of their chronic illness which may naturally evoke a negative illness outcome. Although, as a concept, EE appears to have remained the same throughout psychiatric and physical health literature, questions arise as to whether this should have been adapted to reflect the complex nature of long term health conditions. As this review has noted inconsistencies’ regarding the impact individual components of EE has on illness outcomes, the conceptualization of EE in relation to long term health conditions still remains unclear. Future research would be beneficial in understanding why some components yield a different response in certain conditions than others.

Another point to consider would be the dyadic differences in EE noted in the studies reviewed (Vaughn et al, 1999; Benazon et al, 2006; Wearden et al, 2002; Bressi et al, 2007). Separate components of EE seem to generate a different response, depending on the type and quality of relationship that exists between carer and patient. In previous psychiatric EE based literature, parental EE has been shown to be somewhat higher than spousal EE (Heikkilä, Karlsson, Taiminen, Lauerma, Ilonen, Leinonen, Wallenius, Virtanen, Heinimaa, Koponen, Jalo, Kaljonen & Salakangas, 2002). Heikkilä et al. (2002) suggested that high EOI tends to be more prominent in parents due to the nature of the parent-child relationship where parents are seen as being over protective and cautious with their children. Therefore, exploring these differences in the diverse set of relationships that exist, such as, spousal, parent-child, sibling-patient, would perhaps provide a greater
understanding into the function of EE within the context of the illness and but also within the relationship itself. Furthermore, in cases of multiple family members living together with a patient, defining one key member for purposes of assessing the climate of a household disregards the potential influence of others’ and their relational patterns on the course of illness or adjustment and this also needs to be explored further.

- **Other key methodological limitations in the studies accepted for review**

Several limitations were collectively reported in the studies examined in this review. A common limitation reported was the small sample sizes used in the studies (Vaughn et al, 1999; Bressi et al, 2009; Invernizzi et al, 1991). Some studies recruited participants from specific health related centres and noted this may not have been a true representation of the population diagnosed with these conditions (Vaughn et al, 1999; Benazon et al, 2006; Invernizzi et al, 1991). Additionally, selection bias in recruitment was reported in two studies (Benazon et al, 2006; Wearden et al, 2002) due to a high proportion of families / couples refusing to participate. It was assumed that these relatives may already present with dysfunctional relational patterns or marital discord and therefore would have fallen in the high EE category.

Suitability of study design was only discussed in one study; Weddell (2010) suggested that utilizing a cross-sectional design made it difficult to reliably predict the
direction of causality. It is also difficult to entirely assess the complex illnesses and outcomes associated with TBI patients and draw a link between relative criticism and outcome. Gender specific groups adding to the limitation of studies were reported in two studies. While the sample of Bressi et al. (2009) only included male patients; Manne & Zautra (1989) had only recruited women patients. Both researchers noted that a different response may have been found if it was a mixed sample of both genders.

The majority of studies reviewed used an adapted version of the CFI while some applied the FMSS measure to assess partner or relative EE. As the CFI was adapted for the specific cohort studied, it is unclear to what extent this might have compromised the validity and reliability of the measure. Additionally, those researchers using the FMSS (Vitaliano et al. 1993 and Benazon et al. 2006) noted potential limitations associated with the accuracy in the classification of EE. Although it has been shown to have a strong predictive validity against the CFI, researchers have reported that while the CFI may classify some relatives as high in EE, the FMSS may score them as low in EE, thus underestimating high EE ratings (Hooley & Parker, 2006). These issues indicate that there is an ongoing need to establish a user-friendly, consistent and psychometrically sound measure of EE in the context of long term physical health problems.
Limitations of the present review

There were a number of limitations identified whilst conducting this review. For instance, creating a valid definition for long term health conditions was problematic. The National Institute for Health and Clinical Excellence (NICE) were unable to provide a definition and referred the query of defining long term health conditions to the World Health Organization (WHO) and Department of Health (DH). As these health organizations were unable to provide a list of conditions that would constitute as a long term health condition, further difficulties arose in establishing which illnesses represented a long term health condition and this may have resulted in some conditions being overlooked. Future reviews need to address these issues to establish clarity in what conditions are seen as long term in order to systematically guide their search.

Furthermore, in terms of neurological conditions, this review only accepted two studies (Vitaliano et al, 1993; Weddell, 2010) mainly due to the lack of literature published in peer reviewed journals investigating EE within neurological illnesses. Additionally, it is particularly important to consider that each illness has its own symptomological profile and they are therefore difficult to collectively put together in order to ascertain similarities and differences in relation to the role of EE. Finally, as a number of the reviewed studies had been the first studies of EE and the specific health condition in question, it is difficult to compare findings with similar literature in each specific field.
Clinical implications

The majority of studies in this review consistently advocate psychosocial family-based interventions to target critical and hostile attitudes in a household, psycho-education, improving patient’s coping and quality of life and working with couples and families to help improve reciprocal interactions (Vaughn et al, 1999; Bressi et al, 2009; Invernizzi et al, 1991; Manne & Zautra, 1989; Stanhope et al, 2003; Bressi et al, 2007; Vitaliano et al, 1993; Weddell, 2010). Such interventions could possibly aid in reducing some of the strain and challenges faced within families caring for a relative with a long term health condition, as well as supporting the adjustment needs of the family as a whole unit to cope with and manage the illness better. Furthermore, randomized control trials looking into family interventions to reduce EE, criticism or other negative psychosocial factors associated with the climate of a household may benefit in understanding the link between EE variables and outcome.

Literature has clearly illustrated that EE seems to influence both patients and relatives in terms of psychological distress, increased symptoms and adjustment to illness. Psycho-social interventions specifically designed to target EE levels that are impacting on patients and their relatives would, in theory, be beneficial in such circumstances. Within the psychiatric literature, researchers have investigated the effects of such interventions and drawn positive conclusions about the advantages associated with outcomes (Leff,
1982; Leff, Kuipers, Berkowitz & Sturgeon, 1985). Furthermore, psycho-education, social skills training and combined family therapy have all been effectively utilised in order to reduce negative EE climates and reduce relapse rates in schizophrenia (Anderson, Hogarty & Reiss, 1980; Hogarty, Anderson, Reiss, Kornblith, Greenwald, Ulrich & Carter, 1991; Xiong, Phillips, Hu & Wang, 1994). Systemic family based interventions have also been explored with the aim to reduce EE levels in families, where significant reductions in criticism and EOI components of EE have led to a better course of illness. In the psychiatric literature, as relapse rates have been proven to reduce after implementing interventions aimed at reducing high EE climates, then such interventions tailored to a chronic health population may prove to be valuable in clinical practice.

Conclusions and Future Research

Although the results of this study do not establish a concrete causal link between EE and poor outcome in long term health conditions, an alternative explanation could be that a circular relationship exists between the climate of a household and adjustment and course of illness. For instance, the severity and stages of an illness can evoke different responses from relatives and patients at different times. Other factors, such as life events or different circumstances surrounding social support could also contribute to a complex relational web. For instance, when illness is less severe and managed well, expressions of EE may be lower and healthier relational patterns are seen. However, when illness
progressively worsens, which is perhaps common in long term health conditions, EE levels in turn might worsen, causing ripples in the relational bond. Accordingly, this may lead to poor illness management, adjustment, coping or negative outcomes within both the patient and relative. Hooley and Richters (1995) initially drew attention to a circular relationship possibly existing between EE and relapse in their study; they suggested that it is likely that a patient’s negative or positive behaviours affect a relatives’ EE status and depending upon the EE status of the relative this may in turn influence their illness outcome. Developing and testing this circular EE-outcome hypothesis is perhaps the way forward for a better understanding of the impact of relational factors on illness outcomes.

Other aspects of EE, such as what drives a relative’s EE status or what type of personality traits exist between high / low EE relatives also warrants further investigation. Another debated issue in the literature is whether EE is universal or differs in how it is conceptualised in other cultures. This raises questions as to whether the same components of EE apply or whether they hold the same meaning and impact in relation to different health conditions in different cultures. A number of countries worldwide have studied the concept of EE, where different cultures have expressed a different meaning or impact towards the components of EE. For instance, in Indian families, hostility was seen to be a key factor associated with relapse rather than criticism (Leff, Wig, Ghosh, Bedi, Menon, Kuipers, Korten, Ernberg & Sartorius, 1987). Tanaka, Mino & Inoue (1995) found that in Japan, patients diagnosed with schizophrenia living with high EOI relatives were
most prone to relapse. Understanding these cultural differences may enhance our understanding of how to tailor clinical interventions according to ethnicity.

The links between EE and long term health conditions is clearly an area that requires further investigation. Longitudinal studies may illustrate fluctuations of EE measured over time in relation to stages of illness. Also, as previously noted, gender, dyadic and cultural differences would increase our knowledge of this complex psychosocial factor. Furthermore, certain components of EE, such as, warmth and positive comments, seem to be quite limited in the literature; therefore, future research would provide insight into their specific roles and whether this leads to positive outcomes in illness. Finally, replication studies, as well as exploring other health related conditions, would enhance our understanding of the drivers of EE within the realm of health related conditions. An area particularly lacking in research is how the concept of EE may affect adjustment to neurological or comorbid conditions associated with an acquired or traumatic brain injury. For instance, a wide body of research has illustrated that the majority of people who experience a stroke are discharged for the large part of their rehabilitation to their families. A supportive family structure would therefore seem pivotal to effective adjustment in stroke and ensuring that other comorbid conditions, such as post stroke depression, do not develop or worsen.
References


Johnson, S. Deputy Director. Department of Health – personal correspondence response received 14 April 2011.


Part Two: Empirical Paper

This paper is written in the format ready for submission to Brain Injury.

Please see appendix 2.2 for the guidelines for authors.

Word count (including tables and references): 11,053
Post Stroke Depression and Expressed Emotion

Naheed Rashid, Chris Clarke & Miles Rogish

Correspondence should be addressed to:
Department of Clinical Psychology and Psychological Therapies, The University of Hull, Hull, HU6 7RX, England
Telephone contact number: +44 1482 464106 Fax number: +44 1482 464093
E-mail correspondence: n.rashid@2008.hull.ac.uk
Abstract

Primary objective/s: This study examined the role of expressed emotion (EE) in post stroke depression (PSD) and the extent to which partner / spouse EE interacted with lesion laterality to determine levels of PSD. The relationship between (i) lesion location and levels of PSD and (ii) levels of EE and levels of PSD were investigated. The role of perceived EE from stroke survivors in PSD was also explored.

Design: Cross-sectional, between subjects design.

Methods: Measures applied to stroke survivors included Extended Activities of Daily Living Scale (EADL), Post Stroke Depression Rating Scale (PSDRS) and Level of Expressed Emotion Scale (LEE); spouse / partners completed the LEE.

Results: The interaction between lesion laterality and levels of partner / spouse EE on PSD was not statistically significant (p=0.63, F=0.24 (1,56)df). However, a clear relationship was found between lesion laterality and PSD (p=0.028). As levels of spouse / partner LEE scores increased, levels of PSD also increased (p=0.039). Perceived EE scores illustrated a significant interaction between lesion laterality and levels of EE on PSD (p=0.005, f=8.591, df=1,56).

Conclusion: Whilst spouse / partner EE scores showed no interaction with lesion laterality to determine levels of PSD, a significant interaction was found when compared with stroke survivor perceived EE scores. Furthermore, left hemisphere (LHS) stroke survivors reported higher levels of depression than right hemisphere (RHS) stroke survivors. As levels of EE increased, PSD also increased with LHS being greater than RHS. Further research is warranted to clearly identify the impact of EE in health conditions or how perceived EE may have a greater significance in illness outcomes.

Keywords: Post stroke depression, expressed emotion.
Introduction

According to The Stroke Association, 150,000 people in the UK have a stroke each year [1]; it is seen to be the third most common cause of death and is the single most widespread cause of severe and chronic disability [2]. The disrupting effects of a stroke often result in multiple and varying levels of motor, emotional, cognitive and sensory impairments. This can lead to a permanent effect on an individual’s social and occupational functioning, subsequently impacting on a person’s overall quality of life. Depression is one of the most common psychological difficulties to occur after a stroke [3] and is likely to develop in one third of stroke survivors within the first few months of their injury [4]. Despite the high prevalence of post-stroke depression (PSD), identifying symptoms and providing treatment is often overlooked in clinical practice [5, 6]. Research has suggested that PSD can lead to increased mortality rates [7], impairs effective recovery in cognitive functioning [8], and can lead to low motivation in patients, thus impacting upon effective rehabilitation and recovery [9].

The causes of PSD remain controversial amongst researchers. Although existing research suggests a link between PSD and location of brain lesion, findings in this area are not conclusive. The majority of research indicates that PSD is more common following left and anterior hemispheric injury [5, 10 - 12], however, a number of other studies have
found conflicting evidence, suggesting that right and posterior hemispheric damage is more prevalent in PSD [13 - 16]. In contrast to both of these findings, some studies have found no association between lesion laterality and PSD [14, 17 - 20]. In order to understand the contradictions reported in the literature regarding the association of lesion laterality and PSD, some researchers have suggested that methodological disparity in participant selection may lead to conflicting results [21 – 23]. For instance, variations between the length of time lapsed after suffering a stroke and assessment for PSD may affect the outcome of results [24]. Similarly, the use of different screening measures used to assess PSD adds to the methodological difficulties in evaluating studies [25].

To date, no research has attempted to explore whether the effect of laterality of brain lesion on PSD might be influenced or mediated by other psycho-social factors but such factors have been implicated separately in PSD. Research has indicated that family members, most commonly a patient’s spouse, are a primary source of support during and after a health crisis such as a stroke [26, 27]. Social support is a vital factor in adjustment and rehabilitation and research has illustrated a clear association between the quality and quantity of social contact and the presence of depression following a stroke [23, 28]. Astrom, Adolfsson and Asplund, (1993) suggest, “Under the stressful condition of an acute stroke, being without the social support of a family seems to promote the development of depression” [29: pg 981], thus highlighting the importance of supportive relationships and its link to PSD.
The quality of supportive relationships around a person with a mental or physical health problem has been conceptualised in different ways but prominent amongst these is the concept of ‘expressed emotion’ (EE) which refers broadly to the emotional climate around a person with a disorder or impairment [30]. Originally developed to predict and explain rates of relapse in schizophrenia [31], EE has since been linked to poorer outcomes in adjustment and negative behaviour in chronic health problems [32, 33]. For instance, there is now an increasing amount of literature concerning the role of EE in unipolar depression [34, 35], bipolar disorder [36 – 38], eating disorders [39], chronic heart failure [40] and Alzheimer’s disease [41]. Furthermore, research has illustrated the relationship between EE and adjustment in dementia [42] and diabetes mellitus [43].

EE is most often conceptualised as a trait-like measure of carers’ levels of criticism, emotional over-involvement (EOI), hostility, warmth and positive comments and has generally been rated from a carers’ point of view using a semi-structured interview known as the Camberwell Family Interview (CFI) [44]. Due to the lengthy process of this interview and training required to administer it, alternative assessment measures have since been developed in an effort to reduce the time taken for measurement and make it more user friendly. Questionnaire based measures, such as the Level of Expressed Emotion scale (LEE) [45], have been reviewed and compared to the CFI [46 - 48]. Such work indicates that the LEE scale is a valid and reliable alternative measure of EE. Another advantage of the LEE scale is that it incorporates individual measures for the patient and
carer, which can be administered to both separately. This enables researchers to explore patients’ perceptions of EE, which may be important in understanding how the experience of emotions in close relationships might be linked with the occurrence of PSD.

As problems in regulating emotions after a brain injury have been widely documented [49 – 51], measuring EE from both the patient and carer perspective is therefore potentially significant as a way of illustrating any discrepancies found between patients perceived EE and actual EE ratings from the relatives’ perspective. This could subsequently shed light on the patient’s subjective views of the relational climate of the household, as well as the reciprocal relationship with their spouse or partner. In addition, this also allows for the investigation of perceptual differences between patient groups (e.g. left versus right hemispheric lesions).

Given the potential for EE to influence levels of PSD and the effect that lesion location can also exert on PSD, this present research investigated the extent to which spousal EE might interact with lesion laterality to determine levels of PSD in stroke survivors. Furthermore, given that perceptual differences may arise in EE ratings between stroke survivors and spouse or partners, and some prior research suggests that perceptions of EE on the part of the patient are associated with adjustment and outcomes in other conditions [52 - 54], additional exploratory research was carried out to examine
the extent to which stroke survivors’ perceptions of EE may interact with lesion laterality to determine levels of PSD. Providing a greater insight into the role of EE in adjustment to stroke and how organic and psycho-social factors might relate to each other post-stroke will therefore have implications for facilitating adjustment and rehabilitation for stroke survivors.

A cross sectional, between subjects design was applied to explore the following research questions and main hypotheses:

**Main Research Question (1):** Is there an interaction between lesion laterality and levels of spouse / partner EE on levels of PSD?

**Main Hypotheses (1):** Stroke survivors with a left lesion stroke who also live in a high EE climate will have higher levels of PSD compared to those with a right lesion stroke and living in a low EE climate.

**Research Question (2):** What is the relationship between lesion location and levels of PSD?

**Hypotheses (2):** The level of PSD will be higher in patients who have sustained a left hemispheric stroke compared with those with a right hemispheric stroke.

**Research Question (3):** What is the relationship between levels of EE and levels of PSD?
Hypotheses (3): The level of EE will predict levels of PSD; a positive association will be found between increased EE and PSD.

Exploratory Research Question: Is there a relationship between stroke survivors’ perceived EE scores and lesion laterality on levels of PSD?

Hypotheses: Stroke survivors with a left lesion stroke who perceive to be living in a high EE climate will show higher levels of PSD compared to those with a right lesion stroke perceiving to be living in a low EE climate.
Method

Design: A cross sectional, between subjects design was employed. The main independent variable was side of injury (left / right lesion stroke) and dependent variable was the depression scores taken from the Post Stroke Depression Rating Scale (PSDRS). The Level of Expressed Emotion (LEE) score was the proposed moderator and covariate.

Participants: Participants were recruited through Community Stroke Teams based at three NHS hospital sites in England. The numbers recruited from each site varied due to participant availability and identification.

