VOLUME I

RESEARCH COMPONENT

SPOUSAL RELATIONSHIPS AFTER ACQUIRED BRAIN INJURY, AND CARERS' EXPECTATIONS, WELLBEING, AND INVOLVEMENT IN THE REHABILITATION PROCESS

by

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OVERVIEW

This thesis, comprising both research and clinical volumes, is submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham.

Volume I contains a literature review, empirical paper, and public domain briefing paper. The literature review is on the subject of spousal relationships following acquired brain injury, and evaluates the evidence on demographic and other predictors of relationship stability and quality post-injury. The empirical paper is a follow-up study investigating the links between carer expectations, wellbeing, and involvement in acquired brain injury rehabilitation, and the associations between these factors and clinical outcomes for the person with the injury. These two papers have been prepared as if for submission to the journal Brain Injury, whose Instructions for Authors are presented in Appendix 27. Certain instructions have not been adhered to, so as to comply with University regulations. Finally, the public domain briefing paper represents an accessible summary of the main findings of the empirical paper.

Volume II contains five clinical practice reports pertaining to clinical work conducted whilst on placement in adult mental health, child and adolescent, inpatient neurorehabilitation, and learning disability services. The first report describes a 60-year-old gentleman with a history of panic attacks, which are formulated from cognitive-behavioural and systemic perspectives. Secondly, an evaluation of a day service for adults with severe and enduring mental health difficulties is detailed. The third report is a single case experimental design study evaluating a cognitive-behavioural and family intervention with a seven-year-old boy showing aggressive behaviours. This is followed by a case study of a 44-year-old lady with left-hemisphere stroke. The fifth report is a case study of a 16-year-old boy with autism, which was presented orally. As such, a one-page summary of this work is included.

DEDICATION

This thesis is dedicated to my husband Steve, for his persistent and unquestioning support throughout this whole process.

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I would first like to acknowledge the contribution of the participants and brain injury services involved in the empirical study, without whom this research would not have been possible. I would especially like to thank the carers and care recipients for giving their valuable time to this work, and for making the data collection interesting and enjoyable.

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LITERATURE REVIEW

WHAT ARE THE PREDICTORS OF MARITAL STABILITY AND QUALITY AFTER ACQUIRED BRAIN INJURY?

ABSTRACT

Background: After acquired brain injury (ABI), maintaining a strong spousal relationship[1] may improve mental wellbeing considerably, for both parties (Myers, 2000). Despite its potential importance, factors that may sustain a good relationship following ABI have received relatively little research attention.

Method: This review appraises quantitative evidence as to the variables associated with relationship stability and quality post-ABI. A systematic literature search identified thirteen studies suitable for inclusion. The review comprises three main sections, covering demographic variables, injury-related variables such as ABI severity, and pre-existing psychosocial and sociocultural characteristics of the couple and relationship.

Results: Age, length of pre-morbid relationship, ethnicity, injury severity, neurobehavioural sequelae including fatigue and aggression, and post-injury employment were linked to differences in relationship outcomes. Gender, socioeconomic variables, coping style, and sociocultural factors demonstrated weak or no associations.

Conclusions: Taking account of the studies' methodological strengths, the most persuasive findings were that younger age, increased ABI severity, and violent cause of ABI predict marital breakdown. The evidence on psychosocial and sociocultural influences was limited in scope and quality and requires further exploration. Many papers had inherent methodological weaknesses, including cross-sectional designs, uncontrolled confounds, and small samples. Future research would benefit from addressing such issues.

Keywords: marital relationships, acquired brain injury, traumatic brain injury, stroke, adjustment, neurobehavioural sequelae.

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[1] The use of the term "spousal" within this document is not intended to exclude or discount non-marital partnerships: this is reflected in the search terms used in the review. The term is used for ease of reading, since the vast majority of existing research in this area focuses on married couples.

INTRODUCTION

Acquired brain injury (ABI) is defined by the World Health Organisation (1996) as "damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial maladjustment". An ABI is typically the result of either head trauma or stroke, but it can also arise following a tumour or infection in the brain.

Whether a person sustains an ABI via an internal or external event, there are numerous potential consequences for the person and those close to them (Wood & Yurdakul, 1997). It is widely accepted that relatives of the brain-injured person, particularly if they assume the role of carer, experience adverse mental health outcomes following the ABI (Carnes & Quinn, 2005; Oddy & Herbert, 2003; Verhaeghe, Defloor, & Grypdonck, 2005). This effect on carer wellbeing appears to persist up to and beyond 15-18 months post-injury (Kumar & Kendrick, 2009; McPherson, Pentland, & McNaughton, 2000).

Many adults who experience a brain injury are married or cohabiting (Office for National Statistics, 2010; Wilson, 2009). For couples, one consequence of ABI is the increased likelihood of difficulties within the relationship. Review evidence suggests that traumatic brain injury (TBI) and stroke have a negative impact on many aspects of spousal relationships (Liss & Willer, 1990; Thompson & Ryan, 2008 respectively), and that TBI increases the likelihood of marital breakdown (Blais & Boisvert, 2005). Oddy (2001) highlighted data demonstrating a twofold increased risk of marital breakdown within seven years post-TBI, compared with rates for the general population. Examining the reasons behind such findings is important since close relationships play a key role in maintaining wellbeing and quality of life (Myers, 2000). Furthermore, good close relationships may enhance rehabilitation for the person with ABI. This idea has been promoted in recent Department of Health and other clinical guideline documents (Department of Health, 2007, 2008; Turner-Stokes, 2003).

Achieving greater insights into why relationships succumb to difficulties post-ABI could improve interventions aimed at helping couples manage injury-related challenges, and ultimately support the maintenance of strong relationships post-ABI. A review of factors associated with relationship breakdown and reduced relationship quality would contribute to this understanding.

Aim

The main aim of this paper is to synthesise and evaluate research that examines the predictors of relationship outcomes after acquired brain injury. The review comprises three sections with associated subsections addressing different facets of the overall research question.

Relationship stability and quality are the outcomes examined. The former is an objective assessment of relationship status, to denote single, married/in a relationship, separated, divorced, or widowed. Relationship quality is rather more subjective and controversial as a construct, with no agreed definition (Hassebrauck & Fehr, 2002). For the purposes of this review, studies using a global measure of quality such as relationship satisfaction and those assessing more than one characteristic of relationship quality were included.

In the first section, research into demographic predictors of the stated relationship outcomes is reviewed. These comprise age, length of the pre-morbid relationship, time since injury, gender, ethnicity/nationality, and socioeconomic factors. The second section considers the association between the relationship outcomes and the following injury-related variables: injury severity; behavioural, cognitive, and psychosocial ABI sequelae; and post-injury employment and financial status. Finally, variables relating to pre-existing psychosocial and sociocultural characteristics of the person with ABI, their partner, or the relationship are evaluated. These include coping and adjusting to the brain injury; pre-existing psychiatric difficulties; and sociocultural predictors such as family structure. Implications of the findings for research and clinical practice are presented, followed by reflections on gaps in the literature and the review's limitations.

Search Strategy and Inclusion and Exclusion Criteria

To identify papers that would most clearly answer the overall research question, an electronic search was conducted using the following databases: EMBASE; Cochrane Library; Ovid MEDLINE(R); PsycINFO; Web of Science, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search comprised all English language journal articles published from 1988 to late 2011 that contained the keywords HEAD INJUR* *or* BRAIN INJUR* *or* NEUROLOGICAL* IMPAIR* *or* STROKE* *or* SUBARACHNOID *or* SUBDURAL* *or* BRAIN TUMO* *or* BRAIN INFECTION* *and* COUPLE* *or* SPOUS* *or* PARTNER* *or* MARITAL *or* MARRI* *or* SEXUAL* in their title (asterisk denotes truncation). The keyword RELATIONSHIP was not included in the final search, as a preliminary search using this as a search term yielded a vast amount of extraneous material.

In addition to those listed above, the main inclusion criteria were that the research included quantitative measurement of relationship status (still married/in a relationship vs. separated, divorced, or widowed) and/or global relationship quality (measuring either general satisfaction with the relationship or more than one relationship variable considered to constitute a “good” relationship); and analysis of the association between at least one demographic, injury-specific, or pre-existing psychological, social, or cultural variable and at least one of these relationship outcomes. The relationships investigated by the study needed to involve spousal or equivalent relationships where one member of the couple had sustained an ABI. Editorials, case studies, reviews[2], dissertations and qualitative papers were excluded. So, too, were studies measuring only one specific aspect of the relationship such as communication or sexual satisfaction.

Application of the above criteria produced an initial shortlist of 11 papers, the reference lists of which were inspected and potential papers’ abstracts scrutinised to ensure no relevant papers were missed; a citation search was also performed on the initial shortlist. Two further papers meeting the inclusion criteria were identified from these latter searches. The 13 selected papers are summarised in Table 1.

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[2] Three reviews in the area of marital relationships and ABI were published between 1988 and 2010 (Liss & Willer, 1990; Blais & Boisvert, 2005, and Thompson & Ryan, 2008). These differ in focus to the present paper in several respects. Since the current review was conceived, a further review was published on this topic (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). The main similarity between the Godwin et al. (2011) paper and the current review is the evaluation of marital stability and quality as outcomes. Predictors of these outcomes are discussed by these authors, but to a far lesser extent than in the current paper, which has these as its main focus. The Godwin et al. (2011) review also includes only papers on traumatic brain injury as opposed to all types of ABI. Finally, the review examines its findings in the context of family therapy, which does not feature in the present paper.

Table 1

Summary detail on the final shortlist of papers

Author(s)	**Sample size (N)**	**Participant information** **a) Average age of pwABI[a] (years)** **b) Gender of pwABI** **c) Study location**	**Brain injury type and/or severity**	**Variable(s) examined** (relating to pwABI unless stated) **and outcome measure(s) used**	**Main findings** (for ABI group, if control group present)	**Research quality grading** (based on NICE criteria)
Arango-Lasprilla et al. (2008)	N = 977 pw traumatic brain injury (TBI)	a) 46 b) 728 (75%) male; 249 (25%) female c) USA (national database)	Non-violent cause (N = 904) Violent cause (N = 65)	Age, gender, injury severity, ethnicity, socioeconomic factors *Outcome:* Marital stability[b]	Age, ethnicity, and injury severity significantly predicted marital stability 2 years post-TBI.	2++
Blais & Boisvert (2007)	N = 70 TBI couples[c]; N = 70 controls (couples without TBI)	a) 48 b) 49 (70%) male; 21 (30%) female c) Quebec, Canada	Mild (N = 24 (34%)) Moderate (N = 27 (39%)) Severe (N = 19 (27%))	Coping, communication skills *Outcome:* Marital quality. Both partners completed Marital Adjustment Test (MAT) & Kansas Marital Satisfaction Scale (KMSS)	Strong correlation between positive perception of spouses' communication skills & marital satisfaction Avoidance coping linked to reduced marital satisfaction	2+
Burridge et al. (2007)	N = 20 ABI couples; N = 20 chronic pain couples; N = 20 controls	a) 53 (pwABI) b) 12 (60%) male; 8 (40%) female c) Exeter, UK	Mild (N = 7) Moderate (N = 8) Severe (N = 5)	Cognitive, emotional & social function *Outcome:* Marital quality. Both partners completed The Relationship Questionnaire	Poorer cognitive and emotional functioning and poorer socio-emotional skill linked to lower marital satisfaction for partners of pwABI.	2-

Gosling & Oddy (1999)	N = 18 TBI couples	a) 42 b) 18 (100%) male c) London & East Sussex, UK	Post-traumatic amnesia >6 days (range 21-140 days; mean 56 days)	Physical, cognitive & psychosocial TBI sequelae *Outcome:* Marital quality. Partners of pwTBI completed the GRIMS (a measure of marital satisfaction)	Number of TBI sequelae not significantly related to spouses' marital satisfaction.	2-
Kreuter et al. (1998)	N = 92 pwTBI N = 167 pw spinal cord injury (SCI) N = 264 controls	a) 41 (range 20-70) b) 65 (71%) male; 27 (29%) female c) Gothenburg, Sweden	Tetraplegic = 51% Paraplegic = 49% Wheelchair user = 73%	Gender *Outcome:* Marital stability.	Around half of relationships in TBI and SCI groups broke down post-injury. Gender did not predict marital breakdown in TBI group.	2+
Kreutzer et al. (2007)	N = 120 pwTBI	a) 41 (range 19-69) b) 68% male; 32% female c) Virginia, USA	Mild = 21% Moderate = 23% Severe = 57%	Age, gender, ethnicity, level of education, severity of injury, time since injury, length of relationship *Outcome:* Marital stability.	Older pwTBI more likely to remain married. Increased TBI severity linked to greater risk of marital breakdown. Couples with longer pre-morbid relationships more likely to remain together.	2+
McPherson et al. (2011)	N = 56 couples with one partner with stroke	a) 65 b) 50 (88%) male; 7 (12%) female c) Ottawa, Canada	Stroke type: Infarct = 71% Haemorrhagic = 25% Infarct & Haemorrhagic = 4%	Age, gender, education, time since stroke *Outcome:* Marital quality. Partners of pwStroke completed The Quality of Marriage Index	None of the demographic variables was significantly associated with post-stroke relationship satisfaction.	2+

Peters et al. (1990)	N = 55 TBI couples	a) 47 b) 55 (100%) male c) Manitoba, Canada	Mild (N = 10) Moderate (N = 25) Severe (N = 20)	Severity of injury, time post-injury, financial strain *Outcome:* Marital quality. Partners of pwTBI completed Dyadic Adjustment Scale & Personal Assessment of Intimacy in Relationships	Greater post-injury financial strain linked to poorer marital quality. Greater injury severity linked to poorer marital quality. Injury severity not related to intimacy.	2-
Peters et al. (1992)	N = 48 spouses of pwTBI N = 24 spouses of pwSCI	a) 47 b) 48 (100%) male c) Manitoba, Canada	Moderate (N = 31) Severe (N = 17)	Severity of injury *Outcome:* Marital quality. Partners of pwTBI completed Dyadic Adjustment Scale	Wives of pw severe TBI reported significantly poorer marital quality than wives of pw moderate TBI.	2-
Sabhesan et al. (1991)	N = 105 TBI couples	a) Under 30 (39%); 30-45 (35%); Over 45 (26%) b) 90 (86%) male; 15 (14%) female c) Madurai, India	Mild (N = 22) Moderate (N = 19) Severe (N = 17) *No GCS*[d] *(N = 47)*	Age, gender, type of family system, severity of injury *Outcome:* Marital stability/quality. Couples reported on relationship strain & likelihood of marital breakdown via 3-point scale.	Age, gender, type of family system, injury severity were not significantly related to marital stability/quality post-TBI.	2-
Vanderploeg et al. (2003)	N = 626 pwTBI N = 3896 controls	a) 37 b) 626 (100%) male c) Florida, USA (sample were Vietnam veterans)	Mild TBI with no loss of consciousness (LOC) N = 373 TBI with at least brief LOC N = 253	Age, gender, education, ethnicity, early psychiatric problems. *Outcome:* Marital stability.	Predictor variables (esp. demographics) accounted for 17% of total variance in marital stability. Older, white participants in full-time work more likely to be married post-TBI (pre-injury marital status not documented)	2++

Wood & Yurdakul (1997)	N = 131 pwTBI	a) Range 22-84 b) 97 (74%) male; 34 (26%) female c) Milton Keynes, UK	RTA[e] = 73% Work-related = 15% Other = 12%	Age, gender, severity of injury, time since injury. *Outcome:* Marital stability	No correlation between age or sex and marital status post-TBI. Risk of separation/ divorce increased with time since injury.	2-
Wood et al. (2005)	N = 48 partners of pwTBI	a) 41 b) 35 (73%) male; 13 (27%) female c) Swansea & Gloucester, UK	Mean days of post-traumatic amnesia = 14	Age, gender, time since injury, length of relationship, cognitive & psychosocial TBI sequelae. *Outcome:* Marital stability	Relationship breakdown not related to severity of injury, length of relationship, or age of pwTBI.	2-

Note. All information is presented as described and as available within each study. If injury is described as “ABI” in Sample size column, this denotes ABI of mixed cause within the sample (e.g. might include those with TBI, stroke, and tumour). Research gradings are made by the current author, based on the criteria detailed by the National Institute for Health and Clinical Excellence (NICE, 2004). See Appendix 1 for a table outlining these grading criteria. Further detail as to the criteria used to evaluate the literature contained in this review is provided below.

[a]”pw...” is an abbreviation for “people with”.

[b]”Marital stability” denotes marital status post-ABI, i.e. still married, separated, divorced, or widowed.

[c]”TBI couples” and “ABI couples” denotes a couple where one partner has sustained a traumatic brain injury or acquired brain injury respectively.

[d]GCS stands for “Glasgow Coma Scale”, which classifies brain injury severity by the following scores: severe = 8 or less; moderate = 9-12; mild = 13 or greater.

[e]RTA stands for “road traffic accident”.

Evaluation criteria

Due to the types of studies included in this review, quality frameworks such as CONSORT guidelines or those proposed by Chambless and Hollon (1998) were not applicable. Instead, the research was largely evaluated based on the critical appraisal criteria of Sale and Brazil (2004), which were developed from a literature review of mixed-method studies. The criteria goals and examples of associated individual methodological points are summarised in Table 2, for quantitative studies only.

Table 2
Summary of critical appraisal criteria of Sale and Brazil (2004) for quantitative studies

Goals of criteria	Methodological points
Truth value (credibility vs. internal validity)	Extraneous or confounding variables identified
	Extraneous or confounding variable(s) or baseline differences controlled for in the analysis
Applicability (transferability/fittingness vs. external validity/generalisability)	Objective of study explicitly stated or described
	Design stated explicitly, i.e. case study, cross-sectional study, RCT
	Study population defined or described
	Control or comparison group described
	Power calculation to assess adequacy of sample size or sample size calculated for adequate power
	Statistical procedures referenced or described
	Data collection instruments or source of data described
Consistency (dependability vs. reliability) **Neutrality (confirmability vs. objectivity)**	Standardisation of observers described

The National Institute for Health and Clinical Excellence (NICE) guidelines on reviewing and grading evidence (NICE, 2004) were also consulted (see Appendix 1). Gradings range from level 4 ("*Expert opinion, formal consensus"*) to 1++ ("*High quality meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias"*). Levels 1 and 2 have "++", "+" and "-" variations. Table 1 includes gradings for each paper reviewed, based on these guidelines. The studies were judged to be of poor to very good quality, ranging from 2- (*"Case-control or cohort studies with a high risk or confounding bias, or chance and a significant risk that the relationship is not causal"*) to 2++ (*"High-quality case-control or cohort studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal"*), with only two studies gauged to be of this higher standard.

1. DO CERTAIN DEMOGRAPHIC VARIABLES PREDICT RELATIONSHIP OUTCOMES FOLLOWING ACQUIRED BRAIN INJURY?

The literature on relationship stability and quality in the general population has identified a number of demographic variables important in the maintenance and breakdown of romantic partnerships. For example, age (O'Mahoney & Carroll, 1997), gender (Jose & Alfons, 2007), and socioeconomic factors (Starkey, 1996; Tzeng & Mare, 1995) have each been found to impact upon the relationship outcomes evaluated in the current review.

In view of the apparent multiple demographic influences on spousal relationships, it is important that these aspects are examined when appraising the literature on relationships post-ABI. The findings on this subject are discussed below, concerning each variable in turn.

1.1 Age

Seven papers analysed connections between age and relationship outcome in couples where one partner sustained an ABI.

Vanderploeg, Curtiss, Duchnick and Luis (2003) presented a population-based study involving large groups of Vietnam-era army veterans who had either sustained a mild TBI or no TBI since completing their military service. Demographic and other data were obtained from a database concerning a random selection of individuals who had taken part in a mid-1980s study on Vietnam veterans' experiences. Logistic regression analyses were undertaken, exploring various demographic factors alongside work and marital status. Age explained 1.9% of the variance in marital status ("married" vs. "not married") in the TBI sample, and only 0.1% in the control sample. Whether this difference is statistically significant was not stated. Odds ratios revealed that those aged 38-45 had a 1.8 times greater likelihood of remaining married at around eight years post-TBI than 31- to 37-year-olds. The statistical significance of this age effect was not reported. This study benefits from the large sample and inclusion of a well-matched control group. Weaknesses included the incomplete statistical analyses and lack of delineation of the "married" and "not married" groups to denote unmarried participants as single, separated/divorced, or widowed.

Kreutzer, Marwitz, Hsu, Williams and Riddick (2007) provided further evidence that older couples are more likely to stay together following ABI. Demographic and general health data were gathered for 120 individuals via interview and self-report questionnaires. In examining differences between married and separated/divorced participants, those married at follow-up – approximately four years post-injury – were significantly more likely to be older than those separated or divorced at this point. On average, couples who remained married were 10 years older than the latter group.

In a study examining the predictors of marital stability for 977 individuals with moderate to severe TBI, Arango-Lasprilla et al. (2008) consulted follow-up data for research participants at one and two years post-TBI; a strong research design. A range of variables were analysed, with ethnicity as a moderating factor. Age (range = 18 to 86 years) was a highly significant predictor of marital stability for all participants; younger people were significantly more likely to have separated or divorced post-injury. Specifically, individuals of around 36 years of age were over four times more likely to have experienced a relationship break-up than those of around 57 years.