Prior data [55] indicated that the standard deviation of the total EE score would be approximately 20 in both participant groups and that the raw standard deviation of the PSDRS scores would be around 9.5 [23]. A correlation of 0.5 between the depression measure and the EE measure was assumed. The standard deviation of the regression errors was estimated to be approximately 8.23. This determined that the study would detect true differences in the slopes of the regression lines of approximately 0.3 with 80% power when a 5% two-tailed significance level is used. A power calculation using PS Power and Sample Size Calculations [56] indicated a sample size requirement of 30 left lesion stroke participants and 30 right lesion stroke participants and their partner / spouses, which was achieved.
A total of 120 participants were recruited; this involved 60 stroke survivors together with their partners/spousal carers who met the following inclusion criteria:

_Inclusion and exclusion criteria for stroke survivors_

Stroke survivors were identified and invited to participate on the basis of the following criteria. A clinical diagnosis of ischaemic or haemorrhagic stroke had to be confirmed and stated in their medical records; to be able to speak English, understand the participant information sheet and provide informed consent to take part; to be able to communicate verbally well enough to complete self-report questionnaires or verbally understand measures that are administered as a semi-structured interview; to be the partner or spouse of their carer and have lived with them for at least one year prior to their stroke and also to have lived at home with their partner or spousal carer for between 3 months and two years following discharge from hospital or inpatient rehabilitation services.

Stroke survivors were excluded from this study if they had suffered a severe stroke and were at risk of dying. They were also excluded if they had suffered a bilateral hemispheric stroke or had severe receptive speech and / or language difficulties; if they lived in residential care away from their partner or spouse; or lived at home but had full-time care from an outside agency (i.e. more than 28 hours per week); and if they had a confirmed clinical diagnosis of progressive dementia.
Inclusion criteria for partners or spousal carers

Partners or spousal carers were invited to take part if they were able to understand the participant information sheet and provide informed consent to take part. They had to be the partner or spouse of the stroke survivor and had to have lived at home with the stroke survivor for at least one year prior to their stroke and up to 3 months to two years following discharge from hospital or inpatient rehabilitation services. Partners or spouses had to be able to speak English and identify themselves as the main source of support or primary carer for the stroke patient. Finally, partners or spouses had to have had no prior history of stroke or diagnosis of progressive dementia.

Description of the sample

All participants (n = 120) lived in the East Riding of Yorkshire district of England and were mainly white-British, with the exception of one stroke survivor and spouse who were of Pakistan origin. Furthermore, all participants were heterosexual couples with the exception of one homosexual couple. Table 1 details the demographic information regarding the participants.
Table 1: Participant demographic information

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>Stroke Survivor</th>
<th>Spouse / Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>n = 43</td>
<td>n = 16</td>
</tr>
<tr>
<td>71.7% of the sample</td>
<td>26.7% of the sample</td>
<td></td>
</tr>
<tr>
<td>Age range 44 to 84</td>
<td>Age range 46 to 80</td>
<td></td>
</tr>
<tr>
<td>Mean age = 68.14</td>
<td>Mean age = 67.81</td>
<td></td>
</tr>
<tr>
<td>sd = 10.094</td>
<td>sd = 9.189</td>
<td></td>
</tr>
<tr>
<td>10 smoked</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RHS – n=7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LHS – n=3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>n = 17</td>
<td>n = 44</td>
</tr>
<tr>
<td>28.3% of the sample</td>
<td>73.3% of the sample</td>
<td></td>
</tr>
<tr>
<td>Age range 33 to 88</td>
<td>Age range 27 to 81</td>
<td></td>
</tr>
<tr>
<td>Mean age = 65.35</td>
<td>Mean age = 64.89</td>
<td></td>
</tr>
<tr>
<td>sd = 13.477</td>
<td>sd = 11.376</td>
<td></td>
</tr>
<tr>
<td>3 smoked</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RHS – n=1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LHS – n=2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Sample</td>
<td>Overall age = 33 to 88</td>
<td>Overall age = 27 to 81</td>
</tr>
<tr>
<td>Mean age = 67.35</td>
<td>Mean age = 65.67</td>
<td></td>
</tr>
<tr>
<td>sd = 11.108</td>
<td>sd = 10.839</td>
<td></td>
</tr>
</tbody>
</table>

Procedure

Ethical approval was granted by South Humber Research Ethics Committee on the 26th July 2010 (please refer to appendix 3 for confirmation letter and appendix 4 for Humber NHS Foundation Trust approval letter) which was subject to Research and Development approval from selected sites for participant recruitment (please refer to appendix 5 for approval letters for each site).
Out of the 5 sites approved (named site 1, 2, 3, 4 & 5) for participant recruitment, only 3 were successful in providing participants. Sites 1 and 2 merged into 1 catchment area and acted as one team; and site 5 were unable to provide participants due to structural changes taking place in the stroke unit. Site 1 & 2 is a 24 bedded acute stroke unit and the staff team are responsible for supporting patients in the community following discharge from the acute setting. Site 3 comprises a 25 bedded unit for acute stroke care and rehabilitation. It is a purpose designed stroke unit and the team are responsible for day-care facilities as well as integrative support following discharge. Site 4 is a 15 bedded direct admissions acute stroke unit and caters for a large catchment population. It provides support to 3 further rehabilitation wards in the Trust and ongoing support after discharge. Due to the structural changes of site 5, description of this site was unobtainable.

Meetings with key members of each stroke team, other than the team at site 5, were held and a brief introduction of the study was presented. Key team members were given information relating to participant inclusion / exclusion criteria, covering letter and information packs.

Consequently, 57 couples were identified by the stroke team from sites 1 and 2, out of which 46 agreed to take part (81% of the identified participants). For the remaining
11 participants, 4 did not want to take part, 2 had moved to a residential care home, 2 had changed address and could not be contacted on the telephone, 1 stroke survivor had become widowed and 2 stroke survivors had since passed away. 15 couples were identified by site 3, out of which 9 agreed to take part (60% of the identified participants). For the remaining 6 participants, 3 did not want to take part, 1 had dementia and did not meet the full criteria for this study and 2 stroke survivors had become widowed. 11 couples were identified by site 4, out of which 5 agreed to take part (45% of the identified participants); this made up the total required number for this study and no further participants were approached. Nevertheless, for the remaining 6 participants, 2 did not want to take part, 3 had recently moved to a Nursing Home and 1 had dementia.

All identified participants (n = 83) were sent a cover letter (please refer to appendix 7.1) and an additional cover letter on behalf of sites 1 and 2 stroke team was sent to participants identified by them (please refer to appendix 7.2). An information pack was enclosed with the cover letters (please refer to appendix 7.3 and 7.4). Participants were advised in the cover letter that the primary researcher would contact them by telephone within 24 hours of receiving the letter and information pack to ascertain whether they would like to take part in this study.
Once interest in taking part in this research had been established, a convenient appointment was arranged with each participant dyad; all participants requested a home visit to conduct the research. Prior to obtaining consent, the couple (stroke survivors and partner / spouses) were verbally advised of the research and details of their involvement relating to the study were given. The couple were then given the opportunity to raise any questions or clarification regarding taking part. Written consent was obtained from both stroke survivor and partner / spouse (please see appendix 7.5 and 7.6).

The partner / spouse of the stroke survivor was asked to complete a Demographic Information Sheet (please refer to appendix 7.7) and the ‘relative’ version of the LEE scale. They were requested to do this in another room while the stroke survivor remained with the researcher. The stroke survivor was initially asked to complete the EADL measure; this was followed by the ‘client’ version of the LEE scale and the PSDRS measure. The administration of the measures carried out with each stroke survivor was alternated to avoid order effects. Following completion of all measures, stroke survivors and their partner / spouses were invited to ask any questions or talk about anything they had found distressing during this process.

Out of 60 couples seen, no-one reported any distress during the data collection process, however, 4 reported difficulties in other areas and gave verbal consent for their
stroke team to be advised. Difficulties included referrals to be chased up, stroke team to be advised of recent physical problems and a re-assessment from occupational therapy. The relevant stroke teams were informed of each query.

All participants were thanked for their participation and given the option to be informed of the research findings at the end of the study by way of a feedback letter being posted to them. The total number of participants (n = 120) welcomed the option of receiving feedback of the research findings.

Measures for stroke survivors and spouse / partners

*Nottingham extended activities of daily living scale (EADL)* [57] – This scale provides a brief assessment of independence in instrumental activities of daily living and contains mobility, kitchen, domestic and leisure subscales. The EADL scores range from 0-22, higher scores indicate greater ability in instrumental activities of daily living and lower scores in the range indicate an impaired ability. Research has shown this scale to be a suitable measure of assessment with good reliability and construct validity [58, 59]. This measure was included to assess stroke survivors’ general level of functional ability. See appendix 8.1 for an example of this measure as given to stroke survivors.
Post Stroke Depression Rating Scale (PSDRS) [60] – This scale is used to describe and measure depressive symptoms and relies less on symptoms that can be due to a stroke injury itself, such as vegetative and sleep disturbances. The scale comprises 10 sections which consider the following different components of post stroke depression: (1) depressed mood; (2) guilt feelings; (3) thoughts of death and / or of suicide; (4) vegetative disorders; (5) apathy and loss of interest; (6) anxiety; (7) catastrophic reactions; (8) hyper-emotionalism; (9) anhedonia; and (10) diurnal mood variations. The scores for each section range between 0-5 with the exception of (10) diurnal mood variations which is not included in the composite score. Quaranta, Marra & Gainotti (2007) found this scale to be very effective with good test-retest reliability and sensitive towards patients affected by functional depressive disorders [61]. See appendix 8.2 for an example of this measure as given to stroke survivors.

Level of Expressed Emotion (LEE) [45] – This is a self report questionnaire designed to measure levels of EE in a household. It consists of four sub-scales: lack of emotional support, intrusiveness, irritation and criticism. Both ‘client’ (stroke survivor) and ‘relative’ (partner / spousal carer) versions were administered in order to assess levels of EE. A comparison study with the Camberwell Family Interview established the validity and value of the LEE and this is seen to demonstrate sound internal consistency and reliability [48]. See appendix 8.3 and 8.4 for an example of this measure together with answer sheet and scoring key as given to stroke survivors and spouse / partners.
Statistical analysis

The statistical software package SPSS version 17.0 was used to analyse the data of this research. To test the hypothesis that levels of spouse / partner EE affect levels of depressive symptom scores differently for left and right hemispheric lesion strokes, a regression of the PSDRS on LEE (relative version) was carried out allowing for different regression slopes (beta coefficients) for the two locations. A test of equality of regression slopes (beta coefficients) (i.e. an interaction between LEE and lesion location) was performed. An ANOVA test was used to check whether there was an interaction between lesion location and levels of EE on PSD. Furthermore, the following model checks were carried out; (i) the residuals were checked to see whether these were normally distributed and (ii) the predicted values were plotted against the standardised residuals.

The same interactional analysis was repeated with stroke survivor perceived LEE scores, which were used as a continuous variable in the main ANOVA analysis. O’Farrell, Hooley, Fals-Stewart & Cutter (1998) similarly used the EE measure as a continuous variable in their analysis and applied median splits to categorize high and low EE groups [62]. However, categorizing the composite measure of EE into low and high groups was not carried out in this research. Researchers have highlighted disadvantages to using median splits in continuous variables and dichotomising the LEE scores by a median split would result in a loss of effect size and thus reduce power [63]. Descriptive analyses of
the differences between stroke survivor and spouse/partner LEE scores were also carried out. A local linear regression (LLR) smoother curve was also fitted to the data as an informal graphical check for a non-linear relationship between PSDRS and LEE. See appendix 9 for output files of the results of the main analysis.
Results

Descriptive statistics

The length of time stroke survivors (n = 60) had spent in hospital or rehabilitation services ranged between 1 week to 35 weeks. The mean length of time stroke survivors spent in hospital or rehabilitation services was 10.07 weeks (sd = 8.78). The mean number of months since stroke was 10.75 (sd = 7.0) and ranged between 3 and 31 months.

The length of time stroke survivors and their partners / spouses had lived together prior to their stroke ranged between 2 years to 60 years. The mean length of time couples had lived together was 37.32 years (sd = 16.7) and the mean length of time they had been living at home since their stroke was 38.65 weeks (sd = 24.3) which ranged between 12 weeks to 104 weeks (3 months to two years).

46 couples (76.7% of the sample; stroke survivors and their partner / spouses) had no other people living in the same household as them. 10 couples (16.7%) had 1 person living with them. 4 couples (6.7%) had 2 people living with them.

26 stroke survivors (43.3%) reported no other significant health problems and 51 stroke survivors (85%) reported no prior history of depression. 34 stroke survivors (56.7%)
reported having other significant health problems and 9 stroke survivors (15%) reported having a prior history of depression. Table 2 and 3 illustrates the between group differences of significant health problems and prior history of depression in stroke survivors. Chi-square tests were carried out to test for significance; stroke survivor significant health problems were not significantly different between LHS and RHS groups (Chi-Square = 0.27, df=1, p=0.602) and stroke survivor prior history of depression was not significant between LHS and RHS groups (Chi-Square = 1.176, df=1, p=0.278).

<table>
<thead>
<tr>
<th>Side of injury</th>
<th>RHS</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18</td>
<td>12</td>
<td>30</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>14</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>26</td>
<td>60</td>
</tr>
</tbody>
</table>

*Table 2: Stroke survivor between group differences in significant health problems*

<table>
<thead>
<tr>
<th>Side of injury</th>
<th>RHS</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
<td>27</td>
<td>30</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>51</td>
<td>60</td>
</tr>
</tbody>
</table>

*Table 3: Stroke survivor between group differences in prior history of depression*
In relation to partner / spouses, 29 (48.3%) reported significant health problems and 31 (51.7%) reported no significant health problems. Chi-square test showed that levels of partner / spouses significant health problems were not significantly different between LHS and RHS groups (Chi-Square = 1.669, df=1, p=0.196). Table 4 below illustrates the between group differences in spouses / partners reports of significant health problems.

<table>
<thead>
<tr>
<th>SP Significant Health Problems</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Side of injury</td>
<td>RHS</td>
</tr>
<tr>
<td>Side of injury</td>
<td>LHS</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

*Table 4: Spouse / partner (SP) between group differences in significant health problems*

Only 3 stroke survivors (5%) received respite care between 4 to 5 weeks per year (1 RHS injured stroke survivor reported 5 weeks per year and 2 LHS injured stroke survivors reported 4 weeks each per year). The mean amount of respite care was 1.08 weeks (sd = 0.381). 16 stroke survivors, an equal ratio of 8 RHS and 8 LHS injured received between 1 hour to 25 hours per week support from an outside care agency. The mean amount of support from outside care agencies was 11.97 weeks (sd = 8.53).
Scores for EADL, PSDRS, LEE

The following tables provide general information about the participant scores for each measure. All measures showed a positive skewed distribution to the right. No outliers were found for the EADL measure and the LEE measure for the spouse / partners. The 2 outliers found in the PSDRS measure were checked and it was established that they were not recording errors and were therefore retained in the statistical analysis. The stroke survivor LEE scores indicated 1 outlier; similarly this was not a recording error and was retained in the statistical analysis. Table 5 illustrates the minimum and maximum stroke survivor scores for the EADL, PSDRS and LEE. Table 6 illustrates the minimum and maximum range of spouse / partner scores for the LEE.

<table>
<thead>
<tr>
<th>Stroke Survivor Measures</th>
<th>Minimum score</th>
<th>Maximum score</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extended Activities of Daily Living (EADL)</td>
<td>1</td>
<td>22</td>
<td>10.95</td>
<td>6.69</td>
</tr>
<tr>
<td>Post Stroke Depression Rating Scale (PSDRS)</td>
<td>0</td>
<td>33</td>
<td>13.23</td>
<td>7.96</td>
</tr>
<tr>
<td>Level of Expressed Emotion Scale (LEE)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male LEE score (n = 43)</td>
<td>2</td>
<td>44</td>
<td>18.05</td>
<td>10.90</td>
</tr>
<tr>
<td>Female LEE score (n = 17)</td>
<td>8</td>
<td>31</td>
<td>14.65</td>
<td>5.99</td>
</tr>
<tr>
<td>LEE waking hours spent together (Weekday)</td>
<td>2</td>
<td>20</td>
<td>14.15</td>
<td>3.56</td>
</tr>
<tr>
<td>LEE waking hours spent together (Weekend)</td>
<td>10</td>
<td>36</td>
<td>28.82</td>
<td>6.25</td>
</tr>
</tbody>
</table>

Table 5: Stroke survivor EADL, PSDRS and LEE scores
### Spouse / Partner Measures

<table>
<thead>
<tr>
<th>Measures</th>
<th>Minimum score</th>
<th>Maximum score</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Expressed Emotion Scale (LEE)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male LEE score (n = 16)</td>
<td>2</td>
<td>29</td>
<td>9.94</td>
<td>6.14</td>
</tr>
<tr>
<td>Female LEE score (n = 44)</td>
<td>2</td>
<td>27</td>
<td>13.45</td>
<td>6.18</td>
</tr>
<tr>
<td>LEE waking hours spent together (Weekday)</td>
<td>2</td>
<td>20</td>
<td>14.22</td>
<td>3.71</td>
</tr>
<tr>
<td>LEE waking hours spent together (Weekend)</td>
<td>12</td>
<td>36</td>
<td>29.03</td>
<td>6.18</td>
</tr>
</tbody>
</table>

*Table 6: Spouse / partner LEE scores*

**Between group differences in Measures**

Stroke survivors with a RHS injury appeared to have greater functional abilities and scored higher on the EADL measure (mean=11.40, sd=6.81) than those with a LHS injury (mean=10.50, sd=6.66). A t-test for equality of means indicated that this difference was not significant (p=0.607, t=.518, df=58).

In terms of the PSDRS measure, stroke survivors with a RHS injury had lower scores (mean=10.87, sd=6.51) than those with a LHS injury who scored higher in depressive symptoms (mean=15.60, sd=8.66). A t-test for equality of means was significant (p=0.02, t=-2.39, df=53.83), indicating that stroke survivors in the LHS group had higher PSDRS scores than those in the RHS group.
The stroke survivors in the RHS injured group had lower scores on the perceived LEE scale (mean=16.40, sd=9.35) than those in the LHS injured group (mean=17.76, sd=10.42). A t-test for equality of means indicated this was not significant (p=0.595, t=-0.535, df=58). Similarly, spouse / partners in the RHS injured group had lower scores in the LEE scale (mean=11.93, sd=6.85) than those in the LHS group (mean=13.10, sd=5.79) but this difference was not significant (p=0.479, t=-0.712, df=58).

*Stroke survivor and spouse / partner differences in LEE scores*

In comparing stroke survivor and spouse / partner LEE scores, results indicated that stroke survivors, on average, had higher LEE scores than their respective spouses / partners. The overall mean of differences between the couples’ LEE scores was -4.57, (sd = 8.49). A paired samples t-test was conducted to compare the stroke survivor and spouse / partner LEE scores. There was a significant difference in the couples’ LEE scores (t=-4.166, df=59, p<0.001). These results indicate that stroke survivor LEE scores are significantly higher than that of their spouse / partner LEE scores. Between group differences in terms of side of injury indicated 18 LHS and 20 RHS stroke survivors perceived EE to be higher than their spouse / partners. In contrast, 9 LHS and 9 RHS stroke survivors perceived EE to be lower than their spouse / partners. Only 4 stroke survivors and spouse / partners had identical scores in the LEE measure (LHS: n=3; RHS: n=1).
Main research question: Is there an interaction between lesion laterality and levels of EE on levels of PSD?

The first independent variable was lesion laterality, a factor with 2 levels, the second independent variable was EE, an interval level variable, and the dependent variable was the PSDRS score. An F-test was used to test for an interaction between lesion laterality and EE in a general linear model. It was predicted that an interaction would be found between lesion laterality and levels of EE in their effects on PSD. Specifically, patients with a left lesion stroke living in a high EE climate would show higher levels of PSD compared to those with a right lesion stroke living in a low EE climate. However, contrary to this prediction, the interaction was not statistically significant with reference to relative EE (p=0.63, F=0.24 with (1, 56)df. The graph in figure 1 illustrates the lack of interaction found between left and right lesion stroke survivors with levels of PSD and EE.

Figure 1: PSDRS and relative LEE scores for left (LHS) and right (RHS) lesion stroke survivors
Secondary research questions: What is the relationship between lesion location and levels of PSD? What is the relationship between levels of EE and levels of PSD?

The first independent variable was lesion laterality, a factor with 2 levels, the second independent variable was EE, an interval level variable, and the dependent variable was the PSDRS score. F-tests were used to test for differences between left and right lesions and for an effect of EE on PSDRS score after removal of the interaction term between lesion laterality and EE from the general linear model. The graph in figure 1 illustrates the relationship found between left and right lesion stroke survivors with levels of PSD and EE. Although no interaction was found between lesion laterality and levels of EE on PSD, a clear relationship between lesion location and levels of PSD was found (p=0.028). Firstly, right lesion stroke survivors had lower depressive symptoms than left lesion stroke survivors. Secondly, as the spouse / partners’ LEE scores increased, the predicted levels of PSD also increased (p=0.039). The estimated difference of the predicted PSDRS scores between left and right lesion side was 4.354 with a 95% confidence interval (0.488, 8.22) with left lesion side being higher than right lesion side. The effect size was 0.08. The estimate of the slope of regression line was 0.326 with a 95% confidence interval of 0.017 up to 0.634 for the level of EE. The effect size was 0.07.

Predictions of PSDRS scores were calculated based on spouse / partner LEE scores and the extremes of the population (5th and 95th percentiles) were used in order to avoid
difficulties posed with median split analysis. Therefore, the following predictions between spouse / partners LEE and PSDRS scores were noted in relation to stroke survivor side of injury: spouse / partners LEE score of 3.05 (5th percentile) predicted a PSDRS score of 9.67 (RHS) and 7.44 (LHS); spouse / partners LEE score of 24.85 (95th percentile) predicted a PSDRS score of 12.86 (RHS) and 27.02 (LHS). This suggests that RHS stroke survivors living with a low EE spouse / partner are predicted to score marginally higher in PSDRS than LHS stroke survivors. Whereas, LHS stroke survivors living with a high EE spouse / partner are predicted to score significantly higher in PSDRS than RHS stroke survivors.

*Exploratory Research Question: Is there a relationship between perceived EE scores, lesion laterality and PSD?*

The first independent variable was lesion laterality, a factor with 2 levels, the second independent variable was perceived EE, an interval level variable, and the dependent variable was the PSDRS score. An F-test was used to test for an interaction between lesion laterality and perceived EE in a general linear model. On the basis of existing literature indicating that perceived EE is also linked to health-related outcomes [57 – 59], it was predicted that an interaction between lesion laterality and levels of stroke survivor perceived EE on the effect of PSD would be found. Specifically, it was hypothesised that stroke survivors with a LHS stroke perceiving themselves to be living in a high EE climate would show higher levels of PSD compared to those with a right lesion stroke perceiving themselves to be living in a low EE climate. Interestingly, a statistically significant
interaction between lesion laterality and levels of perceived stroke survivor EE was found (p=0.005, F=8.591, error df=1, 56). The effect size for the interaction was 0.133. The slope difference between LHS and RHS groups shown from the parameter estimate table is -0.498, indicating that in stroke survivors with a LHS injury depression increases as the stroke survivors LEE scores increase and is greater than that of stroke survivors with a RHS injury. Figure 2 presents this interaction between lesion laterality and levels of perceived stroke survivor EE.

As above, predictions were calculated based on stroke survivor LEE scores taken from the 5th and 95th percentiles. The following predictions between stroke survivor LEE and PSDRS scores were noted in relation to side of injury: stroke survivor LEE score of 4.05 (5th percentile) predicted a PSDRS score of 9.57 (RHS) and 6.85 (LHS); stroke survivor LEE score of 36.95 (95th percentile) predicted a PSDRS score of 11.69 (RHS) and 19.82 (LHS). This suggests that stroke survivors who perceive to be living in a high EE climate are predicted to markedly differ in PSD depending upon their side of stroke injury, LHS injured stroke survivors being predominantly higher in PSD than RHS injured stroke survivors.
Model Checking

The plots of standardized residuals predicted values did not have any discernable pattern, indicating no problems with the model and the residuals were normally distributed. The Kolmogorov-Smirnov test of normality was carried out to check the normality of residuals (statistic = 0.057, df=60, p=0.2). This suggests that the normality assumption was reasonable.
Discussion

This was the first study of its kind to investigate the extent to which spousal EE may interact with lesion laterality to determine levels of PSD in stroke survivors. The prediction that stroke survivors who had a left hemisphere stroke (LHS) injury living in a high EE climate would experience a higher degree of PSD compared to those with a right hemisphere stroke (RHS) injury living in a low EE climate was not directly supported. However, whilst the main results indicated no interaction between spousal EE with lesion laterality on levels of PSD, secondary predictions regarding the relationship between (i) lesion location and level of PSD and (ii) level of EE and level of PSD were supported. Interestingly, the exploratory analysis carried out investigating the interaction between stroke survivors’ perceived EE scores and lesion laterality on levels of PSD was significant. Stroke survivors’ with a LHS injury who perceived to be living in a high EE climate significantly had higher levels of PSD compared to those with a RHS injury perceived to be living in a low EE climate. This finding clearly indicates that the role of stroke survivors’ perceived EE has a greater impact in PSD than actual EE ratings from their spouses.

In relation to the main hypothesis of this study, a number of factors could account for the apparent absence of an interaction between lesion location and spousal EE on PSD levels. For instance, it is possible that the aetiology of PSD is predominantly associated with a direct biological pathway involving the relative functions of the right and left
hemispheres, suggesting that hemispheric lesion location is highly correlated with depression post stroke [12, 23, 64]. Thus, it could be argued that regardless of the emotional climate in a household, location of stroke will inevitably predict the development of PSD. Alternatively, another view to consider is whether stroke survivors own subjective perceptions of their environment, derived from perceived EE scores, has a greater influence on PSD and is more dominant than spousal EE. This fits with the exploratory findings of this research indicating stroke survivors perceived EE was found to be more significant than spousal EE in interacting with lesion location to predict levels of depression. Implications of these findings are reviewed in the later part of this discussion.

Two further key findings emerged from this study. Firstly, LHS stroke survivors reported significantly higher PSD symptoms than RHS stroke survivors. This echoes a wide body of research examining the association between lesion laterality and PSD, specifically that stroke survivors with a LHS injury are more likely to present with higher PSD than those with a RHS injury [10-13]. As noted above, from a biological perspective, research has shown that a left lesion damage that is in close proximity to the frontal pole leads to higher prevalence in PSD [12]. Furthermore, the left side of the brain is largely responsible for language and communication, therefore, the presence of language disorders, such as, aphasia is common in stroke survivors with a LHS injury. It could be argued that severe language impairments can lead to several difficulties, such as, the inability to communicate, read, write or understand speech. Consequently, higher
dependency in others and the possible frustrations of being unable to express how they feel could be linked to why people with a LHS injury are more prone to developing PSD. Alongside these difficulties, other factors that may be seen to increase PSD are the effects of hemiplegia, hemiparesis or memory problems (which can occur in both LHS and RHS injuries).

Another explanation for the higher levels of PSD found in left injured stroke survivors comes from the emotional processing literature. Several theories have been suggested regarding the role of hemispheres in relation to emotional processing; for instance, the right hemisphere hypothesis suggests that the right hand side of the brain is dominant for processing all emotions [65]. Meanwhile, the valence hypothesis splits the hemispheres in relation to emotional processing and suggests the right hemisphere holds or processes negative emotions whilst the left hemisphere holds or processes positive emotions [66]. As this research has shown, the impact of a high EE environment leads to higher depression in stroke survivors with a left hand side injury. Exploring this in relation to the valence hypothesis, it could be argued that left injured stroke survivors are impaired in their ability to detect and experience positive emotions.

Alternatively, the impact of a high EE environment in stroke survivors with a RHS injury could suggest that as their ability to process negative emotions is impaired, they do
not respond to negative stimuli or in this case a negative high EE environment, thus lower scores in depression are found. This could also help clarify the finding that stroke survivors perceived EE significantly interacted with side of injury rather than actual spouse / partner EE scores. Thus, it could be argued that left lesion injured stroke survivors will perceive negative environmental stimuli more acutely than those with a right lesion injury due to impairments in processing positive emotion. Consequently, perceiving their environment to be higher in EE than their spouse / partners would lead to higher depression levels.

A second key finding was that as spousal levels of EE increased, PSD levels in stroke survivors also increased. This is the first study of its kind to draw a link between EE and PSD but echoes research findings in relation to depression generally. For example, in a sample of elderly patients with a major depressive disorder, Hinrichsen and Pollack (1997) similarly found that relatives high EE significantly predicted higher rates of depression [67]. Furthermore, the predictive validity of the EE construct in relation to depressive disorders has been illustrated in a number of studies [68 – 70]. A further point to highlight is the mediating factors associated with spousal EE levels and it could be argued that spouses have an increased vulnerability to depression, and this could be seen as a key aspect in influencing their EE levels. Tompkins, Schulz & Rau (1988) suggested that adjustment problems is not just limited to the stroke survivor but may also exist in family members [71]. Furthermore, research has illustrated high prevalence of depression [72],
diminished life satisfaction and adjustment difficulties in stroke survivor’s spouses [73]. Therefore, it is likely that these factors may also contribute to higher levels of EE in spouses. Given the significant role of spousal EE to depression, the family environment is potentially an important predictor of levels of PSD experienced by stroke survivors and consequently vital in adjustment and rehabilitation outcome.

Issues of emotional processing have previously been noted above and research evidence clearly illustrates that after a stroke, emotional deficits, such as regulating and identifying basic emotions, may exist in stroke survivors [74 - 76]. It is therefore possible that a stroke injury has the potential to affect how stroke survivors perceive the emotional climate around them. Perceptual differences are evident in this study as discrepancies between the LEE scores were found in the majority of couples (93% of the sample); firstly, a significantly greater number of stroke survivors perceived their environment to be higher in EE (total: n=38; RHS: n=20; LHS n=18) than was reported by their respective spouse / partners. Secondly, some stroke survivors perceived their environment to be lower in EE (total: n=18; RHS: n=9, LHS: n=9) than their spouse / partners and only a small number of couples (total: n=4; RHS: n=1; LHS: n=3) showed identical scorings in the LEE measure.
As a result of these differences, an exploratory analysis revealed that stroke patients’ perceived EE interacted with lesion location to predict levels of depression. This suggests that stroke survivors with a left lesion injury who subjectively perceive their environment to be high in EE show greater levels of PSD compared to those with a right lesion injury who perceive themselves to be living in a low EE environment. Recent EE studies have focused on the role of perceived EE measured from the patients’ perspective and have also indicated that it is associated with negative clinical outcomes. Hooley and Teasdale (1989) investigated perceived criticism in patients diagnosed with unipolar depression and found patients who perceived their spouses to be highly critical, regardless of whether the spouses rated themselves as highly critical, were significantly more likely to relapse [34]. Similarly, Di Paola et al (2010) found a strong correlation between patients’ perceived EE and poorer clinical outcomes in eating disorders [52]. Further evidence illustrating the negative influence of patients perceived EE on relapse is available from the psychiatric literature [77 - 80]. Given the findings of these studies, patient’s subjective views, mostly regarding how they perceive their relatives attitudes towards them, can have a negative outcome in their course of illness. Therefore, further research is warranted to explore the role of patients’ perceived EE and how this may impact within other health related conditions.

Whilst the results of this study do not clearly demonstrate that spousal EE levels interact with PSD in stroke survivors whilst considering lesion laterality factors, this does
not necessarily discount that factors, such as social support, are entirely unrelated to PSD. Indeed, this study found that levels of EE, regardless of lesion location, are significantly associated with levels of PSD. Other researchers have also found that social and psychological factors play a role in the occurrence and maintenance of PSD [81, 82]. Therefore, adopting a biopsychosocial stance in future research on PSD would help integrate and fully understand the impact of psychological and social factors in mood disorders, stroke rehabilitation and clinical outcomes [83 - 85].

**Methodological Issues**

A number of methodological problems were highlighted in the present study. For instance, difficulties were encountered in recruiting LHS stroke survivors with no severe language impairments. As speech is predominantly in the left side of the brain, disorders such as dysphasia or aphasia (Broca’s or Wernicke’s) are common in people who suffer a left lesion stroke injury. Previous research has highlighted that relatives caring for a stroke survivor with language disorders are significantly more depressed than those who have little or no stroke related language deficits [86]. Given these findings, relatives who are depressed perhaps due to the frustration or demands faced in caring for a stroke survivor with expressive or receptive language difficulties, may be likely to also rate high in EE. As this study aimed to recruit stroke survivors who had an adequate level of communication and understanding to be able to complete measures, the exclusion of
stroke survivors who had severe language impairments may have biased the sample selection. Future research should perhaps include a more representative sample of LHS stroke survivors by using measures such as the Stroke Aphasic Depression Questionnaire (SADQ) [87] to assess depressed mood in stroke survivors with communication problems. In addition, exploring how best to assess and measure perceived EE in people who have language impairment would also seem important.

A methodological strength in this study was the use of a depression measure specific to stroke [60]. Although it was developed over a decade ago, the PSDRS has not been frequently used within research studies and has only been cited in some of the literature [8]. One of the reasons is due to the length of time it takes to administer compared to short non specific depression scales, such as, the Beck Depression Scale [BDI: 88] or the Zung scales [89]. The PSDRS is administered by way of a semi-structured interview that allows patients to give a subjective answer to the questions presented to them. However, a noted difficulty posed is that the scores result from an interaction between the patient’s responses and the researcher or clinician’s observation. Interpretation of such interactions could differ between researchers thus there is the possibility of incurring a researcher bias in scoring.

Clinical implications

Previous research has clearly illustrated the benefits associated with social interventions designed to reduce high EE in families within the psychiatric domain [90 - 94]. More
recent studies investigating the impact of EE in chronic illness have frequently suggested psychosocial family based interventions and psycho-education to help improve family functioning and adjustment [95 - 102]. Since the findings of this study indicate a link between EE and post-stroke depression, such interventions applied to families caring for a stroke survivor could be crucial. Specifically, psycho-educational techniques would aid in identifying specific behaviours or emotional responses associated with a stroke. Stress reduction techniques would also assist families in managing the challenges a stroke injury evokes, as would supporting families in enhancing existing coping strategies or developing new methods of effectively coping in order to combat the everyday challenges faced by the family as a whole. Furthermore, family based interventions would assist families in understanding their own positive and negative relational interactions with the aim of developing a relational climate that is constructive for all.

**Future research**

Further research should include longitudinal designs to be able to capture the effects of EE over-time rather than just a snapshot of the family’s relational interaction at one given time. A larger sample size in this study may have enabled clearer interpretations to be drawn about the individual components of the LEE measure. For instance, exploring individual carer or patient responses related to the four components of the LEE, intrusiveness, emotional response, negative attitude and low tolerance or high expectations, might identify patterns of responses that relate most to outcome. Past
research has illustrated these sub-scales to be similar to the attributes seen in criticism and EOI [103]. Furthermore, as the design of this study was cross-sectional, it was therefore difficult to determine the direction of causality between EE and PSD. Whether high levels of EE cause higher PSD or high PSD leads to high EE remains unclear. Future longitudinal studies would provide a greater understanding into these causal links.

It may also be useful to consider using the golden standard measure of EE, the CFI [44], to rule out any differences created by the use of different assessment tools. Furthermore, the inclusion of a basic emotion test, such as, the Feel Test [104], may be useful to determine whether a stroke survivor has impairments in emotional perception and to examine their ability to recognize basic emotions. This could help establish the extent to which emotion perception deficits affect the ability to differentiate between a high and low EE environment. Finally, more research is warranted into the effects of perceived EE, as how a person subjectively views the quality of their close relationships is fundamentally as important to clinical outcomes as how their partner or carer rates it to be.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.
References


Part three: Appendices
Appendix 1

Reflective statement

This section provides the opportunity for me to reflect and comment on my entire research process; from formation of ideas to submitting this finished thesis.

Research ideas and design

The motivation behind my research was drawn from my personal experiences of the challenges faced when my Mum suffered a stroke. Being a part of the gradual transformation that took place within my family, such as, change of role / identity, frustrations of slow recovery, adjustment and the denial of accepting this new life was very difficult and distressing for us all. I knew then that any research I would be fortunate enough to carry out would without a doubt be within the area of stroke. A few ideas were initially thought about before arriving at how a family environment can evoke a negative or positive influence on stroke survivors, particularly in relation to adjustment and rehabilitation. It struck me how fitting this research was and how much I related to it from a personal level. I felt this helped me tremendously during the data collection stage as I was able to reflect on my own experiences whilst collecting data and listening to stroke survivors and their families own difficulties in adjustment.
Recruitment and data collection

After meeting with the stroke teams, it was a relief to be reassured that there would be no difficulty in obtaining the large number of participants for my research. As one of the stroke units had already been involved in assisting in previous research this deemed very beneficial as they had pre-existing knowledge of what to expect during the recruitment process. There were no problems sourcing and recruiting stroke survivors with a right hand side injury; however, difficulties became apparent in finding stroke survivors with a left hand side injury with no severe language impairments. It seemed that the stroke teams themselves found this quite challenging and what initially appeared to be ease of recruitment became incredibly difficult towards the end. Also, as the stroke teams were relatively small and covered a large area, their job involved being out of the office a great deal, therefore, at times it was frustrating rely on them for participants. Meeting with the teams on more than one occasion, taking chocolates to show my appreciation and offering support to look through databases under supervision helped tremendously. They began to know me as person rather than another researcher requiring participants.