With a UK sample, Wood and Yurdakul (1997) investigated relationship outcomes after TBI for 131 individuals. Demographic data were gathered from archives, which enabled analysis of changes in marital status between time of injury and approximately eight years post-TBI. Participants' age range was 22 to 84 years. Grouping participants into "under 35s" and "over 35s", no significant difference in marital status was found post-injury as regards age. Although the analyses and results were presented clearly, this method of classifying participants' age seems simplistic and would likely increase the Type II error risk.

Further lack of support for the role of age comes from Wood, Liossi and Wood (2005). This study focused on the effects of TBI neurobehavioural sequelae on relationships, but considered age as a potential factor when comparing characteristics of "together" and "separated" groups of couples. Age was not significantly related to relationship breakdown post-injury.

In an Indian study, Sabhesan, Rajasakthivel and Natarajan (1991) investigated "marital disharmony" as an outcome of TBI. They followed up 105 couples every three months for 18 months, assessing marital outcome via interview alongside a four-point scale they devised. Using the scale, couples were given a marital harmony score based on comparisons with their pre-morbid relationship. Scores were described as follows: 0 = "same or better than before"; 1 = "at least one of the spouses experienced strain on marital relations"; 2 = "both partners experienced strain, there arose frequent misunderstandings, and yet, they were able to live together", and 3 = "at least one of the partners foresaw the impending possibility of break in the relations, or the marriage was already broken" (p. 354). Patients' age (described as "below 30", "30-45", or "over 45") was not significantly associated with differences in marital harmony. The sparse methodological detail and unclear analyses within this study reduce readers' confidence in its findings. As with Wood and Yurdakul (1997), the method of categorising participants by age may have increased the risk of Type II error.

In a recent study examining marital relationships post-stroke, McPherson, Wilson, Chyurlia, and Leclerc (2011) measured spousal caregivers' perceptions of relationship satisfaction. Age, which ranged from 29 to 88 years for caregivers and 32 to 88 for partners, was analysed as a predictor variable and found to have no significant association with relationship satisfaction. The sample size was reasonable, yet all caregivers were female. The relationship satisfaction measure used (Quality of Marriage Index) demonstrated excellent internal consistency, and the analyses and results were described clearly.

Summary: Taking power issues into account, it is noticeable that the studies revealing no age effects employed smaller samples than those reporting significant results. It is possible that the former were not sufficiently powered to detect an age effect, and also that age may be less relevant for couples living with stroke than TBI. On balance, the findings suggest the impact of TBI on marital relationships is moderated by age. Specifically, older individuals appear more likely than their younger counterparts to remain in a relationship post-TBI.

Length of the pre-morbid relationship is discussed below, but it is relevant to note that this factor is likely to be confounded with age. Perhaps surprisingly, none of the papers included in this review controlled for either factor when exploring the other. Cohort effects may also be worth considering, but these too have not received attention within the 13 papers discussed.

1.2 Length of pre-morbid relationship

A minority of the 13 studies included analysis of pre-morbid relationship length in connection with post-injury relationship outcome. These findings are examined below.

Wood and Yurdakul (1997) reported participants' mean length of pre-morbid relationship as 13 years (SD = 11.68). Pre-morbid relationship length was significantly greater in participants who had remained married post-injury. In contrast, Wood et al. (2005) found no significant differences in length of pre-morbid relationship in terms of marital stability. These papers were similar in design, methodology, and quality, yet greater weight may be assigned to the significant finding of Wood and Yurdakul (1997), since the sample size of Wood et al. (2005) may have been too small to detect an effect.

Kreutzer and colleagues (2007) identified a significant difference in pre-injury relationship length between married and separated or divorced participants. In this instance, the pre-morbid relationship was almost three times longer for individuals still married at follow-up. For those married for longer than 30 years pre-morbidly, none had separated post-injury.

Summary: Overall, there is greater evidence to suggest that longer pre-morbid relationships are associated with increased likelihood of couples remaining married post-ABI. Interpretations are limited, in that length of pre-morbid relationship and age are confounded and few studies controlled for this. The relationship between these factors and marital outcome is therefore unclear.

1.3 Time since injury

This may be an important factor to consider when investigating marital outcomes post-ABI, yet it was only analysed in two papers. Wood and Yurdakul (1997) identified a significant difference between those married and divorced at follow-up depending on time since injury. Their analyses suggest that as time post-TBI increases, incidence rates of separation and/or divorce also increase. Five to six years post-injury seemed a particularly critical period. In the absence of a control group, however, it is unclear whether this pattern was specific to those with TBI. McPherson et al. (2011) considered time since injury in relation to marital satisfaction post-stroke. Time since stroke was categorised as "under 6 months"," 6-12 months", or "over 12 months" and was not significantly associated with relationship satisfaction post-stroke. However, this classification method may have increased the risk of Type II error.

1.4 Gender

Seven papers explored gender and its link to relationship outcomes. Sabhesan et al. (1991) found no significant association between patient gender and marital harmony post-TBI. Similarly, Wood and Yurdakul (1997) identified no significant gender differences in likelihood of relationship breakdown post-TBI. These authors comment that their data do not support the common assumption that females are more likely to remain in the relationship after their partner's brain injury than are males. Wood et al. (2005) also found no gender differences between "separated" and "together" groups of participants in their study; Kreutzer et al. (2007) corroborated this finding in their sample of 120 individuals.

Kreuter, Sullivan, Dahllöf, and Siösteen (1998) described a large-sample comparative study involving participants with TBI, spinal cord injury, and healthy controls. No significant differences were found for marital status by gender in any of the groups.

In the Arango-Lasprilla et al. (2008) study, males with TBI were almost twice as likely to have experienced separation or divorce at one or two years' follow-up than females with TBI. This was statistically significant (p = .02), and other predictor variables including age and cause of injury were controlled for in the analyses.

With regard to evidence on marital quality, gender had no significant association with partners' reports of relationship satisfaction post-stroke in the McPherson et al. (2011) study.

Summary: Although more studies found that gender did not play a significant role in relationship outcomes following ABI, the methodological quality of the Arango-Lasprilla et al. (2008) paper, especially with regard to power, is sufficiently superior to attract more weight to their finding that males are more likely to experience marital breakdown post-TBI. However, it may be that the effect of gender is relatively small and is only apparent in larger samples. The available evidence suggests that relationship satisfaction is not significantly linked to gender. Despite the papers broadly representing gender ratios in the incidence of ABI (Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006), the relative scarcity of female ABI participants limits our understanding of male partners' perspectives. Finally, only heterosexual couples participated in the research, highlighting a further gap in the literature.

1.5 Ethnicity/nationality

Much of the literature originated from the UK, USA, or Canada. Studies where ethnicity, culture, or nationality were explored are included below.

Vanderploeg et al. (2003) included analyses based on participants' ethnicity. All participants were USA residents, and ethnicity was defined as "White" (82% of sample) and "Minority" (18%). Ethnicity accounted for 2.5% of the variance in marital status for the TBI group and 1.2% for the control group. After controlling for other predictor variables, it emerged that White individuals were 2.4 times more likely to be married at approximately 16 years post-TBI than Minority participants. Whether these findings were statistically significant is unclear.

Kreutzer et al. (2007) reported on a sample comprising 74% White individuals, 19% African-American, and 7% "other". Ethnicity was analysed in relation to differences in marital status at follow-up (three to eight years post-TBI), and found to be non-significant.

Ethnicity had a strong focus in the large-sample American study of Arango-Lasprilla et al. (2008). Ethnicity was defined as "Caucasian", or "Minorities", which included African American, Hispanic, Asian, and Native American individuals. The Caucasian group comprised 77% of the sample. Extensive analyses were conducted to identify predictors of post-TBI marital stability, with ethnicity as a moderating variable in each case. Overall, ethnicity significantly predicted marital stability: Minority participants were 1.72 times more likely to be single, separated, or divorced by two years post-TBI than were Caucasians. This finding remained significant when other demographic predictors were controlled for. An interaction effect was also found between ethnicity and TBI partners' level of disability. Participants in the Minorities group were significantly less likely to separate from their partners as level of disability increased; the opposite trend, although not significant statistically, was identified for Caucasian participants.

Summary: The above findings help elucidate the potential influence of ethnicity on marital status after TBI. The Vanderploeg et al. (2003) and Arango-Lasprilla et al. (2008) studies, both reporting a greater likelihood of divorce or separation for non-white individuals, perhaps merit greater attention given their methodological strengths. Arango-Lasprilla et al. (2008) in particular provided excellent insights into the moderating effects of ethnicity on relationship outcomes for people post-TBI, and the interaction effect found may help clarify the non-significant result of Kreutzer et al. (2007), whose participants largely comprised individuals with severe TBI.

1.6 Socioeconomic variables

Socioeconomic variables in terms of pre-morbid educational attainment and income feature in some of the research reviewed. The following discussion focuses on studies that analysed socioeconomic predictors of marital outcome.

Arango-Lasprilla et al. (2008) reported on participants' years in education and employment status upon admission to hospital. Unadjusted odds ratios revealed that employment status at admission, income at admission, and education at admission were not significant predictors of marital stability post-TBI.

Level of education was detailed for Kreutzer et al.'s (2007) participants, regarding whether or not they had finished high school or attended university. No significant differences were found between individuals who were married versus divorced or separated in terms of this variable. It does not appear that other demographic factors were controlled for in the analyses, however.

Vanderploeg et al. (2003) provided analysis of pre-injury socioeconomic status by way of participants' years in education. The authors' analyses revealed that level of education did not significantly predict marital status after TBI; nor was it associated with marital status for control participants.

McPherson et al. (2011) considered both partners' level of education across the categories "more than high school", "high school", and "less than high school". This variable was not significantly associated with spouses' reported relationship satisfaction following their partner's stroke.

Summary: Although a minority of papers analysed socioeconomic variables, the methodological quality of this research was generally strong, as discussed previously. None of the four studies found a significant relationship between pre-morbid education and post-injury marital status or satisfaction when taken as unique variables. In light of the overall strength of these studies, one may be reasonably confident to accept the findings as a good reflection of socioeconomic variables having a weak or non-existent effect on marital outcomes post-ABI.

2. WHICH BRAIN INJURY-RELATED VARIABLES AFFECT RELATIONSHIP OUTCOMES?

Research into health problems other than ABI suggests that illness-related factors influence relationship outcomes. In renal patients, Binik, Chowanec and Devins (1990) found that the "intrusiveness" of the disease (the extent to which it impacts upon daily life) was significantly related to marital adjustment and role strain. Similarly, Davies et al. (2010) identified that for partners of individuals with dementia, symptoms such as memory loss and physical difficulties had a negative impact upon intimacy and sexuality. In contrast, partners of people with mild memory loss reported less significant declines in these outcomes.