Another main advantage was that I had received ethical approval to recruit from 5 different sites at the early stages of the research procedure. At the time this seemed an unnecessary chore having to complete ethical approval forms, etc for 5 individual sites, especially as 1 site had assured that they would be able to source the required number of
participants. This extra work, however, did eventually pay off as I had the option of various recruitment sites when difficulties arose in sourcing left injured stroke survivors and I was then able to communicate with a number of stroke teams rather than rely solely on one.

**Participant experience**

One aspect which stood out for me during meeting with participants and data collection was the constant battle I had juggling the clinician versus researcher approach. In many households, the distress and challenges a stroke injury evokes were apparent and the clinician side of me wanted to help by listening and offering support. The researcher side of me, however, tried to keep focused on the data collection and timings so that I could leave in time for my next participant appointment. Upon reflection of the different roles I was trying to manage, my own personal experiences of relating to such challenges frequently led me towards a clinician role. Having said that I felt I had soon developed a system which was adapted into a combination of clinician and researcher roles and both were applied depending upon the situation and emotive experiences each household conveyed.
When I initially began planning the write up, this felt like such a daunting task and I had several concerns; two of my main concerns were (i) would I be able to finish this in time (ii) would I be able to write this in an academic standard worthy enough for the University and also that which is required for journal publication. Furthermore, looking back I realise that working on the systematic literature review earlier would have avoided a great deal of undue stress. Formulating ideas for a literature review that had not been carried out before or ensuring that there were an adequate number of research papers on ideas considered was incredibly time-consuming. In hindsight, the process of a review paper should be encouraged and organized prior to planning empirical research. The demands of endless searches, dissecting and analysing the chosen review papers and drawing conclusions before writing this up was at times overwhelming. However, in saying that I learnt a great deal of new information on the topic of expressed emotion and was able to utilize some of this knowledge for my empirical paper.

Mixed emotions were again felt during the writing stage of the empirical research paper; firstly, the statistical analysis part of the write up unfortunately filled me with dread. My last experience of SPSS and statistics was around 10 years ago; therefore, I felt whilst conducting my analysis I had to self teach myself a great deal of complicated information. Had I the time in my first or second year of this course, I would have most
certainly taken additional classes to learn more about SPSS. This I feel is still an ongoing process of learning different statistical models and practices, one which I would like to become less fearful of. Secondly, I felt very happy and excited that I had come so far from my initial research ideas and this was finally coming together. Going through the initial stages of putting my ideas forward, obtaining ethical approval, data collection and writing up the report has made me feel I had accomplished something worthwhile and most certainly has reinforced my wish to continue research in this field.

While I have learnt a great deal academically and personally during this research process, the aspects I would improve on for future research endeavours would be to educate myself in the complex field of statistics, to improve on the quality and style of my report writing and to ensure that I plan ahead for unforeseen difficulties that may arise, such as, within participant recruitment. There is no limit to what can be learnt, and for me this research was achieved by the valuable guidance from my supervisors and the support of my peers and family.
Appendix 2: Guidelines for submission to journals

**Appendix 2.1:** Instructions for authors submitting to Clinical Psychology Review

**Appendix 2.2:** Instructions for authors submitting to Brain Injury
Appendix 2.1: Instructions for authors submitting to Clinical Psychology

Clinical Psychology Review publishes substantive reviews of topics germane to clinical psychology. Its purpose is to help clinical psychologists keep up-to-date on relevant issues outside of their immediate areas of expertise by publishing scholarly but readable reviews. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, behavioural medicine, community mental health, assessment, and child development.

Reviews on other topics, such as psychophysiology, learning therapy, and social psychology, often appear if they have a clear relationship to research or practice in clinical psychology. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies are not appropriate.

GUIDE FOR AUTHORS
BEFORE YOU BEGIN

Ethics in Publishing

Conflict of interest
All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also http://www.elsevier.com/conflictsofinterest.

Submission declaration
Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere including electronically in the same form, in English or in any other language, without the written consent of the copyright-holder.
Changes to authorship
This policy concerns the addition, deletion, or rearrangement of author names in the authorship of accepted manuscripts:

Before the accepted manuscript is published in an online issue: Requests to add or remove an author, or to rearrange the author names, must be sent to the Journal Manager from the corresponding author of the accepted manuscript and must include: (a) the reason the name should be added or removed, or the author names rearranged and (b) written confirmation (e-mail, fax, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed. Requests that are not sent by the corresponding author will be forwarded by the Journal Manager to the corresponding author, who must follow the procedure as described above. Note that: (1) Journal Managers will inform the Journal Editors of any such requests and (2) publication of the accepted manuscript in an online issue is suspended until authorship has been agreed.

After the accepted manuscript is published in an online issue: Any requests to add, delete, or rearrange author names in an article published in an online issue will follow the same policies as noted above and result in a corrigendum.

Copyright
Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (for more information on this and copyright see http://www.elsevier.com/copyright). Acceptance of the agreement will ensure the widest possible dissemination of information. An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement. Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations (please consult http://www.elsevier.com/permissions). If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has pre-printed forms for use by authors in these cases: please consult http://www.elsevier.com/permissions.

Retained author rights
As an author you (or your employer or institution) retains certain rights; for details you are referred to: http://www.elsevier.com/authorsrights.

Role of the funding source
You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the paper for publication. If the funding source(s) had no such involvement then this should be stated. Please see http://www.elsevier.com/funding.
**Funding body agreements and policies**
Elsevier has established agreements and developed policies to allow authors whose articles appear in journals published by Elsevier, to comply with potential manuscript archiving requirements as specified as conditions of their grant awards. To learn more about existing agreements and policies please visit http://www.elsevier.com/fundingbodies.

**Language and language services**
Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who require information about language editing and copyediting services pre- and post-submission please visit http://webshop.elsevier.com/languagediting or our customer support site at http://support.elsevier.com for more information.

**Submission**
Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts source files to a single PDF file of the article, which is used in the peer-review process. Please note that even though manuscript source files are converted to PDF files at submission for the review process, these source files are needed for further processing after acceptance. All correspondence, including notification of the Editor's decision and requests for revision, takes place by e-mail removing the need for a paper trail.

**PREPARATION**

*Use of word processing software*
It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic illustrations. To avoid unnecessary errors you are strongly advised to use the "spell-check" and "grammar-check" functions of your word processor.

*Article structure*
Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Manuscripts should ordinarily not exceed 50 pages. Exceptions may be made with prior approval of the Editor in Chief for manuscripts including extensive tabular or graphic material, or appendices.

*Appendices*
If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2),
etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

**Essential title page information**

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note:** The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.

*Author names and affiliations.* Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

*Abstract.* A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

*Graphical abstract.* A Graphical abstract is optional and should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership online. Authors must provide images that clearly represent the work described in the article. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. See [http://www.elsevier.com/graphicalabstracts](http://www.elsevier.com/graphicalabstracts) for examples.

*Highlights.* Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters including spaces, or, maximum 20 words per bullet point). See [http://www.elsevier.com/highlights](http://www.elsevier.com/highlights) for examples.

*Keywords.* Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for
example, "and", "of"). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

**Abbreviations**

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

**Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

**Footnotes**

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many word processors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

**Table footnotes** - Indicate each footnote in a table with a superscript lowercase letter.

**Electronic artwork**

**General points**

- Make sure you use uniform lettering and sizing of your original artwork.
- Save text in illustrations as "graphics" or enclose the font.
- Only use the following fonts in your illustrations: Arial, Courier, Times, Symbol.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Produce images near to the desired size of the printed version.
- Submit each figure as a separate file.

A detailed guide on electronic artwork is available on our website: http://www.elsevier.com/artworkinstructions

You are urged to visit this site; some excerpts from the detailed information are given here.

**Formats**-Regardless of the application used, when your electronic artwork is finalised, please "save as" or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

- **EPS**: Vector drawings. Embed the font or save the text as "graphics".
- **TIFF**: Color or grayscale photographs (halftones): always use a minimum of 300 dpi.
- **TIFF**: Bitmapped line drawings: use a minimum of 1000 dpi.
- **TIFF**: Combinations bitmapped line/halftone (color or grayscale): a minimum of 500 dpi is required. If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply "as is".

**Please do not:**

- Supply files that are optimised for screen use (like GIF, BMP, PICT, WPG); the resolution is too low;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

**Color artwork**
Please make sure that artwork files are in an acceptable format (TIFF, EPS or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge that these figures will appear in color on the Web (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for color in print or on the Web only. For further information on the preparation of electronic artwork, please see http://www.elsevier.com/artworkinstructions. Please note: Because of technical complications which can arise by converting color figures to "gray scale" (for the printed version should you not opt for color in print) please submit in addition usable black and white versions of all the color illustrations. 

Figure captions - Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References
Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from http://books.apa.org/books.cfm?id=4200067 or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either "Unpublished results" or "Personal communication" Citation of a reference as "in press" implies that the item has been accepted for publication.

Web references
As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue
Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software
This journal has standard templates available in key reference management packages EndNote (http://www.endnote.com/support/enstyles.asp) and Reference Manager
(http://refman.com/support/rmstyles.asp). Using plug-ins to word processing packages, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style which is described below.

**Reference style**

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**


**Video data**

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labelled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a preferred maximum size of 50 MB. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: [http://www.sciencedirect.com](http://www.sciencedirect.com). Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages at [http://www.elsevier.com/artworkinstructions](http://www.elsevier.com/artworkinstructions).

**Note:** since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

**Supplementary data**

Elsevier accepts electronic supplementary material to support and enhance your scientific research. Supplementary files offer the author additional possibilities to publish supporting applications, high-resolution images, background datasets, sound clips and more. Supplementary files supplied will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: [http://www.sciencedirect.com](http://www.sciencedirect.com). In order to ensure that your submitted material is directly usable, please provide the data in one of our recommended file formats. Authors should submit the material in electronic format together with the article and supply a concise and descriptive caption for each file. For more detailed
instructions please visit our artwork instruction pages at http://www.elsevier.com/artworkinstructions.

Submission checklist
The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:
One Author designated as corresponding Author:
• E-mail address
• Full postal address
• Telephone and fax numbers All necessary files have been uploaded
• Keywords
• All figure captions
• All tables (including title, description, footnotes)
Further considerations
• Manuscript has been "spellchecked" and "grammar-checked"
• References are in the correct format for this journal
• All references mentioned in the Reference list are cited in the text, and vice versa
• Permission has been obtained for use of copyrighted material from other sources (including the Web)
• Color figures are clearly marked as being intended for color reproduction on the Web (free of charge) and in print or to be reproduced in color on the Web (free of charge) and in black-and-white in print
• If only color on the Web is required, black and white versions of the figures are also supplied for printing purposes
For any further information please visit our customer support site at http://support.elsevier.com.

AFTER ACCEPTANCE
Use of the Digital Object Identifier
The Digital Object Identifier (DOI) may be used to cite and link to electronic documents. The DOI consists of a unique alpha-numeric character string which is assigned to a document by the publisher upon the initial electronic publication. The assigned DOI never changes. Therefore, it is an ideal medium for citing a document, particularly 'Articles in press' because they have not yet received their full bibliographic information. The correct format for citing a DOI is shown as follows (example taken from a document in the journal Physics Letters B): doi:10.1016/j.physletb.2010.09.059
When you use the DOI to create URL hyperlinks to documents on the web, they are guaranteed never to change.

Proofs
One set of page proofs (as PDF files) will be sent by e-mail to the corresponding author (if we do not have an e-mail address then paper proofs will be sent by post) or, a link will be provided in the e-mail so that authors can download the files themselves. Elsevier now provides authors with PDF proofs which can be annotated; for this you will need to download Adobe Reader version 7 (or higher) available free from http://get.adobe.com/reader. Instructions on how to annotate PDF files will accompany the proofs (also given online). The exact system requirements are given at the Adobe site: http://www.adobe.com/products/reader/tech-specs.html.
If you do not wish to use the PDF annotations function, you may list the corrections (including replies to the Query Form) and return them to Elsevier in an e-mail. Please list your corrections quoting line number. If, for any reason, this is not possible, then mark the corrections and any other comments (including replies to the Query Form) on a printout of your proof and return by fax, or scan the pages and e-mail, or by post. Please use this proof only for checking the typesetting, editing, completeness and correctness of the text, tables and figures. Significant changes to the article as accepted for publication will only be considered at this stage with permission from the Editor. We will do everything possible to get your article published quickly and accurately – please let us have all your corrections within 48 hours. It is important to ensure that all corrections are sent back to us in one communication: please check carefully before replying, as inclusion of any subsequent corrections cannot be guaranteed. Proofreading is solely your responsibility. Note that Elsevier may proceed with the publication of your article if no response is received.

**Offprints**
The corresponding author, at no cost, will be provided with a PDF file of the article via e-mail. For an extra charge, paper offprints can be ordered via the offprint order form which is sent once the article is accepted for publication. The PDF file is a watermarked version of the published article and includes a cover sheet with the journal cover image and a disclaimer outlining the terms and conditions of use.

**AUTHOR INQUIRIES**
For inquiries relating to the submission of articles (including electronic submission) please visit this journal's homepage. Contact details for questions arising after acceptance of an article, especially those relating to proofs, will be provided by the publisher. You can track accepted articles at [http://www.elsevier.com/trackarticle](http://www.elsevier.com/trackarticle). You can also check our Author FAQs ([http://www.elsevier.com/authorFAQ](http://www.elsevier.com/authorFAQ)) and/or contact Customer Support via [http://support.elsevier.com](http://support.elsevier.com).
Appendix 2.2: Instructions for authors submitting to Brain Injury

Journal Details

Title: Brain Injury
ISSN:
Publication Frequency:
Subjects:
Publisher:

Brain Injury

Instructions for Authors

Brain Injury publishes critical information relating to research and clinical practice, adult and paediatric populations. The Journal covers a full range of relevant topics relating to clinical, translational, and basic science research. Manuscripts address emergency and acute medical care, acute and post-acute rehabilitation, family and vocational issues, and long-term supports. Coverage includes assessment and interventions for functional, communication, neurological, and psychological disorders.

Manuscript Preparation

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(s) 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".

Brain Injury considers all manuscripts at the Editors' discretion; the Editors' decision is final.

Brain Injury considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), 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. Copyright will be transferred to the journal *Brain Injury* and Informa UK Ltd., if the paper is accepted.

**General Guidelines**

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 below for further information.

Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

**File preparation and types**

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (on separate pages); figures; figure captions (as a list).

**Title Page**

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should
be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing your article. The title page should be uploaded separately to the main manuscript and designated as “title page – not for review” on ScholarOne Manuscripts.

Abstract

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.

Tables, figures and illustrations

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.

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).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here
Each table and/or figure must have a title that explains its purpose without reference to the text. Tables and/or figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. The filename for the tables and/or figure captions should be descriptive of the graphic, e.g. table 1, figure 2a. Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. 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). All files must be 300 dpi or higher.

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.

Letters to the Editor

Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously.

Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via Scholar One Manuscripts and should contain a Declaration of Interest statement.
Notes on Style

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.

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

- *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
- *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.
- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.
- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- *Brain Injury* is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.
- 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.
- 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).
- Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from heurism to constructivism in the design of [British] science courses'.
• The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. ‘The African American presidential candidate, Jesse Jackson...’ For the UK, African-Caribbean (not ‘West Indian’), etc.
• Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.
• n (not N), % (not per cent) should be used in typescripts.
• Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: The authors report no declarations of interest. When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest“ field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

Click here to view our full Declaration of Interest Policy.
Mathematics

Click for more information on the presentation of mathematical text.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:


Appendix 3: Ethical Approval

Appendix 3.1: Ethical approval confirmation letter

Appendix 3.2: Ethical approval confirmation letter for amendment
Appendix 3.1: Ethical approval confirmation letter

Bradford Research Ethics Committee
Yorkshire & Humber REC Office
Mill Pond Lane
Mashamwood
Leeds
LS4 4RA
Telephone: 0113 2050166
Facsimile:

25 July 2010

Ms Naheed Rashid
Trainee Clinical Psychologist
University of Hull
Postgraduate Medical Institute
Department of Clinical Psychology
Coftonham Road, Hull
HJ6 7RX

Dear Ms Rashid

Study Title: Post Stroke Depression and Expressed Emotion
REC reference number: 10/H1302/35
Protocol number: 1

Thank you for your letter of 26 June 2010, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdonline.nhs.uk.
Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation’s involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigator CV</td>
<td>N. Rasnida</td>
<td></td>
</tr>
<tr>
<td>Investigator CV</td>
<td>C Clarke</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>M. Rogish</td>
<td></td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>REC application</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire: Nottingham Extended ADL Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>1</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>Participant Information Sheet For Spouse / Partner</td>
<td>2</td>
<td>18 June 2010</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>23 June 2010</td>
</tr>
<tr>
<td>Participant Information Sheet For Stroke Survivor</td>
<td>2</td>
<td>18 June 2010</td>
</tr>
<tr>
<td>Participant Consent Form: For Stroke Survivor</td>
<td>1</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>Participant Consent Form: For Spouse / Partner</td>
<td>1</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>Questionnaire: Post Stroke Depression Rating Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire: Level of Emotion Scale</td>
<td>Client Version</td>
<td></td>
</tr>
<tr>
<td>Questionnaire: Level of Expressed Emotion Scale</td>
<td>Relative Version</td>
<td></td>
</tr>
<tr>
<td>Questionnaire: Demographic Information Sheet</td>
<td>1</td>
<td>03 April 2010</td>
</tr>
<tr>
<td>Referees or other scientific critique report</td>
<td>1</td>
<td>21 December 2009</td>
</tr>
</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.mrsa.nhs.uk.