This second section focuses on relationship outcomes in conjunction with variables relating to the ABI itself. Firstly, papers examining injury cause and severity are explored, followed by consideration of behavioural, cognitive, and psychosocial sequelae of ABI. Finally, post-injury employment and financial status are discussed.

2.1 Injury cause and severity

Within the papers reviewed, ABI severity was typically reported based on participants' Glasgow Coma Scale (GCS) scores upon hospital admission, corresponding to the categories "mild" "moderate" and "severe". A minority of studies analysed cause and/or type of injury in association with relationship outcomes.

The two-year follow-up study of Arango-Lasprilla et al. (2008) mostly involved participants with moderate to severe TBI. Analysed using a logistic regression model with other predictor variables adjusted for, participants' GCS scores upon hospital admission significantly predicted marital stability. Individuals with moderate TBI were over twice as likely to have separated at follow-up as those with severe injuries; violent TBI was associated with an almost three-fold increase in separation risk compared with non-violent TBI. These findings were statistically significant.

Sabhesan et al. (1991) reported that GCS scores did not significantly predict marital difficulties. Similarly, in the Kreutzer et al. (2007) study GCS scores were not related significantly to post-TBI marital breakdown. However, participants who were separated or divorced post-injury were three times more likely to have experienced a TBI via violent cause than those who remained married. This was statistically significant.

Concerning marital quality, Peters et al. (1990) described a cross-sectional study investigating relationship intimacy and satisfaction in 55 males with TBI and their spouses. Wives' perceived intimacy was reported via the Personal Assessment of Intimacy in Relationships (PAIR) questionnaire, which gauges emotional, social, sexual, intellectual, and recreational intimacy. Wives also completed the Dyadic Adjustment Scale (DAS), assessing their perceived marital satisfaction. The DAS includes the subscales "dyadic satisfaction" and "affectional expression". The authors' hypothesis that wives of those with severe TBI would report significantly poorer marital outcomes than wives of individuals with mild or moderate TBI was partly supported: wives of partners with severe TBI reported significantly poorer marital outcomes, in particular less affectional expression, than wives in the other two groups. There were no significant differences in PAIR scores as regards injury severity. This study's relatively small sample size, cross-sectional design, and focus on healthy spouses' perspectives limit its quality and generalisability.

In a study by Peters et al. (1992), marital quality in couples where the husband sustained a moderate or severe TBI or spinal cord injury (SCI) were compared, based on wives' reports[3]. Here, wives of individuals with severe TBI reported poorer marital outcomes according to the DAS than wives of those with moderate TBI or SCI. In particular, wives in the severe TBI group reported significantly less expressed affection and feelings of cohesiveness than wives in the other groups. The inclusion of a control group strengthens this study's design, yet the sample size and other design elements contain flaws akin to the Peters et al. (1990) paper.

Summary: The above findings offer a mixed picture as to the connections between severity and cause of brain injury and marital outcomes. Again, for its methodological strengths, more weight may be assigned to Arango-Lasprilla et al.'s (2008) intriguing finding that greater marital stability coincides with increased TBI severity. There is tentative evidence that severe TBI is linked with spousal perceptions of poorer marital quality. There seems relatively strong evidence for increased marital breakdown risk in those with TBI of violent cause.

2.2 Behavioural, cognitive, and psychosocial sequelae

Three studies examined the association between ABI sequelae and relationship outcomes. Wood et al. (2005) asked 350 partners of men and women with TBI to name any behaviour or personality changes in their partner post-TBI that impacted upon relationship quality. Fifty-four per cent of the sample (N = 189) reported relationship difficulties due to TBI sequelae. A shortlist of 12 neurobehavioural sequelae, including memory, aggression, fatigue, and libido, was created following a content analysis of partners' responses. Forty eight partners

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[3] Participants were recruited from the same hospital as those of Peters et al. (1990), although the studies appear to have used different samples.

took part in the second phase of the study, 60% of whom were from the original sample. Participants rated the 12 items based on the strain they placed on the relationship. The items were rated as more strain-inducing by separated/divorced participants than those still together. These differences were only statistically significant for mood swings, however, according to the stringent alpha level of 0.004 that was deemed necessary following a Bonferroni correction. Strengths of this study include the thorough methodological descriptions, detailed analyses, and promising psychometric data for the measure used. A prominent weakness is that one would expect the identified sequelae to predict marital breakdown, since participants were asked to list those characteristics causing the greatest relationship strain.

Gosling and Oddy (1999) explored 18 wives' perceptions of their marital and sexual relationship one to seven years after their husband's TBI. Author-devised scales assessed wives' relationship satisfaction and husbands' functioning in areas including cognition, personality, and physical function. Interviews were also conducted. Wives' ratings of marital and sexual satisfaction were significantly poorer post-injury compared with retrospective estimations regarding the pre-morbid relationship. Relationship satisfaction was not significantly connected to husbands' post-TBI functioning in any area. The small sample size and reliance on retrospective reports are notable weaknesses of this study.

Burridge et al. (2007) investigated post-ABI cognitive, emotional, and social functioning alongside socio-emotional skill, in connection with relationship satisfaction. Twenty individuals with ABI of mixed aetiology, 20 with chronic pain, and 20 healthy controls participated. Socio-emotional skill was measured using a questionnaire covering empathy, relationship skills, emotion recognition, public behaviour, and anti-social behaviour. Both partners rated their relationship satisfaction. Partners' reports of poorer relationship satisfaction were correlated with reduced socio-emotional skill and general functioning of the individual with ABI. This study's inclusion of two control groups suggests improved validity, yet the sample sizes were small and the authors acknowledged significant differences between the groups in age and education level, which may have created bias.

Summary: Methodological flaws considered, there was speculative support for the idea that marital stability and quality are negatively affected by neurobehavioural and socio-emotional consequences of ABI.

2.3 Post-injury employment and financial status

Earlier discussion indicated that pre-morbid socioeconomic factors were not clear predictors of relationship stability after ABI. The ensuing discussion explores evidence on changes in aspects of SES and marital relationships post-ABI, examined in three papers.

In the large-sample study of Vanderploeg et al. (2003) on war veterans, current employment status was analysed as a potential predictor for marital stability. This factor accounted for 1.7% of the variance in post-injury marital status in the TBI group, compared with 3.2% in the healthy control sample. After controlling for other predictor variables, participants in full-time employment were almost twice as likely to be married post-TBI than those not working full-time. It is not clear whether these findings were statistically significant, or whether those not working full-time were in part-time employment, unemployed, or retired.

Kreutzer et al. (2007) gathered data on participants' employment status post-injury, classified as "employed", "unemployed", or "retired". This was not significantly linked to participants' likelihood of being separated or divorced three to eight years post-TBI.

Financial strain was explored by Peters et al. (1990). Family income was compared pre- and post-TBI. This only differed for participants with severe TBI, who reported a reduced income post-injury. A five-point Likert scale gauged spouses' reports of financial strain. Regression analyses revealed associations between increased financial strain and poorer expressed affection and overall marital quality. The influence of injury severity on this finding was unclear.

Summary: The literature provides mixed evidence for the influence of post-injury employment and income on marital relationships. Methodological strengths add weight to the suggestion that employment increases the likelihood of marital stability. Perhaps the relative lack of power and less stringent control of other variables accounted for the inconsistent finding. General marital quality may be improved when the couple faces less financial strain, but injury severity likely confounds this observation.

3. DO PRE-EXISTING PSYCHOSOCIAL OR SOCIOCULTURAL CHARACTERISTICS OF THE PERSON, PARTNER, OR RELATIONSHIP SHAPE RELATIONSHIP OUTCOMES AFTER BRAIN INJURY?

Pre-existing psychosocial variables such as coping style appear to influence relationship outcomes following difficult life events. Cohan and Bradbury (1997) outlined a model of people's vulnerability and adaption to stressful events, describing how adaptive coping strategies positively affect marital quality, in turn predicting relationship stability. O'Mahoney and Carroll (1997), reviewing research on the impact of breast cancer on marital relationships, discussed the importance of quality communication between partners in maintaining stable relationships. Associations between cultural and religious factors and marital satisfaction have also been observed (Lev-Wiesel & Al-Krenawi, 1999).

The papers reviewed offer insights into a limited selection of psychosocial characteristics that may influence relationship outcomes post-ABI. Studies evaluating the roles of coping style, pre-existing psychiatric difficulties, and sociocultural factors are appraised; a general summary of this section follows.

3.1 Coping and adjustment

The French-Canadian study of Blais and Boisvert (2007) investigated associations between personal coping strategies and marital quality for 70 couples living with TBI, and 70 well-matched control couples. Seven established questionnaires were administered to all participants, with psychometric data presented for the French language versions of each measure. Spouses' coping and communication skills were significantly related to the marital satisfaction of partners with TBI. Use of problem-solving strategies, infrequent use of avoidance coping, and positive perceptions of own communication skills had the strongest links with the TBI partner's marital satisfaction. A major strength of this study lies in the level of detail presented across all aspects of the research, enhancing its replicability. It is unclear, however, whether spouses' coping strategies reflected a pre-existing coping style or were related to factors such as injury severity, which was not controlled for.

Peters et al. (1990) explored the impact of spouses' coping strategies on marital quality and intimacy. Multiple regression analyses were conducted, to test the authors' hypothesis that the number of coping strategies used by spouses would predict marital quality. Spousal coping style did not account for significant variance in couples' DAS scores in terms of dyadic consensus and affectional expression.

3.2 Pre-existing psychiatric difficulties

This was an explicit exclusion criterion in one study (Gosling & Oddy, 1999) and controlled for in another (Wood et al., 2005), since none of their sample reported previous psychiatric disorder. Participants' psychiatric histories were only specified in one paper.

Vanderploeg et al. (2003) gathered data on participants' pre-morbid psychiatric difficulties, categorised as "internalising problems" (to include anxiety, depression, mania, and psychosis) and/or "externalising problems" (defined as conduct disorder and/or substance misuse). In the TBI group, to a greater degree than the control group, participants without pre-morbid externalising difficulties were more likely to be married post-injury than those with a history of such difficulties. It is not clear whether this was statistically significant. A significant interaction effect was identified between the presence or absence of early psychiatric difficulties, participants' years in education, and whether or not the person lost consciousness post-TBI: participants with 16 or more years of education were significantly less likely to be married if they had a history of internalising psychiatric difficulties, particularly so if they had experienced a loss of consciousness alongside their injury. An explanation for this interaction is not offered, but the authors propose that the former finding suggests TBI enhances the predisposing effect of externalising psychiatric problems on future marital breakdown.

3.3 Sociocultural factors

It is implied that participants in the Sabhesan et al. (1991) study were native to India, since the authors discussed the Indian cultural tradition of the extended family playing a key role in the couple’s life, either living all together (“joint family system”) or having a heavy involvement (“extended nuclear family”). Of the 105 study participants, 21% lived within a joint family structure; the remaining 79% lived within nuclear and extended nuclear families. Only seven couples had divorced or separated at the 18-month follow-up, and all were from nuclear families. This was not statistically significant, perhaps not surprising given the low number of separated couples. Nevertheless, the study raises the possibility that different family structures may vary in the extent to which they facilitate marital stability.

Summary: The research presented gives an indication that pre-existing psychosocial characteristics of one or both partners affect relationship outcomes post-ABI. There was mixed evidence as to the influence of healthy spouses’ use of problem-solving strategies on marital quality post-ABI, and tentative support for the importance of cultural practices in maintaining marital relations after TBI.

DISCUSSION

Demographic predictors

The research reviewed here was equivocal with regard to the role of demographic factors in predicting relationship quality and stability following ABI. Some studies reported connections between marital outcomes and age, length of pre-morbid relationship, gender, ethnicity, and socioeconomic variables, yet others' findings did not support such links.

There were a number of methodological issues concerning the research. A major weakness relates to the failure of most studies to control for potential confounding variables. Factors such as age and length of the pre-morbid relationship would be confounded, as might gender or ethnicity and levels of education or income. There were further problems in terms of primitive and/or poorly-described statistical analyses in certain papers, making it difficult to draw accurate inferences from the results. Many studies had small sample sizes, increasing the risk of Type II errors, and from available information it seems most researchers did not use random sampling methods when recruiting participants. There may be an inherent selection bias here, whereby findings are confounded by characteristics shared by individuals or couples willing to take part in such research. Finally, no study attempted to account for differences in marital outcomes by factors identified as predictors within the general population: without control samples, the extent to which the reported associations between different variables and marital outcomes may be attributed to the brain injury is uncertain.

Two papers (Arango-Lasprilla et al., 2008; Vanderploeg et al., 2003) did control for many of the potential confounds listed above. Furthermore, their data were sourced from archive databases, circumventing the selection bias issue. With these relative strengths in mind, it can be reasonably concluded that increased age predicts marital stability. Gender appears less of a factor in predicting marital outcomes, yet many studies focused on males with TBI. Non-White ethnicity seems to increase the likelihood of separation post-TBI, yet this may reflect difficulties associated with living as an ethnic minority within one's community, such as lack of support or opportunities: such issues were not explored. Finally, socioeconomic factors do not appear to impact significantly on relationship stability post-ABI, reflecting findings within the general literature (Aubé & Linden, 1991).

Brain injury-related variables

The literature offered a mixed picture as to the connections between ABI characteristics and marital outcomes. Links were found in some studies between various injury-related factors and risk of marital difficulties.

Methodological weaknesses in many studies, as outlined previously, make any conclusions on the impact of injury-related variables tentative. Likely confounding relationships here include employment status with injury severity, which was not controlled for in most studies. The reliance on cross-sectional rather than longitudinal designs represents a further weakness for many of these studies, since conclusions are then limited as to cause and effect links.

The evidence was fairly strong in favour of the assertion that TBI severity and violent cause of injury are linked to an increased likelihood of marital breakdown. Although some important predictors were controlled for in reaching these conclusions, further possible reasons for the latter finding include the potential influence of circumstances surrounding a person sustaining violent head trauma. Post-injury employment status may impact upon marital relationships in that individuals with TBI in full-time work appear more likely to have maintained their relationships, yet this may not be a causal association. There was speculative evidence that financial strain is associated with poorer marital adjustment post-injury, but injury severity likely helps explain this finding.

Psychosocial and sociocultural factors

The research reviewed offered few insights as to the role of pre-existing psychosocial and sociocultural variables in influencing relationship outcomes post-ABI. The quality of the research investigating these factors was poorer overall than that of the two preceding sections. Particular problems included unclear statistical analyses that lacked rigour, and the use of small, self-selected samples.

One study proposed that certain spousal coping strategies encourage better marital satisfaction for individuals with ABI. Due to the cross-sectional design, it was not clear whether the coping strategies characterised spouses' pre-existing coping style or whether factors not controlled for, such as injury severity, had played a role. A further study, of inferior quality, found no link between coping style and marital quality. A study with excellent methodological strength revealed an increased likelihood of marital breakdown in individuals with a history of psychiatric disorder. Finally, there was a suggestion that cultural factors may play a role, although further research would be needed here due to this study's significant methodological flaws.

IMPLICATIONS FOR RESEARCH AND CLINICAL PRACTICE

Considering the difficulties many couples face after acquired brain injury and the importance of a strong alliance for the wellbeing of both parties, maintaining intimate relationships following ABI is a clear priority for both researchers and clinicians. This requires an understanding of the factors associated with healthy relationships and relationship difficulties post-ABI. This review indicates that current research evidence is still very limited in offering these insights. Methodological weaknesses of many studies add to the challenge of drawing firm conclusions and proposing clinical implications.

Taking into account the reservations expressed about drawing definite conclusions from any of the research, the strongest evidence suggests that brain injury rehabilitation services could benefit patients by helping prevent marital breakdown in several ways. Dedicated support for younger individuals and people from black and minority ethnic groups post-ABI may be helpful. Information and support could be offered to individuals and their partners on consequences of ABI specific to the presenting difficulties, so that they are better equipped to cope. Finally, couples in which the partner's head injury had a violent cause may value specialist relationship advice and support.

To enhance the evidence base in this area, researchers should employ careful consideration in designing studies such that potential confounds are identified and controlled for. Where possible, follow-up designs would be preferable if researchers are seeking to explore relationship outcomes over time, especially where retrospective accounts might otherwise be relied upon. Power issues should be considered, as further larger-sample studies would strengthen the evidence base.

This review revealed that much of the literature on relationship outcomes after brain injury focuses on TBI. Further research involving individuals with stroke and other types of ABI is needed. A general difficulty for researchers of marital outcome lies in attempting to follow up participants whose relationships have ended: this would be an important group to investigate. Additionally, there are many psychosocial variables that would benefit from exploration given their potential influence on marital outcomes, such as attitudes towards marriage, personal resilience, and cohort effects.

The research in this area has also failed to develop psychological theories about the connections between various factors and relationship outcomes post-ABI. If such theories are not developed and tested, clinical implications will remain sorely limited. There is, for example, a clear gap in recognising why factors such as age, injury severity, and coping strategies may strengthen or weaken marital relationships. Without such knowledge, it will be difficult for services to offer the right kinds of support to couples.

The review itself was limited in scope. Inevitably, aspects of the research question were not explored, for example evidence on the influence of couples' children on marital outcomes after brain injury. Furthermore, the exclusion of qualitative studies hindered a comprehensive understanding of how certain variables might impact upon relationship outcomes.

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EMPIRICAL PAPER

A FOLLOW-UP STUDY OF CARERS’ WELLBEING, EXPECTATIONS, AND INVOLVEMENT IN THEIR RELATIVE’S REHABILITATION FROM ACQUIRED BRAIN INJURY

ABSTRACT

Background: This quantitative study was a follow-up to a project exploring associations between carers' expectations (illness perceptions), wellbeing, and involvement in acquired brain injury rehabilitation. Consistent with research on other populations, carers' pessimistic expectations about their relative's recovery were correlated with poorer mental wellbeing and less rehabilitation involvement. Little is known about changes in these factors over time, or their impact on rehabilitation outcomes.

Aims and methods: Phase 1 extended the original sample to 60 and sought to replicate the above findings. Phase 2 followed up 23 carers 12-18 months after Phase 1, re-examining the variables and their associations with key rehabilitation outcomes. Data on carers' illness perceptions, wellbeing, and involvement were gathered; relatives completed measures of general functioning, life satisfaction, and community integration.

Results: Phase 1 findings reflected those of the original study. Phase 2 revealed a continued link between carers' involvement and beliefs in its impact, but no ongoing association between wellbeing and negative perceptions of the injury's consequences. Carers' expectations were generally over-optimistic initially; greater over-optimism was linked to more significant declines in wellbeing. Carer involvement did not predict rehabilitation outcomes. Insufficient data precluded confirmation of disability level as a confound. Study limitations and implications are proposed.

Keywords: Acquired brain injury, rehabilitation, carers, expectations, involvement, wellbeing, outcomes.

INTRODUCTION

Acquired brain injury (ABI)[4] has a range of potential consequences. Individuals may experience difficulties with memory, communication, aspects of physical functioning, emotional difficulties such as anxiety and low mood, or a combination of such outcomes. Since ABI is typically acute in onset and unexpected, it frequently presents challenges not only to the person with the injury, but also to family members who take on caregiving tasks: often the spouse or partner.

The current study is a follow-up to that of Hough (2010a). Based on Leventhal's Common Sense Model of illness perceptions (Hagger & Orbell, 2003), Hough designed a questionnaire to assess the expectations of family caregivers of those with ABI as to the consequences, controllability, and treatability of the condition. Hough administered the questionnaire, alongside measures of carer wellbeing and level of rehabilitation involvement, to 42 individuals identifying themselves as primary caregivers for a person with ABI currently on a rehabilitation unit or having recently left such a facility. Consistent with earlier research using the illness perceptions model, carers who reported more pessimistic expectations about the injury's consequences also described significantly poorer mental wellbeing. Carers with optimistic expectations about the controllability and treatability of the ABI were more engaged in the rehabilitation process.

The present investigation expanded upon Hough's (2010a) study in several areas. Firstly, a further 18 participants were recruited, extending the original pool to 60 carers. This larger sample enabled a more reliable evaluation of the relationships between carer expectations,

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[4] Brain damage occurring after birth as a result of head trauma, stroke, infection, or tumour.

wellbeing, and involvement in ABI rehabilitation. A subset of this sample took part in a follow-up study approximately 12 months after their initial participation. The aims of this second phase, discussed below in relation to previous research, were:

1. To establish whether carers' emotional wellbeing was still associated at follow-up with their perceptions of ABI consequences, as it had been in the original study.
2. To determine whether carer involvement in rehabilitation was linked at follow-up with their perceptions of controllability and treatability, as it had been initially.
3. To examine whether carer involvement earlier in the post-injury phase predicted rehabilitation outcomes for the relative with ABI.
4. To establish whether carers' initial expectations about their relative's recovery had been realised at follow-up, and to explore the impact of unfulfilled expectations on carer wellbeing.