Yours sincerely

Laura Sawiuk
REC Co-ordinator
On Behalf of
Professor Alan Roberts
Chair

Email: laura.sawiuk@leedspt.nhs.uk

Enclosures: “After ethical review – guidance for researchers”

Copy to: Mr Stephen Walker
Research and Development
Trust Headquarters
Witterby Hill
Witterby
East Yorkshire
HU10 6ED
Appendix 3.2: Ethical approval confirmation letter for amendment

National Research Ethics Service
Bradford Research Ethics Committee
Yorkshire & Humber REC Office
Mildside
Mill Pond Lane
Meerwood
Leeds
LS6 4RA
Tel: 0113 305 0116

01 November 2010

Ms Naheed Rashid
Trainee Clinical Psychologist
University of Hull
Postgraduate Medical Institute
Department of Clinical Psychology
Cottingham Road, Hull
HU6 7RX

Dear Ms Rashid

Study title: Post Stroke Depression and Expressed Emotion
REC reference: 10/H1302/35
Amendment number: 1
Amendment date: 20 September 2010

The above amendment was reviewed at the meeting of the Committee held on 19 October 2010.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td>16 September 2010</td>
</tr>
<tr>
<td>Letter from Community Stroke Team</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Notice of Substantial Amendment (non-CTIMPs)</td>
<td></td>
<td>20 September 2010</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td>20 September 2010</td>
</tr>
</tbody>
</table>

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet:

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority.
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.
R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1362/35: Please quote this number on all correspondence

Yours sincerely

Claire Kelly
Committee Assistant Co-ordinator

E-mail: Claire.kelly@leedspft.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Mr Stephen Walker
Bradford Research Ethics Committee

Attendance at Committee meeting on 19 October 2010

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sinead Audsley</td>
<td>REC Co-ordinator</td>
<td>None</td>
</tr>
<tr>
<td>Prof Diana Anderson</td>
<td>Professor of Biomedical Sciences</td>
<td>Expert</td>
</tr>
<tr>
<td>Dr Mark Busby</td>
<td>Consultant Neurologist</td>
<td>Expert</td>
</tr>
<tr>
<td>Dr David Dawson</td>
<td>Consultant in Anaesthetics</td>
<td>Expert</td>
</tr>
<tr>
<td>Mr Simon Geithorpe</td>
<td>Head of Psychological Therapies</td>
<td>Expert</td>
</tr>
<tr>
<td>Mrs Ellice Heston</td>
<td>Retired Teacher, JP</td>
<td>None</td>
</tr>
<tr>
<td>Professor Alan Roberts</td>
<td>Chairman OBE, TD, DL., MPhil, PhD, DSc, LLD, DTech.</td>
<td>Expert</td>
</tr>
<tr>
<td>Mr Andrew Scally</td>
<td>Statistician</td>
<td>Expert</td>
</tr>
<tr>
<td>Dr Adrian Williams</td>
<td>Consultant Haematologist</td>
<td>Expert</td>
</tr>
</tbody>
</table>

Also in attendance:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann Tunley</td>
<td>NRES Regional Manager</td>
</tr>
<tr>
<td>Denise Ross</td>
<td></td>
</tr>
<tr>
<td>Dr Matthew EJ Callister</td>
<td>Consultant Respiratory Physician</td>
</tr>
<tr>
<td>Prof Mark Conner</td>
<td>Director of Research</td>
</tr>
<tr>
<td>Miss Penelope Cook</td>
<td></td>
</tr>
<tr>
<td>Dr Christopher Herbert</td>
<td>Business Development Manager</td>
</tr>
<tr>
<td>Dr Muhammad Fayaz khan</td>
<td></td>
</tr>
<tr>
<td>Dr Tracy M Sandberg</td>
<td>Postdoctoral Research Fellow</td>
</tr>
<tr>
<td>Mrs Kathryn Vowden</td>
<td>Nurse Consultant Wound Care</td>
</tr>
<tr>
<td>Mr Roger Young</td>
<td>Managing Director</td>
</tr>
</tbody>
</table>

Written comments received from:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Stan Dobrzanski</td>
<td>Clinical Services Manager Pharmacy</td>
</tr>
<tr>
<td>Mr Andrew Scally</td>
<td>Statistician</td>
</tr>
</tbody>
</table>
Appendix 4: Humber NHS Foundation Trust Approval

Appendix 4.1: Humber NHS Foundation Trust Research and Development sponsorship letter

Appendix 4.2: Humber NHS Foundation Trust Research and Development approval confirmation letter
Appendix 4.1: Humber NHS Foundation Trust Research and Development sponsorship letter.

Wednesday, 16 June 2010

Naheed Rashid
Department of Clinical Psychology
University of Hull,
Cottingham Road
Hull
HU6 7RX

Dear Naheed

Re: R&D ID: 10/04/437  REC ID: 10/H1302/35

Post Stroke Depression and Expressed Emotion

I am pleased to notify you formally that this study will be Sponsored by the Humber NHS Foundation Trust.

However, the research cannot begin within any NHS Trust until you receive separate notification from research and development that it has been approved and it is fine to begin the research in each team.

Humber NHS Foundation Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported

You must ensure that the protocol is followed at all times. Should you need to amend the protocol, please follow the national research ethics service procedures. You should forward a copy of all amended versions of the protocol and documentation together with written confirmation that a favourable opinion has been given by the REC, to the R&D office at the trust.

I would like to wish you every success with this project

Yours sincerely

Stephen Walker
Clinical Audit & Research Governance Coordinator
Appendix 4.2: Humber NHS Foundation Trust Research and Development approval confirmation letter

02/08/2010
Ms Naheed Rashid
Department of Clinical Psychology
University of Hull,
 Cottingham Road
Hull
HU6 7RX

Dear Ms Naheed Rashid

Re: R&D ID: 10/04/437
REC ID: 10/H1302/35
Post Stroke Depression and Expressed Emotion

I am pleased to notify you formally that this study has been approved by the Humber NHS Foundation Trust.

As your research is not taking place at Humber NHS Foundation Trust, you will need to await R&D approval from the trusts in which your research is based in to undertake your research there.

Humber NHS Foundation Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported

You must ensure that the protocol is followed at all times. Should you need to amend the protocol, please follow the national research ethics service procedures. You should forward a copy of all amended versions of the protocol and/or documentation together with written confirmation that a favourable opinion has been given by the REC, to the R&D office at the trust.

You will be required to complete electronic progress reports and a final monitoring form on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum, however, if you fail to supply the information requested, the trust may withdraw approval.

I would like to wish you every success with this project

Yours sincerely

Duncan Courtney
Clinical Governance and Research Manager
Appendix 5: Research Governance Approval for Recruitment Sites

Appendix 5.1: Research Governance Approval for HEY Hospital NHS Trust

Appendix 5.2: Honorary Contract for HEY Hospital NHS Trust

Appendix 5.3: Research Governance Approval for York Hospital NHS Trust

Appendix 5.4: Research Governance Approval for NLG Hospital NHS Trust

Appendix 5.5: Research Governance Approval for Calderdale and Huddersfield Hospital NHS Trust

Appendix 5.6: Research Governance Approval for Doncaster Hospital NHS Trust
Appendix 5.1: Research Governance Approval for Hull and East Yorkshire Hospital NHS Trust.

Hull and East Yorkshire Hospitals NHS Trust

Human Resources Department
Alderson House
HULL ROYAL INFIRMARY
Anlaby Road
HULL  HU3 2JZ

2nd July 2010

275 Cottingham Road
Hull
HU5 4AT

Dear Ms Naheed Rashid

Letter of access for research – R1064 - Post Stroke Depression and Expressed Emotion

This letter confirms your right of access to conduct research through Hull & East Yorkshire Hospitals NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 1st September 2010 and ends on 1st August 2011 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Hull & East Yorkshire Hospitals NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Hull & East Yorkshire Hospitals NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided
by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Hull & East Yorkshire Hospitals NHS Trust** you will remain accountable to your employer **Humber NHS Foundation Trust** but you are required to follow the reasonable instructions of **Mr Mike Wright, Deputy Chief Executive** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Hull & East Yorkshire Hospitals NHS Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Hull & East Yorkshire Hospitals NHS Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Hull & East Yorkshire Hospitals NHS Trust** premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice ([http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf](http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf)) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days’ written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. As from
26 July 2010, your HEI employer may initiate your Independent Safeguarding Authority (IISA) registration (where applicable), and thereafter, will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

**Hull & East Yorkshire Hospitals NHS Trust** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Mr Patrick Anson  
HR manager Hull & East Yorkshire Hospitals NHS Trust  
cc: R&D Office, Daisy Building, Castle Hill Hospital, Cottingham Hu16 5JQ  
HR department, Humber NHS Foundation Trust, Trust HQ, Beverley Road, Willerby, HU10 6ED
Appendix 5.2: Honorary Contract for HEY Hospital NHS Trust.

Hull and East Yorkshire Hospitals NHS Trust

9th September 2010

In Confidence
Ms Naheed Rashid
Trainee Clinical Psychologist
The University of Hull
Postgraduate Medical Institute
Department of Clinical Psychology and Psychological Therapies
Cottingham Road
Hull
HU6 7RX

Dear Naheed

HONORARY CONTRACT

Hull and East Yorkshire Hospitals NHS Trust ("HEYHT") Honorary Contract Policy governs the basis on which individuals who are employed by other organisations may provide services for NHS Patients and/or in NHS facilities.

An Honorary Contract is not a contract of employment.

Post

In accordance with HEYHT’s Honorary Contract Policy, you are hereby appointed in an honorary (unpaid) capacity as Trainee Clinical Psychologist from 1st September 2010, expiring 1st August 2010.

Your Current Employer/Place of Study is University of Hull.

Work

Location

Your principal place of work for the purposes of this Honorary Contract is in Stroke Unit of Hull Royal Infirmary and Castle Hill Hospital.

You will report to Research and Development at Castle Hill Hospital. www.hey.nhs.uk
Duties
This post allows you to undertake the duties [as a Trainee Clinical Psychologist on the premises and using the facilities of HEYHT. To the extent that your duties involve clinical and/or administrative duties connected with patient care, you are granted access to the associated records.

Conditions of Honorary Contract
Criminal Records Bureau
Your appointment under this Honorary Contract will be subject to a satisfactory disclosure from the Criminal Records Bureau if, in the normal course of your work, you have access to patients and relatives.

Immigration
In accordance with the Immigration, Asylum and Nationality Act 2006 it is also a condition of this appointment that you provide evidence to HEYHT that you have current and valid permission to work within the United Kingdom.

Mandatory Training
You are required to attend all mandatory training courses as required by HEYHT including Moving and Handling, Health and Safety and Fire Training. Your Contracting Department is responsible for ensuring that you are booked on and attend this training that is relevant to your Honorary Contract post as part of your Induction.

Policies and Procedures

General
You are required to comply with the policies and procedures of HEYHT as they may from time to time be in force in connection with your duties under this Honorary Contract and to observe all HEYHT policies and procedures in respect of clinical and research activities. Copies of all HEYHT policies and procedures are available from the Human Resources Department or on the Intranet.

Grievance Procedures
The agreed procedure for setting differences between you and HEYHT will be in accordance with HEYHT’s Grievance Procedure. If you wish to raise concerns or complaints about your commitments under this Honorary Contract, you should first raise the matter with your supervisor.

If you observe an incident(s) or practice(s) within HEYHT which you feel is a cause for concern, please refer to HEYHT’s “Policy for Staff Reporting Concerns about Patient Care and Other Matters (Whistleblowers)”, available on the Intranet.

Disciplinary Matters
Wherever possible, any issues relating to conduct and competence should be resolved without recourse to formal procedures. However, should HEYHT consider that your conduct or performance in the course of carrying out this Honorary Contract is inconsistent with the high standards of work and behaviour expected by HEYHT, the matter will be resolved through HEYHT’s Disciplinary and Capability Procedure.
HEYHT reserves the right to terminate this Honorary Contract [with / without notice] where your conduct or performance is inconsistent with the high standards of work and behaviour expected by HEYHT.

You should be aware that termination of your Honorary Contract may have implications for your substantive contract of employment with University of Hull.

Effect of Termination of Substantive Contract of Employment
You are required to inform your supervisor and the Human Resources Department immediately in the event that your substantive contract of employment is suspended, or terminated, at any time. This will result in a review of the terms and conditions of your honorary appointment with HEYHT.

Intellectual Property
You and your Substantive Employer recognise HEYHT’s right to benefit from Intellectual Property (“IP”) arising from work undertaken under this contract in accordance with the Health and Social Care Act 2001. In circumstances where there is potential IP, you are required to notify HEYHT Research and Development department. For IP generated under this contract HEYHT will, where necessary, seek to agree with you and/or your Substantive Employer how it should be treated, if that organisation has an interest, on an individual case-by-case basis.

Research Governance
HEYHT manages all research in accordance with the requirements of the Research Governance Framework*. If, in the course of your duties, you undertake any form of research, you agree to make yourself familiar with the Research Governance Framework and agree to accept the responsibilities associated with your role that are outlined within it. You agree to comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance.

Dress Code
HEYHT wishes to ensure a smart, professional image is conveyed at all times to patients and other visitors. Please refer to HEYHT’s Corporate “Uniform Policy” for further details.

Please ensure you wear your name badge at all times.

Absence Reporting
In the event of sickness or unavoidable absence, you must notify your Supervisor and the Human Resources Department at the earliest opportunity and in any event report such absence in accordance with HEYHT’s Absence Reporting Policy/Procedure. You must report any accident or injury, however trivial, arising out of or in the course of your activities for HEYHT to your Supervisor and make appropriate records and statements as required.

Failure to comply with HEYHT’s Absence Reporting Policy/Procedure may result in disciplinary action against you.

Annual Leave
You should discuss holiday entitlement with your substantive employer before you commence your honorary contract with the Trust. Any annual leave you wish to take during the period of your honorary contract should be communicated to your HEYHT based supervisor.
NHS Indemnity
In law, HEYHT is liable in respect of your negligent acts and omissions to the degree that those acts and omissions were carried out whilst working on behalf of HEYHT and in accordance with your appointment under this Honorary Contract. You must, however, observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other Honorary Contract holder. You must act appropriately and responsibly at all times.

Whilst undertaking officially sanctioned NHS duties, you are covered by the NHS indemnity against claims for negligence. In other circumstances, [eg when providing services for which you receive a separate fee, or if undertaking research which has not received the Trust’s approval] you are not covered by the indemnity.

If you intend to treat private patients on HEYHT premises, you must have a valid indemnity. Medical practitioners are advised to maintain membership of a medical defence organisation and submit a copy of current membership to both HEYHT’s Human Resources Department and to their Substantive Employer.

Confidentiality and Data Protection
You are required to ensure the security and confidentiality of all information regarding patients or staff at all times. You should not release any such information to anyone other than an Approved Person in the course of your duties. Disclosure of any confidential information contrary to HEYHT’s policies and procedures may be an offence under the Data Protection Act or other legislation and can result in prosecution.

Inappropriate disclosure of confidential information is also a disciplinary offence and may lead to termination of your Honorary Contract unless it is authorised by law or disclosed in accordance with HEYHT’s "Policy for Staff Reporting Concerns about Patient Care and Other Matters (Whistleblowers)".

If, as an honorary contract holder, you handle patient or staff related information stored on computers, you must ensure that it remains on HEYHT-owned computers and is not transferred to computers owned by other organisations, including those of your Substantive Employer, without appropriate authorisation. This authorisation might be in the form of a formal agreement between HEYHT and your Substantive Employer with regard to specific types of information or a specific agreement between yourself and HEYHT with regard to storage of such information. You should be aware of your responsibilities under the Data Protection Act and only use such information for a registered purpose, not disclosing it to any unauthorised person. You should make yourself familiar with relevant HEYHT policies.

If you agree to accept this Honorary Contract on the terms specified above, please sign the form of acceptance at the foot of this page and return it to the Human Resources Department. A second copy of this letter is attached, which you should also sign and keep for further reference.
Yours sincerely

Miss Tina Dales
Acting Team Leader - Recruitment
Human Resources Department
Alderson House

-----------------------------------

PLEASE DO NOT DETACH

I have read and agree to the above conditions and I enclose a copy of my current professional registration certificate.

Signed: .................................................................

Dated: 15th Sept 2010
Appendix 5.3: Research Governance Approval for York Hospital NHS Trust.

R&D Unit reference: ERY-P01709

Ms Naheed Rashid
Trainee Clinical Psychologist
University of Hull
Postgraduate Medical Institute
Department of Clinical Psychology
Cottingham Road
Hull HU6 RX

7th September 2010

Dear Ms Rashid

NHS Permission to undertake a research study

Trust: NHS East Riding of Yorkshire
Study Title: Post Stroke Depression and Expressed Emotion
Ethics Committee Favourable Opinion dated: 26th July 2010

Thank you for submitting details of this study for NHS Permission from the above-named Trust, which is a member of the North and East Yorkshire R&D Alliance.

I confirm that the study has NHS Permission and can now begin in the Trust.

Please note that the study must be conducted in accordance with the approved protocol, the Department of Health Research Governance Framework for Health and Social Care and any applicable legislation.

Please check that you are aware of the sponsor’s Standard Operating Procedures that are applicable to this study. If your study is sponsored by the Trust, please refer to the Standard Operating Procedures published on the Unit’s website www.northyorkshiresearch.nhs.uk. These should also be used as a default for externally sponsored studies where the sponsor does not have its own procedure or where there are gaps in the sponsor’s procedure due to local circumstances.

Please note that this NHS Permission applies only to those documents granted a favourable ethical opinion on the above date. Please ensure that you notify the R&D Unit if there are any amendments to the study or when the study has ended and send me details of any publications that result from it.

May I wish you every success with the study.

Yours sincerely

Caroline Mozley
On behalf of NHS East Riding of Yorkshire

cc: Liz Cook

The R&D Service for: NHS East Riding of Yorkshire, Harrogate and District NHS Foundation Trust, NHS Hull, NHS North Yorkshire and York, York Hospitals NHS Foundation Trust
Appendix 5.4: Research Governance Approval for NLG Hospital NHS Trust.

Northern Lincolnshire and Goole Hospitals NHS Foundation Trust

24th August 2010

Ms Naheed Rashid
Trainee Clinical Psychologist
University of Hull
Postgraduate Medical Institute
Department of Clinical Psychology
Cottingham Road
Hull
HU6 7RX

Dear Ms Rashid

Re: Post Stroke Depression and Expressed Emotion

To inform you that in addition to the REC approval, of which the Trust has been informed, this study has been processed by the Northern Lincolnshire & Goole Hospitals NHS Foundation Trust Research & Development department and is compliant with the requirements of Research Governance.

However, you are required to inform the Trust Research & Development department of any significant proposed changes to the original protocol, adverse events or issues of safety. Your project will be subject to monitoring in line with the requirements for Research Governance. In addition the Northern Lincolnshire & Goole Hospitals NHS Foundation Trust Research & Development department will require an end of study notification.

Should you require any further assistance regarding this study, please do not hesitate to contact me.
Wishing you every success.

Kind regards

[Signature]

Mr Jim Bold
Assistant to the Medical Director
Northern Lincolnshire & Goole Hospitals NHS Foundation Trust
Appendix 5.5: Research Governance Approval for Calderdale and Huddersfield Hospital NHS Trust.

Calderdale and Huddersfield NHS Trust

21 July 2010

Naheed Rashid
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
Hull
HU6 7RX

Dear Ms Rashid

ID: 834  Post Stroke Depression and Expressed Emotion

The Research and Development department has considered the following documents in support of your application for approval to undertake the study on the premises of Calderdale and Huddersfield NHS Foundation Trust:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>dated</th>
</tr>
</thead>
<tbody>
<tr>
<td>NhssRfD Form ReadForSubmission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 H1302 35 LAS Confirmation of booking – Template</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RP4 Amended</td>
<td>final</td>
<td>100410</td>
</tr>
<tr>
<td>NhssRfD Peer Review RP4</td>
<td>211209</td>
<td></td>
</tr>
<tr>
<td>CV’s for Supervisors</td>
<td></td>
<td>2010</td>
</tr>
<tr>
<td>confirmation of sponsorship</td>
<td></td>
<td>160610</td>
</tr>
<tr>
<td>RecForm ReadyForSubmission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>signatures for REC form</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant letter</td>
<td>1</td>
<td>030410</td>
</tr>
<tr>
<td>Demographic Information Sheet</td>
<td>1</td>
<td>030410</td>
</tr>
<tr>
<td>Consent form for Stroke Survivor</td>
<td>1</td>
<td>030410</td>
</tr>
<tr>
<td>Consent form for Spouse Partner</td>
<td>1</td>
<td>030410</td>
</tr>
<tr>
<td>Participant information sheet for stroke survivor amended</td>
<td>2</td>
<td>180610</td>
</tr>
<tr>
<td>Participant information sheet for spouse partner amended</td>
<td>2</td>
<td>180610</td>
</tr>
<tr>
<td>Lee</td>
<td>1992</td>
<td></td>
</tr>
<tr>
<td>Lee – relative</td>
<td>1993</td>
<td></td>
</tr>
<tr>
<td>post stroke depression rating scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Audt</td>
<td>2007</td>
<td></td>
</tr>
<tr>
<td>Ethics amendment letter</td>
<td>280010</td>
<td></td>
</tr>
<tr>
<td>provisional ethics</td>
<td>200510</td>
<td></td>
</tr>
<tr>
<td>Nhsh SoS Form for Calderdale Royal Hosp</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Signed Declaration by Principal Investigator or Local Collaborator</td>
<td>020710</td>
<td></td>
</tr>
</tbody>
</table>

Your study now has R&D approval on the understanding and provision that you will adhere to the following conditions:

That the research should:

- Comply with the requirements of The Research Governance Framework for Health and Social Care (2nd DH 2005);
• Comply with regulatory requirements and legislation relating to: Clinical Trials, Data Protection, Health and Safety, Trust Caldicott Guidelines, and the use of Human Tissue for research purposes;
• Be conducted in accordance with: ICH Good Clinical Practice and/or the MRC guidelines for good clinical practice (as appropriate);
• Not commence until it has received written approval from a UKECA recognised Research Ethics Committee (REC) and that any REC imposed conditions of that approval are implemented;

You must also:

• Request written approval for any change to the approved protocol/study documents that you or the Chief Investigator wish to implement;
• Ensure that all study personnel, not employed by Calderdale and Huddersfield NHS Foundation Trust, hold either an honorary contract with the Trust or a letter of access issued by the Trust, before they have access to any facilities, patients, staff, their data, tissue or organs;
• Complete the Research Governance interim and final reports as requested;
• Submit monthly recruitment and screening data to R&D (if applicable).
• Comply with our audit and monitoring procedures as required.

Please note:

• The use of medicines not in the hospital formulary for the purpose of research is restricted to trust approved trial protocols only. Continued use of them outside or at the end of a clinical trial will require a formal application to and approval from the Medicines Management Committee. Trial participants should be made aware of this situation.

This approval letter constitutes a favourable Site Specific Assessment (SSA) for this site

Please be aware that the R&D department has a database containing study related information, and personal information about individual investigators e.g. name address, contact details etc. This information will be managed according to the principles established in The Data Protection Act.

Yours sincerely

David Birkenhead
Dr David Birkenhead
Director of Research and Development
Appendix 5.6: Research Governance Approval for Doncaster Hospital NHS Trust.

Please ask for: Emma Hannaford
(Research Management & Governance Manager)
Telephone: 01302 566260
Email: emma.hannaford@doncasterpct.nhs.uk

10 September 2010

CONFIDENTIAL
Naheed Rashid
Trainee Clinical Psychologist
Postgraduate Medical Institute
University of Hull
Department of Clinical Psychology
Cottingham Road
Hull
HU6 7RX

Dear Naheed,

Study Title: Post Stroke Depression and Expressed Emotion
Chief Investigator: Naheed Rashid
DPCT Reference: DPCT0141
REC Reference: 10/H1302/35

I am pleased to inform you that the review of the above project is now complete. Your research has now been given Research Governance management authorisation to commence within NHS Doncaster. For your information, the project reference is DPCT0141.

I would be grateful if you could quote this number in any further correspondence with this department.

Documentation

Your authorisation has been granted based on submission of documentation, including the following:

- Study Protocol (Version 1 dated 03 April 2010)
- IRAS Site Specific Information Form (Submission code: 45458/137220/6/418/85446/184086 signed by Naheed Rashid on 02 July 2010)
- IRAS R&D Form (Submission code: 45458/132653/14/320)
- IRAS REC Form (Submission code: 45458/115580/1/576 signed by Naheed Rashid on 03 April 2010)
- CV of Naheed Rashid
- CV of Christopher Clarke (Signed 09 April 2010)
- CV of Miles Thomas Rogish (Signed 09 April 2010)
- Invitation Letter to Participants (Version 1 dated 03 April 2010)
- Participant Information Sheet - Spouse/Partner (Version 2 dated 18 June 2010)
- Participant Consent Form - Stroke Survivor (Version 1 dated 03 April 2010)
- Participant Consent Form - Spouse/Partner (Version 1 dated 03 April 2010)
- Questionnaire: Level of Expressed Emotion Scale - Client
- Questionnaire: Level of Expressed Emotion Scale - Relative
- Questionnaire: Demographic Information Sheet (Version 1 dated 03 April 2010)
• Questionnaire: Post Stroke Depression Rating Scale
• Questionnaire: Nottingham Extended ADL Scale
• Sponsorship Statement - Humber NHS Foundation Trust (dated 16 June 2010)
• Peer Review (dated 21 December 2009)
• Favourable Ethical Opinion from Bradford Research Ethics Committee (dated 28 July 2010)

Please note you must inform us if your project deviates in any way from the original proposal/documentation you have submitted. Your approval is limited to the dates stated on the research application form and that you are obliged to notify the R&D Department of any adverse events that arise during the course of the project. May I remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care (2005). If this is found that this is not the case, this may result in the suspension of your project until changes have been agreed with the Trust, or your research may be terminated pending an enquiry.

Permissions
This letter authorises you in principle to undertake research within the Trust. However, it is your responsibility to ensure that individuals appropriate to your work have no objections to your studies. This department accepts no liability for non-co-operation of staff or patients.

Auditing
I would strongly urge you to maintain an accurate and up to date site file for your documentation, as the Trust randomly audits projects to assess compliance with the relevant frameworks and legislation. If your study is chosen, you will be notified in writing not less than two weeks prior to the required submission date of documentation.

Reporting
In the interest of ensuring the Trust receives maximum benefit from co-operating with research projects such as your own, the Trust places great importance on disseminating findings and conclusions. Therefore we would welcome a short summary of the findings of this project, once completed, along with any formal publications resulting from this work.

I would like to take this opportunity to wish you well with your project. If you have any questions or I can be of any further assistance to you, please do not hesitate to contact me.

Yours sincerely,
Amy Beckitt

On behalf of:
Emma Hannaford
Research Management & Governance Manager

CC Dr Jaswinder Moorhouse
Clinical Psychologist
Magnolia Lodge Neuro Rehabilitation Unit,
Tickhill Road Hospital
Tickhill Road
Doncaster
DN4 6QL
Appendix 6: Supplementary Information for the Systematic Literature Review


Appendix 6.2: Quality Assessment Criteria by Rater A and Rater B

**SLR Quality Assessment Criteria**
Revised version of the Downs and Black Checklist (2009)

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>YES (1)</th>
<th>NO (0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Is the hypothesis/aim/objective of the study clearly described?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Are the main outcomes to be measured clearly described in the Introduction or Methods section?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Are the characteristics of the participants included in the study clearly described?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Are the interventions and measures of interest clearly described?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Are the main findings of the study clearly described?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Have actual probability values been reported (e.g. 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Were the subjects asked to participate in the study representative of the entire population from which they were recruited?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Was an attempt made to blind those measuring the main outcomes of the intervention?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Were the statistical tests used to assess the main outcomes appropriate?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Were the main outcome measures used accurate (valid and reliable)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Did the study clearly report implications and clinical relevance of the findings?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Are the limitations of the study adequately reported?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Are possible areas of further investigation explored?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Appendix 6.2: Quality Assessment Criteria by Rater A and Rater B

## SLR Quality Assessment Criteria

Revised version of the Downs and Black Checklist (2009)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Is the hypothesis/aim/objective of the study clearly described? (Y-1, N-0)</td>
<td>1 1 1 1 1 0 0 1 1 1 1 1 1 0 0</td>
<td>1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Are the main outcomes to be measured clearly described in the Introduction or Methods section? (Y-1, N-0)</td>
<td>1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Are the characteristics of the participants included in the study clearly described? (Y-1, N-0)</td>
<td>1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Are the interventions and measures of interest clearly described? (Y-1, N-0)</td>
<td>0 0 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Are the main findings of the study clearly described? (Y-1, N-0)</td>
<td>1 1 1 1 1 0 0 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Have actual probability values been reported (e.g. 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001? (Y-1, N-0)</td>
<td>0 0 1 1 1 0 1 1 1 0 1 1 1 1 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Were the subjects asked to participate in the study representative of the entire population from which they were recruited? (Y-1, N-0)</td>
<td>0 0 0 0 0 1 0 0 0 0 1 0 1 1 0 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>----------------------</td>
<td>--------------------</td>
<td>---------------------</td>
<td>------------------------</td>
<td>-----------------------</td>
<td>----------------------</td>
<td>-----------------------</td>
<td>----------------------</td>
<td>----------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>8</td>
<td>Was an attempt made to blind those measuring the main outcomes of the intervention? (Y-1, N-0, Unable-0)</td>
<td>1 1 1 1 1 1 0 0 1 1 1 1 0 1 1 0 1 0 1 0 0 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Were the statistical tests used to assess the main outcomes appropriate? (Y-1, N-0, Unable-0)</td>
<td>1 0 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Were the main outcome measures used accurate (valid and reliable)? (Y-1, N-0, Unable-0)</td>
<td>1 1 1 1 0 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Did the study clearly report implications and clinical relevance of the findings? (Y-1, N-0, Unable-0)</td>
<td>1 1 1 1 1 1 1 1 1 1 0 1 1 0 0 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Are the limitations of the study adequately reported? (Y-1, N-0, Unable-0)</td>
<td>1 1 0 0 1 1 1 0 0 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Are possible areas of further investigation explored? (Y-1, N-0, Unable-0)</td>
<td>1 1 0 0 1 0 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL SCORE</td>
<td>10 9 10 10 12 10 9 8 11 11 13 10 12 12 10 9 12 12 12 11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PERCENTAGE AGREEMENT (%)</td>
<td>90 100 83.3 88.8 100 76.9 100 90 100 91.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL AGREEMENT BETWEEN RATER A + B = 91.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 7: Supplementary Information for Empirical Paper

**Appendix 7.1:** Cover letter for stroke survivor and spouse / partner

**Appendix 7.2:** Additional cover letter from Beverley Westwood Stroke Team

**Appendix 7.3:** Participant information sheet for stroke survivor

**Appendix 7.4:** Participant information sheet for spouse / partner

**Appendix 7.5:** Consent form for stroke survivor

**Appendix 7.6:** Consent form for spouse / partner

**Appendix 7.7:** Demographic information sheet
Appendix 7.1: Cover letter for stroke survivor and spouse / partner

Ms Naheed Rashid  
Trainee Clinical Psychologist  
Department of Clinical Psychology  
The University of Hull  
Cottingham Road  
HU6 7RX

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

I am a 5th year trainee clinical psychologist at the University of Hull and am currently carrying out a research study.

The Research investigates the effects of relationships and emotions among stroke survivors and their spouse / 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 after a 24 hour period to see if you have had a chance to read through the information and have a think about whether you would like to take part.

Thank you very much for taking the time to read this letter and the enclosed information.

Kind regards

Naheed Rashid

Participant Letter  
Version 1  
Date: 03/04/10
Appendix 7.2: Additional cover letter from Beverley Westwood Stroke Team

Hull & East Riding Stroke Service
Community Stroke Team
Archway Offices
Beverley Westwood Hospital
Beverley
HU17 8BU
Tel: 01482 344519

Dear .................................................................

We are writing to inform you of a study that is currently being undertaken within the Department that may be of interest to you.

This study is about relationships and emotions after a person has had a stroke. After being discharged from hospital, a stroke survivor is commonly cared for by a family member, often a spouse or partner, and it is known that this can become stressful. The emotional atmosphere between people in a household is referred to as ‘expressed emotion’ by researchers and it can go up and down. Past studies have found that expressed emotion can be linked to people having certain difficulties in adjusting to having a long term illness.

This study is aiming to provide a better understanding of relationships and emotions after a stroke. It is hoped this will help contribute to improvements in services for stroke survivors and their partners and carers.

Taking part in the study 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 from the study at any time without giving a reason, this would by no means affect the care you or your spouse / partner receives from the Community Stroke Team.

If you are interested then full details of this study is enclosed for you to read. We shall contact you in a couple of days by telephone to see if you wish to take part in this study.

Kind regards

[Signature]

Dinah Fuller
Nurse Consultant in Stroke
Appendix 7.3: Participant information sheet for stroke survivor

Participant Information Sheet for Stroke Survivor

Research Project

The effects of relationships and emotions after stroke

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?

This research is aiming to provide a better understanding of relationships and emotions after a stroke. It is hoped this will help contribute to improvements in services for stroke survivors and their partners and carers.

The link between relationships and emotions after a person has suffered a stroke is an area that has not been well investigated. After being discharged from hospital, a stroke survivor is commonly cared for by a family member, often a spouse or partner, and it is known that this can become stressful. The emotional atmosphere between people in a household is referred to as ‘expressed emotion’ by researchers and it can go up and down. Past studies have found that expressed emotion can be linked to people having certain difficulties in adjusting to having a long term illness.

Some research has shown that where in the brain a stroke has happened can have an effect on emotions. With this in mind, this research project will firstly be looking at whether the side of the
brain that the stroke happened is linked with feeling low and depressed. This study will also explore whether this link might be affected by the emotional atmosphere between a stroke survivor and those close to them.

**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 is your main carer. We are inviting approximately 60 stroke survivors and 60 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 spouse / partner receives from the Community Stroke Team.

**What will happen if I decide to take part?**

The primary researcher, Ms Naheed Rashid, will contact you after a 24 hour period 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, NHS location or The Department of Clinical Psychology at University of Hull). 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 tasks:

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 mood and how you have been feeling since having the stroke.
3) Fill in a questionnaire which asks you to rate how your spouse / partner may act towards you.
The primary researcher will meet with you and your spouse / partner either at separate times or within the same appointment. Please note that this study requires information from both stroke survivor and their spouse / partner, therefore both you and your spouse / partner would have to agree to take part otherwise no information can be collected. Should you or your spouse / 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 spouse / 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 is helpful. At the end of the study there will be time available to talk about anything that may have been difficult for you during completion of the questionnaires 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 spouse / partner provide or other issues, then these concerns will be raised with you and passed on to the Community Stroke Team with your consent.

**What are the possible benefits of taking part?**

We cannot guarantee that taking part in this study will benefit you or your spouse / partner personally and directly. However, the information we receive from this study will assist us in understanding the ways in which people cope after a stroke, especially the effects of relationships and emotions and how this links with post stroke depression. Such valuable information can be shared with other health professionals and may contribute to improving health and psychological services for stroke survivors and their spouse / partners 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 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 then destroyed. The filing cabinet can only be accessed by the primary researcher and the research supervisor.
What will happen to the results of this study?

This study will be completed by June 2011. It is hoped that this study will expand our knowledge and understanding of the effects of relationships and emotions after stroke and how this may link to levels of depression experienced by the stroke survivor. 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 Ms Naheed Rashid, 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 and Dr Miles Rogish, 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 NHS Foundation Trust.

Who has reviewed this study?

This study has been reviewed and approved by Bradford Research Ethics Committee.

Contact for further information

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

Naheed Rashid
Trainee Clinical Psychologist and primary researcher
Department of Clinical Psychology
The University of Hull
Cottingham Road
Hull
HU6 7RX

Tel: 07931 780 911
E-mail: n.rashid@2008.hull.ac.uk

Thank you for taking the time to read through the participant information.
Appendix 7.4: Participant information sheet for spouse / partner

Participant Information Sheet for Spouse / Partner

Research Project

The effects of relationships and emotions after stroke

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?

This research is aiming to provide a better understanding of relationships and emotions after a stroke. It is hoped this will help contribute to improvements in services for stroke survivors and their partners and carers.

The link between relationships and emotions after a person has suffered a stroke is an area that has not been well investigated. After being discharged from hospital, a stroke survivor is commonly cared for by a family member, often a spouse or partner, and it is known that this can become stressful. The emotional atmosphere between people in a household is referred to as ‘expressed emotion’ by researchers and it can go up and down. Past studies have found that expressed emotion can be linked to people having certain difficulties in adjusting to having a long term illness.