1. Illness perceptions and emotional wellbeing

The Common Sense Model of Leventhal and colleagues (Hagger & Orbell, 2003) outlines ways in which people make sense of threats to their health, and how these appraisals influence their illness-related behaviour (Leventhal, Diefenbach, & Leventhal, 1992). Applications of the model have suggested that illness perceptions comprise the following elements: beliefs about the cause of the illness; ideas about the illness' consequences such as its impact on quality of life or functioning; illness identity, or beliefs and knowledge relating to the condition's label; cure or controllability, meaning perceptions about the influence of certain behaviours or events on the illness; and timeline, which denotes expectations about the illness' relative permanence.

The Illness Perceptions Questionnaire (IPQ), developed by Weinman, Petrie, Moss-Morris, and Horne (1996) and updated by Moss-Morris et al. (2002), examines the above-mentioned components of Leventhal's model. Using the IPQ, illness perceptions have been investigated in relation to a range of health problems including cardiovascular disease (Grace et al., 2005) and inflammatory bowel disease (Dorrian, Dempster, & Adair, 2009). Illness perceptions have been linked to mental wellbeing in people with myocardial infarction (Alsén, Brink, Persson, Brändström, & Karlson, 2010) and chronic obstructive pulmonary disease (Howard, Hallas, Wray, & Carby, 2009).

Literature in this area has focused on people's perceptions of their own illness, with little consideration of carers' expectations (Weinman, Heijmans, & Figueiras, 2003). More recently, carers' illness perceptions have been investigated within psychosis (Fortune, Smith, & Garvey, 2005; Kuipers et al., 2007), Huntington's disease (Helder et al., 2002), and myocardial infarction (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009). Regarding carers' wellbeing and perceptions of relatives' psychosis, Fortune et al. (2005), using the IPQ, revealed strong associations between carers' distress and firmer beliefs about the severity of the condition's consequences and weaker beliefs in its treatability. In a large-sample study on individuals with oesophageal cancer, Dempster et al. (2011) identified that psychological distress was increased for the relative with cancer where carers' perceptions about the illness' consequences and controllability were more pessimistic.

Research into carers' illness perceptions concerning ABI is limited. Following stroke, carers may have difficulty anticipating their relative's likely course of recovery (Burman, 2001) and may underestimate functional recovery (Stein, Shafqat, Doherty, Frates, & Furie, 2003). There is also evidence of family member uncertainty as regards relatives' prognosis after traumatic brain injury (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005).

Regarding wellbeing exclusively, a substantial body of literature suggests that family members experience emotional difficulties following their relative's ABI (Oddy & Herbert, 2003). Primarily, burden and stress within the caregiver role have been emphasised (Chronister & Chan, 2006; Perlesz, Kinsella, & Crowe, 1999). The impact of ABI on caregivers' mental wellbeing seems notably severe compared with that of drug dependence and psychiatric difficulties (Carnes & Quinn, 2005), for example.

Carers' wellbeing may be particularly susceptible to the cognitive and behavioural changes often seen in individuals post-ABI (Verhaeghe, Defloor, & Grypdonck, 2005). Reduced physical functioning may also play a role: McPherson, Pentland and McNaughton (2000) identified a link between greater functional impairment post-ABI and poorer health and wellbeing outcomes for carers 15-18 months following relatives' hospital discharge. Concerning changes in carer wellbeing over time, Kumar and Kendrick (2009) interviewed stroke caregivers at different stages post-injury. Carers remained distressed 15 months post-stroke, which was predicted by their wellbeing earlier in the rehabilitation process.

The relationship between carers' expectations and wellbeing post-ABI is ultimately unclear from existing research. Tentative suggestions that carers' expectations have a bearing on their psychological adjustment to the ABI have been proposed (Man, 2002; Ruston, 2007; Verhaeghe et al., 2005), but prior to the Hough (2010a) study this issue had not been properly examined within the illness perceptions framework. Given Hough's finding that carers' pessimistic expectations were associated with poorer mental wellbeing, and since this is somewhat supported by the wider literature, gaining a better understanding of this correlation appears crucial.

2. Illness perceptions and involvement in rehabilitation

Considering the uncertainty that may characterise expectations post-ABI, such factors might play a role in rehabilitation engagement. Within the non-ABI literature, research on this idea is limited, but associations between people's own illness perceptions and treatment engagement have been identified in cardiovascular patients (Cooper, Lloyd, Weinman, & Jackson, 1999; MacInnes, 2006) and those with psychiatric illnesses (Phillips, Goldberg, & O'Connell, 1984; Shah, Hull, & Riley, 2009).

Connections between carers' expectations and involvement have received minimal attention within the literature. One qualitative study (Ryan, Wade, Nice, Shenfelt, & Shepard, 1996) investigated family involvement in general rehabilitation settings, including ABI and spinal cord injury units, from 42 physiotherapists' perspectives. Carers' beliefs about their relative's condition were perceived to affect their degree of rehabilitation involvement. Two studies found carer expectations to be obstructive to the ABI rehabilitation process. In a qualitative study of goal-planning for people with ABI, Levack, Siegert, Dean, and McPherson (2009) explored the influence of carer expectations on staff-patient and staff-family alliances during this process. Family members' expectations for recovery tended to be unrealistically high. This made goal-planning difficult, creating tensions between staff and family that also impacted upon patients' rehabilitation experiences. In the aforementioned Lefebvre et al.

(2005) study, carers' uncertainty was associated with lack of information from rehabilitation staff as to their relative's prognosis, which added strain to the staff-family relationship. Within the IPQ framework, Hough's (2010a) study highlighted that carers' beliefs about ABI controllability and treatability were linked to their greater rehabilitation involvement. The suggestion that carer expectations influence the rehabilitation process requires further investigation, particularly if carer involvement improves rehabilitation outcomes.

3. Carer involvement and patient outcomes

The idea that relatives play an important role in a person's recovery from ABI is promoted by Department of Health and other related clinical guideline documents (Department of Health, 2007; 2008; Turner-Stokes, 2003). In this context, "carer involvement" includes such activities as observation and assistance with physiotherapy and occupational therapy sessions on the rehabilitation unit, helping relatives practise rehabilitation tasks at home, and attending and contributing to review meetings. The widely held view is that carer involvement may improve patients' emotional wellbeing and functional and vocational goal attainment; carers' wellbeing and psychosocial functioning; and relationships between the carer, patient, and wider social circle. The present study focused on patient rehabilitation outcomes.

Individuals' rehabilitation goals post-ABI will differ depending on their needs, preferences, and lifestyles. Nevertheless, the outcomes most crucial to people with ABI and their families seem to comprise physical, cognitive, emotional, and psychosocial functioning (Cattelani, Zettin, & Zoccolotti, 2010; Wilson, 2008). Whilst optimal physical functioning is a clear priority for many individuals following ABI (Braga et al., 2005; Hillier, Sharpe, & Metzer, 1997), psychosocial outcomes have also received research attention. Stålnacke (2007) proposed that psychosocial functioning denotes community integration, social support, and life satisfaction: major elements of the broader notion of quality of life (Testa & Simonson, 1996). Community integration has featured in several research studies and policies as an important aspect of ABI rehabilitation (Department of Health, 2007; Kaplan, 1990; Moore, Stambrook, & Peters, 1993; Turner et al., 2007; Turner-Stokes, 2003). Attention has also been paid to vocational outcomes (Sander et al., 2002), cognitive functioning (Stratton & Gregory, 1994) and emotional wellbeing (Anson & Ponsford, 2006).

In a systematic literature review, Hough (2010b) revealed a significant lack of evidence assessing the impact of carer involvement on ABI rehabilitation outcomes. Only three controlled studies addressing this issue were identified: One concerned children with traumatic brain injury (Braga, Da Paz Júnior, & Ylvisaker, 2005); the other two, adults with stroke. Osawa and Maeshima (2010) reported greater improvements in neglect and physical functioning for 7 stroke patients receiving additional rehabilitation with a family member present, compared with 14 receiving standard treatment, over a three-week period. Study weaknesses included the small sample size; non-randomised allocation to groups; and, most tellingly, that the additional treatment itself may have affected that group's outcomes, rather than the family involvement per se. In a randomised controlled trial, Kalra et al. (2004) compared a group receiving usual treatment with participants whose relatives received training in basic nursing tasks and personal care. After 12 months, the experimental group reported mood improvement but no gains in activities of daily living (ADLs). The sole inclusion of ADLs as a functional outcome limited this study's scope. Additionally, the degree of family involvement in the control group was unclear, highlighting a potential confound.

4. How realistic are initial expectations?

As discussed, qualitative research indicates that carers struggle to estimate their relative's progress post-ABI (Burman, 2001; Lefebvre et al., 2005). In another qualitative study, ABI rehabilitation staff considered that, faced with such uncertainty, carers tended to overestimate their relative's likely recovery (Levack et al., 2009).

The issue of whether carers do overestimate recovery, and the long-term impact of that overestimation, merits further investigation. Staff in both the Lefebvre et al. (2005) and Levack et al. (2009) studies felt that carers' over-optimistic recovery expectations caused friction between staff and family and obstructed effective rehabilitation. Furthermore, as noted earlier, non-ABI research suggests that carer illness perceptions about a condition's current impact are associated with poorer emotional wellbeing (e.g. Fortune et al., 2005; Dempster et al., 2011). This raises questions about the longer-term influence of disappointed expectations on carers' mental wellbeing: Might the realisation that earlier expectations were over-optimistic have a negative impact here?

Aims and methods of the current study

In summary, illness perceptions among ABI caregivers may be related to their emotional wellbeing and may affect their degree of involvement in the rehabilitation process. The evidence base on factors influencing carers' expectations, involvement, and wellbeing, particularly in the longer term, is inadequate; the extent and long-term impact of unrealistic expectations is unexplored. Finally, given the lack of empirical support for the ostensibly valuable carer involvement, greater insight into its outcomes for people with ABI is vital.

The research used quantitative methodology and comprised two phases. As outlined earlier, Phase 1 extended Hough's (2010a) participant pool to 60 carers and re-examined the target variables. Hough's version of the IPQ, the Carer Expectations Questionnaire (CEQ), was administered alongside measures of staff-reported carer involvement (Family Involvement Assessment Scale; FIAS), carer-reported involvement (Involvement in Rehabilitation Questionnaire; IRQ), and emotional wellbeing (Warwick-Edinburgh Mental Well-being Scale; WEMWBS). Based on previous research and Hough's findings, it was hypothesised that carers' pessimistic expectations about the ABI's consequences for their relative, themselves, and their family would be linked to reduced wellbeing. Secondly, it was anticipated that carers' pessimistic expectations about the treatability and controllability of the ABI would be associated with less involvement in the rehabilitation process.