Some research has shown that where in the brain a stroke has happened can have an effect on emotions. With this in mind, this research project will firstly be looking at whether the side of the brain that the stroke happened is linked with feeling low and depressed. This study will also
explore whether this link might be affected by the emotional atmosphere between a stroke survivor and those close to them.

**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 the Community Stroke Nurse as you live at home with your spouse / partner and are currently the main source of care and support for them. We are inviting approximately 60 stroke survivors and 60 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 spouse / partner receives from the Community Stroke Team.

**What will happen if I decide to take part?**

The primary researcher, Ms Naheed Rashid, will contact you after a 24 hour period 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, NHS location or The Department of Clinical Psychology at University of Hull). 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 15 minutes of your time, during which you will be asked to do two tasks:

1) Complete a Demographic Information Sheet.

2) Fill in a questionnaire which asks you to rate the way in which you may act towards your spouse / partner.

The primary researcher will meet with you and your spouse / partner either at separate times or within the same appointment. Please note that this study requires information from both stroke
survivor and their spouse / partner, therefore both you and your spouse / partner would have to agree to take part otherwise no information can be collected. Should you or your spouse / 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 spouse / 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 is helpful. At the end of the study there will be time available to talk about anything that may have been difficult for you during completion of the questionnaires and if after this time it is felt that you are experiencing lower mood or a previously unrerecognised 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 spouse / partner provide or other issues, then these concerns will be raised with you and passed on to the Community Stroke Team with your consent.

**What are the possible benefits of taking part?**

We cannot guarantee that taking part in this study will benefit you or your spouse / partner personally and directly. However, the information we receive from this study will assist us in understanding the ways in which people cope after a stroke, especially the effects of relationships and emotions and how this links with post stroke depression. Such valuable information can be shared with other health professionals and may contribute to improving health and psychological services for stroke survivors and their spouse / partners 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 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 then destroyed. The filing cabinet can only be accessed by the primary researcher and the research supervisor.
**What will happen to the results of this study?**

This study will be completed by June 2011. It is hoped that this study will expand our knowledge and understanding of the effects of relationships and emotions after stroke and how this may link to levels of depression experienced by the stroke survivor. 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 Ms Naheed Rashid, 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 and Dr Miles Rogish, 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 NHS Foundation Trust.

**Who has reviewed this study?**

This study has been reviewed and approved by Bradford Research Ethics Committee.

**Contact for further information**

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

Naheed Rashid  
Trainee Clinical Psychologist and primary researcher  
Department of Clinical Psychology  
The University of Hull  
Cottingham Road  
Hull  
HU6 7RX

Tel: 07931 780 911  
E-mail: n.rashid@2008.hull.ac.uk

Thank you for taking the time to read through the participant information.
Appendix 7.5: Consent form for stroke survivor

Consent Form for Stroke Survivor

Title of Project: The effects of relationships and emotions after stroke

Name of Researcher: Naheed Rashid, Trainee Clinical Psychologist

Please Tick

1. I confirm that I have read the Participant Information Sheet dated __________ (version number________) 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 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 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
Appendix 7.6: Consent form for spouse / partner

Consent Form for Spouse / Partner

Title of Project: The effects of relationships and emotions after stroke

Name of Researcher: Naheed Rashid, Trainee Clinical Psychologist

1. I confirm that I have read the Participant Information Sheet dated _________ (version number_______) 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 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 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 Spouse / Partner
Version 1
Date: 03/04/10

University of Hull
Hull, HU6 7RX
United Kingdom
+44 (0)1482 346311
www.hull.ac.uk

196
Appendix 7.7: Demographic information sheet

Participant Numbers:  
Date:  

Demographic Information Sheet

Please complete the following information sheet either by writing an answer or by ticking the appropriate box. Questions to be completed by spouse / partner.

Spouse / Partner:  Age________  Gender:  MALE ☐  FEMALE ☐

Stroke Survivor:  Age________  Gender:  MALE ☐  FEMALE ☐

Does your spouse / partner smoke?  YES ☐  NO ☐

- What date did your spouse / partner have their stroke?_______________
- How long have you and your spouse / partner lived together prior to their stroke?_______________
- How long has your spouse / partner been living at home since their stroke?_______________
- How many other people live in the same household?_______________
- Does your spouse / partner have any other significant health problems?_______________
- Does your spouse / partner have a prior history of depression?_______________
- If so, please provide details (i.e. how long ago, how long did this last, did they receive any medication or formal treatment for this)?_______________
- Do you have any significant health problems?_______________
- Does your spouse / partner receive any respite care?_______________
- If so, how much time do they spend in respite care each week / month / or regular basis? ______
- Does your spouse / partner receive any help from carers or a support agency?_______________
- If so, how many hours care do they receive each week / month / or regular basis?_______________

Thank you for your cooperation.

Demographic Information Sheet
Version 1  
Date: 03/04/10

University of Hull  
Hull, HU6 7RX  
United Kingdom  
+44 (0)1482 346311  
www.hull.ac.uk
Appendix 8: Measures administered to participants

Appendix 8.1: EADL

Appendix 8.2: PSDRS

Appendix 8.3: LEE for client (stroke survivor)

Appendix 8.3: LEE for relative (spouse / partner)
Appendix 8.1:  EADL

Nottingham Extended ADL Scale

The following questions are about everyday activities. Please answer by ticking ONE box for each question. Please record what you have ACTUALLY done in the last few weeks.

DID YOU.......... Not at all with help on your own on your own
                 with difficulty

1. Walk around outside?     
2. Climb stairs?        
3. Get in and out of a car? 
4. Walk over uneven ground?  
5. Cross roads?     
6. Travel on public transport? 
7. Manage to feed yourself? 
8. Manage to make yourself a hot drink?  
9. Take hot drinks from one room to another?  
10. Do the washing up? 
11. Make yourself a hot snack?
<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>With help</th>
<th>On your own with difficulty</th>
<th>On your own</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Manage your own money when out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Wash small items of clothing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Do your own housework?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do your own shopping?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Do a full clothes wash?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Read newspapers or books?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Use the telephone?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Write letters?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Go out socially?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Manage your own garden?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Drive a car?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

© University of Nottingham 2007
Appendix 8.2: PSDRS

THE POST STROKE DEPRESSION RATING SCALE

The examiner must choose for each section the statement which best corresponds to the patient's actual state.
<table>
<thead>
<tr>
<th>Section 1</th>
<th>DEPRESSED MOOD</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-balanced mood. At times happier, at times worried, but not more than before illness</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Mood a little sadder and more worried than before</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>a) because fears not returning as before</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) in general, also with no relationship to illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood clearly more oriented toward sadness and pessimism than before illness</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood clearly oriented toward sadness and pessimism, with fits of crying from time to time (but by speaking it's possible to pull him/her out of it)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very sad and disheartened mood. Cries rather often and for long periods (even speaking, it's hard to pull him/her out of it)</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gloomy, black mood, cries continuously, and there is no way to hearten him/her, or so depressed and dark, can't even cry any more</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 2

GUILT FEELINGS

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Good level of self-esteem. Feeling of having had an essentially positive life without much self-reproach.</td>
</tr>
<tr>
<td>1</td>
<td>Acceptable level of self-esteem, but with some reproach in limited areas (for example, 1 of 3: family, friends, work)</td>
</tr>
<tr>
<td>2</td>
<td>Rather low level of self-esteem, with some reproach (not particularly serious) in various areas</td>
</tr>
<tr>
<td>3</td>
<td>Little self-esteem and many guilt feelings; however does not think illness has been a just punishment</td>
</tr>
<tr>
<td>4</td>
<td>Very little self-esteem and many guilt feelings; thinks illness has been a just punishment</td>
</tr>
<tr>
<td>5</td>
<td>Even without being posed specific questions, spontaneously verbalizes serious expressions of self-accusation, unworthiness and guilt</td>
</tr>
</tbody>
</table>

**Always try to determine if guilt indicates:**

a) more unworthiness

b) responsibility for behavior (smoking, sexual abuse, food abuse, etc)

c) held responsible for illness
Section 3

SUICIDE

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Thinks life is always worth living</td>
</tr>
<tr>
<td>1</td>
<td>Thinks life is worth living only if health, affective and economic conditions are acceptable</td>
</tr>
<tr>
<td>2</td>
<td>Thinks life in general is not worth living, but has never thought of taking it</td>
</tr>
<tr>
<td>3</td>
<td>Besides often thinking life is a burden, recently has had vague ideas about killing him/herself</td>
</tr>
<tr>
<td>4</td>
<td>Recently, has had recurring ideas about suicide, but without making specific plans or concrete attempts</td>
</tr>
<tr>
<td>5</td>
<td>Recently, has made detailed plans (or has made serious attempts) to commit suicide</td>
</tr>
</tbody>
</table>

**Note:** Always determine whether possible suicide tendencies appeared only after illness and are related to consequences of illness.
Section 4

VEGETATIVE DISORDERS

Sum scores of sleep disorders (0-3) and appetite (0-2)

<table>
<thead>
<tr>
<th>Sleep disorders:</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>No sleep disorder</td>
<td>0</td>
</tr>
<tr>
<td>Some difficulty in falling asleep or frequent nocturnal awakening (effectiveness of drugs)</td>
<td>1</td>
</tr>
<tr>
<td>Awakens very early in the morning and is unable to fall back to sleep again (poor drug effectiveness)</td>
<td>2</td>
</tr>
<tr>
<td>Major disorders in all sleep phases; does not allow others to sleep during the night (drugs completely ineffective)</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appetite disorders:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No appetite disorder</td>
<td>0</td>
</tr>
<tr>
<td>Clear loss of appetite, but no weight loss</td>
<td>1</td>
</tr>
<tr>
<td>Complete loss of appetite associated with weight loss</td>
<td>2</td>
</tr>
</tbody>
</table>

---

TOTAL.... .........
**Section 5**  
APATHY/ABULIA/INDIFFERENCE

Sum scores of following parameters:

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>a) Interest in other patients and own state of health:</strong></td>
<td></td>
</tr>
<tr>
<td>-adequate (is interested, asks information, tries to be useful)</td>
<td>0</td>
</tr>
<tr>
<td>-rather scarce both toward other patients and own morbid condition</td>
<td>1</td>
</tr>
<tr>
<td>-completely absent</td>
<td>2</td>
</tr>
<tr>
<td><strong>b) Interest in family members and friends:</strong></td>
<td></td>
</tr>
<tr>
<td>-adequate (waits impatiently for their visits, asks about individuals and situations in family circle, reacts appropriately to emotionally significant events)</td>
<td>0</td>
</tr>
<tr>
<td>-rather scarce (clearly reduced compared to pre-morbid condition)</td>
<td>1</td>
</tr>
<tr>
<td>-completely absent</td>
<td>2</td>
</tr>
<tr>
<td><strong>c) Interest in social situations:</strong></td>
<td></td>
</tr>
<tr>
<td>-adequate, corresponding to pre-morbid levels regarding public and political events or work situations</td>
<td>0</td>
</tr>
<tr>
<td>-clearly reduced compared to pre-morbid situation</td>
<td>1</td>
</tr>
</tbody>
</table>

TOTAL:... ........
Section 6

ANXIETY

Sum scores for psychic anxiety (0-2), somatic anxiety (0-2) and psycho-motor agitation (0-1).

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Calm enough. Rarely tense, nervous or apprehensive.</td>
</tr>
<tr>
<td>1</td>
<td>Appears rather tense, nervous, irritable. Sometimes expresses fears and worries.</td>
</tr>
<tr>
<td>2</td>
<td>Often appears nervous, apprehensive, irritable. Frequently expresses fears about own condition. Often needs to be reassured.</td>
</tr>
<tr>
<td>0</td>
<td>Shows no somatic sign of anxiety, nor complains of headaches, tremors, tachycardia.</td>
</tr>
<tr>
<td>1</td>
<td>Rather often complains of headaches, tremors, palpitations or other gastrointestinal or urinary somatic disorders.</td>
</tr>
<tr>
<td>2</td>
<td>Often appears pale, sweaty. Every day complains of headaches, diffused pains, sense of precordial oppression, or other somatic symptoms.</td>
</tr>
<tr>
<td>1</td>
<td>Besides showing signs of somatic and/or psychic anxiety, also shows marked restlessness or real psychomotor agitation</td>
</tr>
</tbody>
</table>

-------------------------------

TOTAL...... ...........

Section 7

CATASTROPHIC REACTION

(by/in collaboration with whoever carries out neuropsychological evaluation)

Score
<table>
<thead>
<tr>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-controlled reaction to possible difficulties encountered during</td>
<td>0</td>
</tr>
<tr>
<td>examination</td>
<td></td>
</tr>
<tr>
<td>Rather controlled reaction but some signs of impatience, irritation,</td>
<td>1</td>
</tr>
<tr>
<td>restlessness</td>
<td></td>
</tr>
<tr>
<td>More evident anxious or aggressive manifestations; frequent cursing</td>
<td>2</td>
</tr>
<tr>
<td>or expressions of depression</td>
<td></td>
</tr>
<tr>
<td>Clear manifestations of anxiety at somatic (and/or vegetative) level</td>
<td>3</td>
</tr>
<tr>
<td>but without fits of crying</td>
<td></td>
</tr>
<tr>
<td>Clear signs of anxiety with sporadic fits of crying or refusal to</td>
<td>4</td>
</tr>
<tr>
<td>continue test</td>
<td></td>
</tr>
<tr>
<td>Test practically impossible to carry out due to seriousness of</td>
<td>5</td>
</tr>
<tr>
<td>behavioral disorganization and fits of anxiety and crying</td>
<td></td>
</tr>
</tbody>
</table>
### Section 8

**DIFFICULTY IN EMOTIONAL CONTROL**

<table>
<thead>
<tr>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient manages to control emotional reactions normally</td>
<td>0</td>
</tr>
<tr>
<td>Recently becomes emotional a little more than usual</td>
<td>1</td>
</tr>
<tr>
<td>At times laughs or cries even to light stimuli (or is not able to interrupt emotional outburst provoked by an appropriate stimulus)</td>
<td>2</td>
</tr>
<tr>
<td>Often reacts in an emotionally excessive way with fits of laughter or crying. However, is able to control him/herself in the presence of strangers</td>
<td>3</td>
</tr>
<tr>
<td>Bursts out laughing or crying even in the presence of strangers and it is difficult for him/her to break off these attacks.</td>
<td>4</td>
</tr>
<tr>
<td>Patient is completely incapable of controlling emotional reactions</td>
<td>5</td>
</tr>
</tbody>
</table>
Section 9

ANHEDONIA

Sum scores of parameters (A) and (B) and one other choice (in relation to sex and patient’s pre-morbid interests) between parameters (C), (D) and (E).

<table>
<thead>
<tr>
<th>Score</th>
<th>A) Visits of friends or relatives (or receiving good news about them) gives me pleasure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>the same as before the illness</td>
</tr>
<tr>
<td></td>
<td>less than before the illness</td>
</tr>
<tr>
<td></td>
<td>gives me no pleasure</td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>B) A better-than-usual meal (for example, something brought from home) gives me pleasure</td>
</tr>
<tr>
<td></td>
<td>the same as before the illness</td>
</tr>
<tr>
<td></td>
<td>less than before the illness</td>
</tr>
<tr>
<td></td>
<td>gives me no pleasure</td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>C) If my team wins</td>
</tr>
<tr>
<td></td>
<td>it pleases me the same as before</td>
</tr>
<tr>
<td></td>
<td>it no longer interests me</td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>D) Seeing an erotic scene on TV</td>
</tr>
<tr>
<td></td>
<td>it pleases me like before</td>
</tr>
<tr>
<td></td>
<td>has no effect on me</td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>E) The visit of a beautiful child</td>
</tr>
<tr>
<td></td>
<td>it cheers me up the same as before</td>
</tr>
<tr>
<td></td>
<td>no longer gives me pleasure</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL ......

......
Section 10

DIURNAL VARIATIONS

The time when I feel most depressed is:

Always in the early morning, when I wake up and have a whole useless day before me to fill  

-2

It varies from one day to the other, but usually it is worse in the early morning, when I wake up  

-1

I always feel more or less depressed in the same way  

0

There's no rule, but usually I feel more depressed when something happens that makes me feel handicapped  

+1

Always when the situation makes me feel disabled and unable to do basic things, such as...(insert an example consistent with the patient's deficit)  

+2
Appendix 8.3: LEE for client (stroke survivor)

LEVEL OF EXPRESSED EMOTION SCALE

Client Version

John D. Cole, Ph.D.
Shahe S. Kazarian, Ph.D.

Instructions:
The following are a number of statements that describe the way in which someone may act towards you. Please identify the person who has been most influential in your life during the past three months. Examples of influential persons could be: mother, father, brother, sister, husband, wife, relative (e.g., aunt, grandfather) and friend. Then, read each statement and indicate whether this person has acted in these ways towards you over the past three months.

Mark your answers on the separate Answer Sheet provided. Simply circle the (T) box if you feel that the item is TRUE. Circle the (F) box if you feel the item is FALSE. It is important to make sure that the statement number agrees with the number of your response on the Answer Sheet.
1. Understands if sometimes I don't want to talk.

2. Calms me down when I'm upset.


4. Is tolerant with me even when I'm not meeting his/her expectations.

5. Doesn't butt into my conversations.

6. Doesn't make me nervous.

7. Says I just want attention when I say I'm not well.

8. Makes me feel guilty for not meeting his/her expectations.

9. Isn't overprotective with me.

10. Loses his/her temper when I'm not feeling well.

11. Is sympathetic towards me when I'm ill or upset.

12. Can see my point of view.

13. Is always interfering.

14. Doesn't panic when things start going wrong.

15. Encourages me to seek outside help when I'm not feeling well.

16. Doesn't feel that I'm causing him/her a lot of trouble.

17. Doesn't insist on doing things with me.

18. Can't think straight when things go wrong.

19. Doesn't help me when I'm upset or feeling unwell.

20. Puts me down if I don't live up to his/her expectations.

21. Doesn't insist on being with me all the time.

22. Blames me for things not going well.

23. Makes me feel valuable as a person.

24. Can't stand it when I'm upset.

25. Leaves me feeling overwhelmed.

26. Doesn't know how to handle my feelings when I'm not feeling well.

27. Says I cause my troubles to occur in order to get back at him/her.

28. Understands my limitations.

29. Often checks up on me to see what I'm doing.

30. Is able to be in control in stressful situations.

31. Tries to make me feel better when I'm upset or ill.

32. Is realistic about what I can and cannot do.

33. Is always nosing into my business.

34. Hears me out.
37. Always has to know everything about me.
38. Makes me feel relaxed when he/she is around.
39. Accuses me of exaggerating when I say I'm unwell.
40. Will take it easy with me, even if things aren't going right.
41. Insists on knowing where I'm going.
42. Gets angry with me for no reason.
43. Is considerate when I'm ill or upset.
44. Supports me when I need it.
45. Butts into my private matters.
46. Can cope well with stress.
47. Is willing to gain more information to understand my condition, when I'm not feeling well.
48. Is understanding if I make mistakes.
49. Doesn't pry into my life.
50. Is impatient with me when I'm not well.
51. Doesn't blame me when I'm feeling unwell.
52. Expects too much from me.
53. Doesn't ask a lot of personal questions.
54. Makes matters worse when things aren't going well.
55. Often accuses me of making things up when I'm not feeling well.
56. "Flies off the handle" when I don't do something well.
57. Gets upset when I don't check in with him/her.
58. Gets irritated when things don't go right.
59. Tries to reassure me when I'm not feeling well.
60. Expects the same level of effort from me, even if I don't feel well.
THE LEE SCALE (Client Version): ANSWER SHEET

DATE: __________

YOUR NAME: _______________________ AGE: ____  SEX: (circle one) Male  Female

MARITAL STATUS: (circle one)
Single  Married/Common-Law  Separated  Divorced  Widowed

Indicate who has been the most influential person in your life over the past three months:
(Circle one)
Mother  Father  Brother  Sister  Spouse
Other relative (e.g., Aunt, Grandfather)  Friend
Other (Please Specify) _______________________________

Have you been living with your influential person during the past three months?
(circle one)  Yes  No

How many waking hours on a typical weekday have you been spending with your influential person during the past three months? _________ hours per week day

How many waking hours on a typical weekend have you been spending with your influential person during the past three months? _________ hours per weekend
Instructions for each item:

Circle the "T" box if you feel the item is TRUE

Circle the "F" box if you feel the item is FALSE

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>T</td>
<td></td>
<td>16</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>2</td>
<td>T</td>
<td>F</td>
<td>17</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>T</td>
<td>F</td>
<td>18</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>4</td>
<td>T</td>
<td>F</td>
<td>19</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>5</td>
<td>T</td>
<td>F</td>
<td>20</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>6</td>
<td>T</td>
<td>F</td>
<td>21</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>7</td>
<td>T</td>
<td>F</td>
<td>22</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>8</td>
<td>T</td>
<td>F</td>
<td>23</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>9</td>
<td>T</td>
<td>F</td>
<td>24</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>10</td>
<td>T</td>
<td>F</td>
<td>25</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>11</td>
<td>T</td>
<td>F</td>
<td>26</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>12</td>
<td>T</td>
<td>F</td>
<td>27</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>13</td>
<td>T</td>
<td>F</td>
<td>28</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>14</td>
<td>T</td>
<td>F</td>
<td>29</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>15</td>
<td>T</td>
<td>F</td>
<td>30</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>31</td>
<td>T</td>
<td>F</td>
<td>32</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>33</td>
<td>T</td>
<td>F</td>
<td>34</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>35</td>
<td>T</td>
<td>F</td>
<td>36</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>37</td>
<td>T</td>
<td>F</td>
<td>38</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>39</td>
<td>T</td>
<td>F</td>
<td>40</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>41</td>
<td>T</td>
<td>F</td>
<td>42</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>43</td>
<td>T</td>
<td>F</td>
<td>44</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>45</td>
<td>T</td>
<td>F</td>
<td>46</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>47</td>
<td>T</td>
<td>F</td>
<td>48</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>49</td>
<td>T</td>
<td>F</td>
<td>50</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>51</td>
<td>T</td>
<td>F</td>
<td>52</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>53</td>
<td>T</td>
<td>F</td>
<td>54</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>55</td>
<td>T</td>
<td>F</td>
<td>56</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>57</td>
<td>T</td>
<td>F</td>
<td>58</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>59</td>
<td>T</td>
<td>F</td>
<td>60</td>
<td>T</td>
<td>F</td>
</tr>
</tbody>
</table>
Appendix 8.3: LEE for relative (spouse / partner)

LEVEL OF EXPRESSED EMOTION SCALE

Relative Version

John D. Cole, Ph.D.
Shahe S. Kazarian, Ph.D.

Instructions:

The following are a number of statements that describe the way in which someone may act towards you. Please identify the person who has been most influential in your life during the past three months. Examples of influential persons could be: mother, father, brother, sister, husband, wife, relative (e.g., aunt, grandfather) and friend. Then, read each statement and indicate whether this person has acted in these ways towards you over the past three months.

Mark your answers on the separate Answer Sheet provided. Simply circle the (T) box if you feel that the item is TRUE. Circle the (F) box if you feel the item is FALSE. It is important to make sure that the statement number agrees with the number of your response on the Answer Sheet.
1. Understands if sometimes I don't want to talk.
2. Calms me down when I'm upset.
4. Is tolerant with me even when I'm not meeting his/her expectations.
5. Doesn't butt into my conversations.
6. Doesn't make me nervous.
7. Says I just want attention when I say I'm not well.
8. Makes me feel guilty for not meeting his/her expectations.
9. Isn't overprotective with me.
10. Loses his/her temper when I'm not feeling well.
11. Is sympathetic towards me when I'm ill or upset.
12. Can see my point of view.
13. Is always interfering.
14. Doesn't panic when things start going wrong.
15. Encourages me to seek outside help when I'm not feeling well.
16. Doesn't feel that I'm causing him/her a lot of trouble.
17. Doesn't insist on doing things with me.
18. Can't think straight when things go wrong.
19. Doesn't help me when I'm upset or feeling unwell.
20. Puts me down if I don't live up to his/her expectations.
21. Doesn't insist on being with me all the time.
22. Blames me for things not going well.
23. Makes me feel valuable as a person.
24. Can't stand it when I'm upset.
25. Leaves me feeling overwhelmed.
26. Doesn't know how to handle my feelings when I'm not feeling well.
27. Says I cause my troubles to occur in order to get back at him/her.
28. Understands my limitations.
29. Often checks up on me to see what I'm doing.
30. Is able to be in control in stressful situations.
31. Tries to make me feel better when I'm upset or ill.
32. Is realistic about what I can and cannot do.
33. Is always nosing into my business.
34. Hears me out.
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>37.</td>
<td>Always has to know everything about me.</td>
</tr>
<tr>
<td>38.</td>
<td>Makes me feel relaxed when he/she is around.</td>
</tr>
<tr>
<td>39.</td>
<td>Accuses me of exaggerating when I say I'm unwell.</td>
</tr>
<tr>
<td>40.</td>
<td>Will take it easy with me, even if things aren't going right.</td>
</tr>
<tr>
<td>41.</td>
<td>Insists on knowing where I'm going.</td>
</tr>
<tr>
<td>42.</td>
<td>Gets angry with me for no reason.</td>
</tr>
<tr>
<td>43.</td>
<td>Is considerate when I'm ill or upset.</td>
</tr>
<tr>
<td>44.</td>
<td>Supports me when I need it.</td>
</tr>
<tr>
<td>45.</td>
<td>Butts into my private matters.</td>
</tr>
<tr>
<td>46.</td>
<td>Can cope well with stress.</td>
</tr>
<tr>
<td>47.</td>
<td>Is willing to gain more information to understand my condition, when I'm not feeling well.</td>
</tr>
<tr>
<td>48.</td>
<td>Is understanding if I make mistakes.</td>
</tr>
<tr>
<td>49.</td>
<td>Doesn't pry into my life.</td>
</tr>
<tr>
<td>50.</td>
<td>Is impatient with me when I'm not well.</td>
</tr>
<tr>
<td>51.</td>
<td>Doesn't blame me when I'm feeling unwell.</td>
</tr>
<tr>
<td>52.</td>
<td>Expects too much from me.</td>
</tr>
<tr>
<td>53.</td>
<td>Doesn't ask a lot of personal questions.</td>
</tr>
<tr>
<td>54.</td>
<td>Makes matters worse when things aren't going well.</td>
</tr>
<tr>
<td>55.</td>
<td>Often accuses me of making things up when I'm not feeling well.</td>
</tr>
<tr>
<td>56.</td>
<td>&quot;Flies off the handle&quot; when I don't do something well.</td>
</tr>
<tr>
<td>57.</td>
<td>Gets upset when I don't check in with him/her.</td>
</tr>
<tr>
<td>58.</td>
<td>Gets irritated when things don't go right.</td>
</tr>
<tr>
<td>59.</td>
<td>Tries to reassure me when I'm not feeling well.</td>
</tr>
<tr>
<td>60.</td>
<td>Expects the same level of effort from me, even if I don't feel well.</td>
</tr>
</tbody>
</table>
THE LEE SCALE (Relative Version): ANSWER SHEET

DATE: ____________

YOUR NAME: __________________ AGE: ____ SEX: (circle one) Male  Female

MARITAL STATUS: (circle one)
Single  Married/Common-Law  Separated  Divorced  Widowed

Indicate who has been the most influential person in your life over the past three months:
(Circle one)
Mother  Father  Brother  Sister  Spouse
Other relative (e.g., Aunt, Grandfather)  Friend
Other (Please Specify) ________________________________

Have you been living with your influential person during the past three months?
(circle one)  Yes  No

How many waking hours on a typical weekday have you been spending with your influential person during the past three months? _________ hours per week day

How many waking hours on a typical weekend have you been spending with your influential person during the past three months? _________ hours per weekend
Instructions for each item:

Circle the "T" box if you feel the item is TRUE

Circle the "F" box if you feel the item is FALSE

Copyright © 1992, John D. Cole, Ph.D. & Shahe S. Kazarian, Ph.D.
Appendix 9: Data Analysis for Empirical Paper

Appendix 9.1: Main Research Question 1

Appendix 9.2: Secondary Research Questions (2 + 3)

Appendix 9.3: Exploratory Research Question
Appendix 9.1: Main Research Question 1

Univariate Analysis of Variance

Between-Subjects Factors

<table>
<thead>
<tr>
<th>Value Label</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>RHS</td>
<td>30</td>
</tr>
<tr>
<td>LHS</td>
<td>30</td>
</tr>
</tbody>
</table>

Tests of Between-Subjects Effects

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>596.743 a</td>
<td>3</td>
<td>198.914</td>
<td>3.541</td>
</tr>
<tr>
<td>Intercept</td>
<td>923.464</td>
<td>1</td>
<td>923.464</td>
<td>16.438</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>16.891</td>
<td>1</td>
<td>16.891</td>
<td>.301</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>259.670</td>
<td>1</td>
<td>259.670</td>
<td>4.622</td>
</tr>
<tr>
<td>Sideofinjury * SPLEEScore</td>
<td>13.308</td>
<td>1</td>
<td>13.308</td>
<td>.237</td>
</tr>
<tr>
<td>Error</td>
<td>3145.990</td>
<td>56</td>
<td>56.178</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14250.000</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>3742.733</td>
<td>59</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. R Squared = .159 (Adjusted R Squared = .114)
### Tests of Between-Subjects Effects

**Dependent Variable:** PSDRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>.020</td>
<td>.159</td>
</tr>
<tr>
<td>Intercept</td>
<td>.000</td>
<td>.227</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>.586</td>
<td>.005</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>.036</td>
<td>.076</td>
</tr>
<tr>
<td>Sideofinjury * SPLEEScore</td>
<td>.628</td>
<td>.004</td>
</tr>
</tbody>
</table>

### Parameter Estimates

**Dependent Variable:** PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>10.168</td>
<td>3.430</td>
<td>2.964</td>
<td>.004</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>-2.423</td>
<td>4.418</td>
<td>-.548</td>
<td>.586</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td>0 a</td>
<td>. .</td>
<td>. .</td>
<td>.</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>.415</td>
<td>.240</td>
<td>1.727</td>
<td>.090</td>
</tr>
<tr>
<td>[Sideofinjury=0] * SPLEEScore</td>
<td>-.153</td>
<td>.315</td>
<td>-.487</td>
<td>.628</td>
</tr>
<tr>
<td>[Sideofinjury=1] * SPLEEScore</td>
<td>0 a</td>
<td>. .</td>
<td>. .</td>
<td>.</td>
</tr>
</tbody>
</table>

* a. This parameter is set to zero because it is redundant.*
## Parameter Estimates

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>95% Confidence Interval</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lower Bound</td>
<td>Upper Bound</td>
</tr>
<tr>
<td>Intercept</td>
<td>3.297</td>
<td>17.038</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>-11.273</td>
<td>6.428</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>-.066</td>
<td>.896</td>
</tr>
<tr>
<td>[Sideofinjury=0] * SPLEEScore</td>
<td>-.783</td>
<td>.477</td>
</tr>
<tr>
<td>[Sideofinjury=1] * SPLEEScore</td>
<td>.</td>
<td>.</td>
</tr>
</tbody>
</table>
Appendix 9.2: Secondary Research Questions (2 + 3)

Univariate Analysis of Variance

<table>
<thead>
<tr>
<th>Value Label</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>RHS</td>
<td>30</td>
</tr>
<tr>
<td>LHS</td>
<td>30</td>
</tr>
</tbody>
</table>

Tests of Between-Subjects Effects

**Dependent Variable:** PDSRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>583.435(^a)</td>
<td>2</td>
<td>291.718</td>
<td>5.263</td>
</tr>
<tr>
<td>Intercept</td>
<td>1001.347</td>
<td>1</td>
<td>1001.347</td>
<td>18.066</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>281.838</td>
<td>1</td>
<td>281.838</td>
<td>5.085</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>247.369</td>
<td>1</td>
<td>247.369</td>
<td>4.463</td>
</tr>
<tr>
<td>Error</td>
<td>3159.298</td>
<td>57</td>
<td>55.426</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14250.000</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>3742.733</td>
<td>59</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) R Squared = .156 (Adjusted R Squared = .126)
### Tests of Between-Subjects Effects

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>.008</td>
<td>.156</td>
</tr>
<tr>
<td>Intercept</td>
<td>.000</td>
<td>.241</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>.028</td>
<td>.082</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>.039</td>
<td>.073</td>
</tr>
</tbody>
</table>

### Parameter Estimates

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
<th>Lower Bound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>11.336</td>
<td>2.433</td>
<td>4.658</td>
<td>.000</td>
<td>6.463</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>-4.354</td>
<td>1.931</td>
<td>-2.255</td>
<td>.028</td>
<td>-8.220</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td>0^a</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>.326</td>
<td>.154</td>
<td>2.113</td>
<td>.039</td>
<td>.017</td>
</tr>
</tbody>
</table>

^a. This parameter is set to zero because it is redundant.
## Parameter Estimates

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>95% Confidence Interval</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Upper Bound</td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>16.209</td>
<td>.276</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>-.488</td>
<td>.082</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>SPLEEScore</td>
<td>.634</td>
<td>.073</td>
</tr>
</tbody>
</table>
### Appendix 9.3: Exploratory Research Question

#### Univariate Analysis of Variance

**Between-Subjects Factors**

<table>
<thead>
<tr>
<th>Value Label</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>RHS</td>
<td>30</td>
</tr>
<tr>
<td>LHS</td>
<td>30</td>
</tr>
</tbody>
</table>

**Tests of Between-Subjects Effects**

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>1474.514(^a)</td>
<td>3</td>
<td>491.505</td>
<td>12.135</td>
</tr>
<tr>
<td>Intercept</td>
<td>750.118</td>
<td>1</td>
<td>750.118</td>
<td>18.520</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>65.942</td>
<td>1</td>
<td>65.942</td>
<td>1.628</td>
</tr>
<tr>
<td>SSLEEScore</td>
<td>671.861</td>
<td>1</td>
<td>671.861</td>
<td>16.588</td>
</tr>
<tr>
<td>Sideofinjury * SSLEEScore</td>
<td>347.964</td>
<td>1</td>
<td>347.964</td>
<td>8.591</td>
</tr>
<tr>
<td>Error</td>
<td>2268.219</td>
<td>56</td>
<td>40.504</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14250.000</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>3742.733</td>
<td>59</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) R Squared = .394 (Adjusted R Squared = .362)
### Tests of Between-Subjects Effects

Dependent Variable: PSDRS Total Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>.000</td>
<td>.394</td>
</tr>
<tr>
<td>Intercept</td>
<td>.000</td>
<td>.249</td>
</tr>
<tr>
<td>Sideofinjury</td>
<td>.207</td>
<td>.028</td>
</tr>
<tr>
<td>SSLEEScore</td>
<td>.000</td>
<td>.229</td>
</tr>
<tr>
<td>Sideofinjury * SSLEEScore</td>
<td>.005</td>
<td>.133</td>
</tr>
</tbody>
</table>
### Parameter Estimates

**Dependent Variable:** PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>5.034</td>
<td>2.325</td>
<td>2.165</td>
<td>.035</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>4.243</td>
<td>3.325</td>
<td>1.276</td>
<td>.207</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td>0^a</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>SSLEEScore</td>
<td>.595</td>
<td>.113</td>
<td>5.246</td>
<td>.000</td>
</tr>
<tr>
<td>[Sideofinjury=0] * SSLEEScore</td>
<td>- .498</td>
<td>.170</td>
<td>-2.931</td>
<td>.005</td>
</tr>
<tr>
<td>[Sideofinjury=1] * SSLEEScore</td>
<td>0^a</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
</tbody>
</table>

a. This parameter is set to zero because it is redundant.

### Parameter Estimates

**Dependent Variable:** PSDRS Total Score

<table>
<thead>
<tr>
<th>Parameter</th>
<th>95% Confidence Interval</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lower Bound</td>
<td>Upper Bound</td>
</tr>
<tr>
<td>Intercept</td>
<td>.375</td>
<td>9.692</td>
</tr>
<tr>
<td>[Sideofinjury=0]</td>
<td>-2.418</td>
<td>10.904</td>
</tr>
<tr>
<td>[Sideofinjury=1]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSLEEScore</td>
<td>.368</td>
<td>.822</td>
</tr>
<tr>
<td>[Sideofinjury=0] * SSLEEScore</td>
<td>-.838</td>
<td>-.158</td>
</tr>
<tr>
<td>[Sideofinjury=1] * SSLEEScore</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>