Phase 2 followed up 23 of the carer-patient dyads 12-18 months after Phase 1. Its four aims were described on page 44. Carers rated the extent to which their expectations had been met, using a revised version of the CEQ. The WEMWBS was repeated to gauge current wellbeing, and a revised version of the IRQ assessed carers' level of involvement in their relative's ongoing recovery. The following data were gathered on the person with ABI: present functioning in a range of physical, cognitive, and psychological domains (European Brain Injury Questionnaire; EBIQ, and Functional Independence Measure; FIM), subjective life satisfaction (LiSat-11), and degree of community integration (Community Integration Questionnaire; CIQ). Relatives' admission and discharge FIM scores were obtained from inpatient records.

In view of the significant lack of existing research addressing the concerns discussed, this study had the added intention of providing much-needed evidence to inform future clinical guidance on brain injury rehabilitation, helping carers better understand how their expectations and involvement impact on them and their relative, as well as highlighting areas for further research.

PHASE 1: CARERS' INITIAL EXPECTATIONS, INVOLVEMENT, AND WELLBEING

Aims and hypotheses

In this extension of Hough's (2010a) original study and in accordance with its findings, the following hypotheses were proposed:

1. Pessimistic expectations about the consequences of the ABI will be associated with lower mental wellbeing.

2. Perceptions of reduced controllability and treatability will be associated with reduced involvement in the rehabilitation process.

PHASE 1 METHOD

Participants

Forty-two carers, recruited from three brain injury rehabilitation units across the Midlands, participated in an initial piece of research (Hough, 2010a[5]). Participants were required to be over 21, able to complete questionnaires, and be the expected main caregiver of the person with ABI upon hospital discharge. Carers were approached within 12 months of their relative's ABI and no sooner than 6 weeks post-ABI. Some individuals had already been discharged when recruited.

Thirty four of the above participants (81%) consented to the researchers retaining their contact details with a view to participating in Phase 2 of the study around 12 months later. Bearing in mind the intended predominant use of correlational analyses in the follow-up, a power calculation using G*Power (Erdfelder, Faul, & Buchner, 1996) determined that a sample of 26 carer-patient dyads would be required, assuming an alpha level of .05 (two-tailed) and power of 80%. Considering the likelihood of around 50% of people being lost to follow-up (Langley, Johnson, Slatyer, Skilbeck & Thomas, 2010), 18 extra participants were recruited from the three sites shortly after the initial 42 carers were recruited[6]. Table 1 contains demographic data for these 60 participants, obtained via a questionnaire (Appendix 2).

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[5] These participants were recruited by the principal researcher of the Hough (2010) study, who was a Trainee Clinical Psychologist at the University of Birmingham, alongside a collaborator.

[6] These participants were recruited by the present author, alongside two other collaborators.

Table 1

Demographic detail for the participants of Phase 1 (N = 60)

Demographic factor	**Distribution of data**
Gender	19 (32%) male; 41 (68%) female
Age	Range: 17 to 79 years; *M* = 48.85; *SD* = 13.39
Ethnicity	54 (90%) White; 3 (5%) Asian; 1 (2%) Black; 2 (3%) Other
Employment status	38 (63%) employed; 22 (37%) not employed
Relation to pwABI[a]	29 (48%) spouse/partner; 14 (23%) parent; 10 (17%) offspring; 6 (10%) sibling; 1 (2%) other
ABI type	32 (53%) traumatic brain injury; 21 (35%) stroke; 7 (13%) other
ABI severity[b]	1 (2%) mild; 13 (22%) moderate; 43 (72%) severe; 3 (4%) unknown
Time since injury	Range: 1 to 14[c] months; *M* = 4.98; *SD* = 2.95

Note: Aside from injury variables, demographic detail pertains to the carer of the brain-injured individual.

[a] pwABI stands for "person with acquired brain injury".

[b] These were carers' estimations of severity based on information they had been given by the rehabilitation team. It was not possible to obtain more detailed information as to severity, as consent from relatives was not part of the ethical approval agreement for this phase of the research.

[c] One of the additional 18 carers was recruited at 14 months after their relative's ABI.

Measures

Three questionnaires measuring illness perceptions, involvement in rehabilitation, and wellbeing were completed by carer participants; rehabilitation staff who knew the patient well completed a further questionnaire on their perceptions of carers' involvement. Further detail on these measures is provided below.

Carer Expectations Questionnaire Version 1 (CEQ v.1; Hough, 2010a)

Given a lack of suitable measures, this 43-item questionnaire (Appendix 3) was developed to assess carers' expectations of their relative's course of recovery in 12 months' time. There are nine sections assessing different facets of expectation; higher scores indicate more pessimistic expectations. The sections are grouped into three subscales comprising expectations about consequences of the brain injury for the person, carer, and family (CEQ-Consequences); perceived control over the recovery process as regards the influence of the carer and relative (CEQ-Controllability), and the responsiveness of the ABI to rehabilitation (CEQ-Treatability). For the purposes of subsequent analyses, due to conceptual differences, Controllability is regarded as two subscales: Patient Control and Carer Control. Three further sections, concerning the permanence of the condition, confidence in the carer role, and views about the service received, were not included in any analyses as they did not relate to the hypotheses. Internal consistency figures for the CEQ are presented in Table 2.

Table 2
Internal Consistency for the Carer Expectations Questionnaire Version 1 subscales, based on participants' responses in Phase 1 (N = 60).

Measure	Subscale	Number of items	Cronbach's alpha
CEQ Version 1	CEQ-Consequences	15	.928
	CEQ-Patient Control	5	.804
	CEQ-Carer Control	4	.877
	CEQ-Treatability	5	.878

Involvement in Rehabilitation Questionnaire Version 1 (IRQ v.1; Hough, 2010a)

This measure (Appendix 4) gauges carers' level of involvement in their relative's rehabilitation via 10 questions that largely consider their engagement with ward staff and the rehabilitation programmes taking place on the unit. Higher scores indicate greater involvement. In this study, the IRQ had a reasonable level of internal consistency ($\alpha = .856$).

Family Involvement Assessment Scale (FIAS; McNeil, Schulyer & Ezrachi, 1997)

The FIAS is a 37-item measure of staff's perception of a carer's level and type of involvement in their relative's recovery while engaged in a programme of ABI rehabilitation (Appendix 5). As with the IRQ, higher scores denote greater involvement. The FIAS comprises three subscales: Involved-Staff, Support, and Involved-Patient. The latter two subscales contain predominantly negatively-loaded questions about carers' interactions with their relative and the staff team, and were not analysed. The 22-item Involved-Staff subscale (Appendix 6) was found to have superior internal consistency to the other subscales (α = .93: McNeil et al., 1997), and it best captures the construct being investigated here. One rehabilitation staff member completed the questionnaire per carer. Internal consistency for the FIAS Involved-Staff subscale was α = .889 in the current study.

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007)

This measure of emotional wellbeing contains 14 items relating to mental health, interpersonal relationships, and day-to-day functioning (Appendix 7). Higher scores signify better wellbeing. Good face validity, content validity, internal consistency, and test-retest reliability figures have been reported (Tennant et al., 2007). Cronbach's alpha was α = .890 in the present study. The WEMWBS was completed by all carer participants. A user guide to the WEMWBS (Stewart-Brown & Janmohamed, 2008) explains that it has no cut-off score for mental ill-health, but an average WEMWBS score in the general population is 50.7.

Procedure

Approval was sought from an NHS ethics committee and the research and development departments of the NHS Trusts responsible for the three identified sites. Following approval, the three rehabilitation units were contacted. To minimise possible distress to carers in being approached, ward staff identified potential participants and gave them an information sheet (similar to that seen in Appendix 19[7]), which directed them to express an interest in participating to a member of staff or the Chief Investigator[8]. These carers were subsequently contacted via telephone or face-to-face to discuss what participation would entail.

Data analysis

Data were analysed using SPSS version 17.0. After being checked for errors they were subjected to Shapiro-Wilk tests for normality, with stem and leaf plots generated to identify outliers. A small number of outliers were found among the dataset. These scores were adjusted to the value of one unit larger or smaller than the next most extreme score (Tabachnick & Fidell, 2001). The data then met the assumptions for parametric analysis. Pearson correlations were used to analyse associations between participants' scores on the measures administered. Analyses were conducted for each subscale of the CEQ v.1 alongside participants' total scores on the IRQ v.1, FIAS Involved-Staff subscale, and WEMWBS. Supplementary analyses of demographic and injury-related variables were conducted via t-tests and Spearman's correlations.

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[7] The actual participant information sheet and all other ethical information relating to this initial study is contained in Hough (2010a).

[8] Again, in this instance the aforementioned trainee clinical psychologist from the University of Birmingham (for the initial 42 participants), or the present author with two collaborators (for the further 18 participants).

PHASE 1 RESULTS

Descriptive statistics relating to participants' responses for each measure are presented in Table 3. Participants' WEMWBS scores were lower than expected based on population norms (Stewart-Brown & Janmohamed, 2008).

Table 3
Descriptive data pertaining to Phase 1 participants' questionnaire responses.

Measure and subscale	**N**	**Range of scores**[a]	**Mean score**	**Standard deviation**
Carer Expectations Questionnaire v.1				
Consequences Total	60	24-73 *(15-75)*	46.50	11.36
Patient Control Total	60	5-20 *(5-25)*	11.33	3.46
Carer Control Total	60	4-13 *(4-20)*	7.20	2.49
Treatability Total	60	5-17 *(5-25)*	11.25	3.22
Involvement in Rehabilitation Questionnaire v.1	58[c]	29-50 *(0-50)*	39.16	5.29
Family Involvement Assessment Scale				
Involved-Staff subscale	53[b]	44-85 *(22-88)*	63.74	10.03
Warwick-Edinburgh Mental Wellbeing Scale	59[d]	25-63 *(14-70)*	43.05	8.54

Note: Higher scores on the CEQ signify more pessimistic expectations; higher scores on the IRQ and FIAS denote greater involvement, and higher scores on the WEMWBS indicate better wellbeing.

[a] First listed are obtained scores, adjusted for outliers; range in parentheses denotes full range of scores possible for the measure or subscale.

[b] There were seven entirely missing datasets for this measure. Three participants did not consent to a staff member completing the FIAS; four questionnaires were not completed.

[c] One participant did not complete this measure; one answered all questions with "not applicable".

[d] One participant did not complete this measure.

Carer expectations and wellbeing

Pearson correlations were significant and negative for participants' CEQ v.1 Consequences Total scores and WEMWBS total scores ($r(57) = -.415$, $p = .001$).

Carer expectations and involvement

The results of the correlational analyses relating to the CEQ v.1 Consequences, Controllability, and Treatability subscales, FIAS Involved-Staff subscale, and IRQ v.1 total scores are displayed in Table 4.

Table 4

Pearson correlation results for measures of carer expectations and involvement in Phase 1.

Measures/subscales	**Degrees of freedom (df)**	**Pearson's *r***	**Significance (2-tailed)**
CEQ Patient Control Total & IRQ Total	56	-.407**	.002
CEQ Carer Control Total & IRQ Total	56	-.546**	< .001
CEQ Treatability Total & IRQ Total	56	-.432**	.001
FIAS Involved-Staff Total & CEQ Patient Control Total	51	-.049	.728
FIAS Involved-Staff Total & CEQ Carer Control Total	51	-.374**	.006
FIAS Involved-Staff Total & CEQ Treatability Total	51	-.254	.067
IRQ Total & FIAS Involved-Staff Total	51	-.311*	.025

* Correlation is significant at the .05 level (2-tailed)

** Correlation is significant at the .01 level (2-tailed)

Table 4 illustrates strong associations between carers' pessimistic expectations about controllability and treatability regarding their relative's recovery and lower levels of self-reported rehabilitation involvement. The correlation between staff and carer reports of involvement suggests only a modest overlap in measurement between the IRQ v.1 and FIAS, revealing possible validity concerns for one or both measures.

Analysis of demographic and injury-related factors

Selected demographic and injury-related variables (Table 1) were analysed alongside the outcomes measured. Significant findings are described here; all are presented in Appendix 8. Patient Control expectations differed by gender (*t*(58) = -2.734, *p* = .008), such that female carers' expectations as to their relative's control over their condition were more optimistic than those of male carers. Carer expectations about treatability differed depending on the type of injury: Treatability expectations were more pessimistic for carers of individuals with stroke compared to traumatic brain injury (*t*(51) = -2.192, *p* = .033). Finally, time since injury (range: 1-14 months) was correlated with CEQ Consequences (*rho* = .364, *p* = .005), Patient Control (*rho* = .324, *p* = .012), and Treatability (*rho* = .287, *p* = .028): As time since injury increased, carers' expectations were more optimistic.

PHASE 1 DISCUSSION

Phase 1 expanded the original sample of Hough (2010a) and aimed to extend her findings regarding carer expectations, wellbeing, and involvement in the early stages of ABI rehabilitation. The extent to which Phase 1's hypotheses were met is outlined below. These findings will be explored in greater depth in the General Discussion, where implications in the context of Phase 2 findings and previous research will be considered.

The first hypothesis, that carers' pessimistic expectations about the consequences of their relative's ABI would be linked to the carers' poorer emotional wellbeing, was strongly supported by the data. Perceptions of the ABI as having more severe consequences for the person with ABI, the carer, and the family were significantly associated with poorer mental wellbeing.

The second hypothesis, that carers' pessimistic expectations about the controllability and treatability of the ABI would be associated with reduced involvement in their relative's rehabilitation, was strongly supported according to carers' self-reported involvement; only carers' perceptions of their own influence on the recovery process was significantly linked to staff ratings of carer involvement.

PHASE 2: CARERS' EXPECTATIONS, INVOLVEMENT, AND WELLBEING OVER TIME, AND THEIR IMPACT ON THE PERSON WITH ACQUIRED BRAIN INJURY

Aims and hypotheses

As explained in the Introduction, the following aims were proposed for Phase 2:

1. To establish whether carers' emotional wellbeing was still associated with their perceptions of ABI consequences as it had been in the original study.
2. To determine whether carer involvement in rehabilitation was linked at follow-up with their perceptions of controllability and treatability, as it had been initially.
3. To examine whether carer involvement earlier in the post-injury phase predicted rehabilitation outcomes for the individual with ABI.
4. To establish whether carers' initial expectations about their relative's recovery had been realised at follow-up, and explore the impact of unfulfilled expectations.

Research hypotheses for Phase 2 are described in the context of the planned analyses, on page 71.

PHASE 2 METHOD

Participants

As mentioned previously, 34 of the initial group of 42 carers consented to be contacted for potential participation in the study's second phase. Seventeen of the 18 subsequently recruited participants consented to the same. Of these 51 participants, 23 (45%) took part in the follow-up[9]. Reasons for attrition for the remaining 28 are outlined in Table 5.

Table 5

Data on reasons for attrition for the 28 participants not involved in Phase 2 of the study

Reason for attrition	**Number of participants (total N = 28)**	**Percentage of total**
Not contactable	1	3.6%
Patient deceased	1	3.6%
Carer deceased	1	3.6%
Change of personal circumstances	2	7.1%
Opted out (reasons below)	23	82.1%
No reason given	*12*	
No longer interested	*6*	
Personal circumstances	*2*	
Couple split up	*2*	
Moved abroad	*1*	

Note: Participants were not required to provide a reason for opting out of the study, yet some chose to offer this information.

Demographic details for Phase 2 participants are presented in Table 6. Chi-square and t-test analyses were carried out to seek differences between the opt-in (N = 23) and opt-out (N = 28) groups on the basis of demographic and injury-related characteristics. No significant

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[9] The author of the current paper contacted the 51 participants and conducted all of the data collection for the 23 of these participants who agreed to be followed up.

differences were found in relation to age and gender of carer, injury severity, type of injury, or time since injury (see Appendix 9).

Table 6

Demographic detail for the participants followed up for Phase 2 (N = 23)

Demographic factor	**Distribution of data**
Gender	6 (26%) male; 17 (74%) female
Gender of pwABI[a]	20 (87%) male; 3 (13%) female
Age	Range: 25 to 79 years; *M* = 51.30; *SD* = 13.02
Age of pwABI	Range: 16 to 82 years; *M* = 44.91; *SD* = 19.88
Ethnicity	21 (91%) White; 1 (4.5%) Asian; 1 (4.5%) Other
Employment status	15 (65%) employed; 8 (35%) not employed
Relation to pwABI	13 (57%) spouse/partner; 7 (30%) parent; 1 (4%) offspring; 2 (9%) sibling
ABI type	11 (48%) traumatic brain injury; 6 (26%) stroke; 6 (26%) other
ABI severity	5 (22%) moderate; 17 (74%) severe; 1 (4%) unknown
Time since injury	Range: 2 to 14 months; *M* = 5.02; *SD* = 3.37

Note: Aside from injury variables, demographic detail pertains to the carer of the individual with ABI unless stated otherwise. These data were not gathered again at follow-up, and as such are accurate as of participants' involvement in the first phase of the study.

[a] pwABI stands for "person with acquired brain injury".

Measures

Seven questionnaires were administered per participant pair. Three were completed by the carer, two by the person with ABI, and a further two by both individuals but administered by the researcher. The measures used are outlined below, along with relevant psychometric data.

Carer Expectations Questionnaire Version 2 (CEQ v.2; Meader, this volume)

The CEQ v.1 (Appendix 3) assessed carers' perceptions of their relative's condition as regards its likely impact upon the relative, carer, and family (CEQ-Consequences), the degree to which the patient and the carer influence the condition (CEQ-Patient Control and Carer Control), and the effectiveness of rehabilitation (CEQ-Treatability). As before, higher scores signify more pessimistic expectations. The structure and content of CEQ v.2 (Appendix 10) is identical to the original version, but each item has been modified such that items refer to carers' perceptions of the current or past situation rather than, as in the original CEQ, the future, for example: *There is a lot that my relative can do to improve their condition* (CEQ v.1, Q.5.1) versus *My relative has been able to do a lot to improve their condition* (CEQ v.2, Q.5.1). Internal consistency figures for the CEQ v.2 subscales are displayed in Table 7.

Table 7
Internal consistency for the Carer Expectations Questionnaire Version 2 subscales, based on participants' responses in Phase 2 (N = 23).

Measure	**Subscale**	**Number of items**	**Cronbach's alpha**
CEQ Version 2	CEQ-Consequences Total	15	.883
	CEQ-Patient Control Total	5	.861
	CEQ-Carer Control Total	4	.763
	CEQ-Treatability Total	5	.705

Involvement in Rehabilitation Questionnaire Version 2 (IRQ v.2; Meader, this volume)

Since the IRQ v.1 related mainly to the inpatient setting, this version was amended to better reflect relatives' likely living situation and reduced contact with rehabilitation staff. Two versions of the nine-item IRQ v.2 were developed, differing only in the use of male or female pronouns throughout (Appendices 11 and 12). Higher scores indicate greater involvement. Cronbach's alpha (N = 20[10]) was α = .863 in this study.

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[10] Three participants' data could not be used due to a large proportion of "not applicable" responses.

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007)

The WEMWBS was repeated with carers in Phase 2. As mentioned, higher scores denote better wellbeing. For these participants (N = 23), internal consistency was α = .898.

The LiSat-11 Checklist (Fugl-Meyer, Melin, & Fugl-Meyer, 2002)

This 11-item measure of life satisfaction (Appendix 13) was completed by participants with ABI. It was selected because it is not age-specific (Fugl-Meyer et al., 2002), the questions are straightforward, and the low number of items makes it ideal when administering a battery of questionnaires. Higher scores on the LiSat-11 indicate greater life satisfaction. Cronbach's alpha was α = .900 (N = 22[11]).

Community Integration Questionnaire (CIQ; Willer, Rosenthal, Kreutzer, Gordon, & Rempel 1993)

This 14-item questionnaire (Appendix 14) was completed by the relative with ABI. It was chosen due to its popularity, ease of administration, and applicability to ABI (Salter, Foley, Jutai, Bayley, & Teasell, 2008). The CIQ assesses people's degree of engagement in valued social roles and activities, across three subscales: Home Integration (5 items), Social Integration (6 items), and Productivity (2 items). Higher scores on this measure signify greater community integration. In this study, Cronbach's alpha was α = .781 for the total scale, α = .843 for Home Integration, α = .346 for Social Integration, and α = .559 for Productivity. These latter two subscales fell well below the acceptable standard for internal consistency (Peterson, 1994).

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[11] One participant was not able to complete this questionnaire due to unforeseen language issues.

The European Brain Injury Questionnaire (EBIQ; Teasdale et al., 1997)

The EBIQ (Appendix 15) is a broad measure of ABI consequences for the individual, where higher scores indicate greater symptom presence. It contains 63 items, divided into 8 subscales evaluating different aspects of function: Somatic (8 items); Cognitive (13 items); Motivation (5 items); Impulsivity (13 items); Depression (9 items); Isolation (4 items); Physical (6 items); and Communication (4 items). A Core scale comprises 34 of the total items. The EBIQ is designed to be completed either by the person with the ABI, or a carer. In this study, it was administered by the author to the carer-patient dyad, to ensure response accuracy and to vary participants' experience of completing the questionnaire pack. Internal consistency data are presented in Table 8.

Table 8
Internal consistency for the European Brain Injury Questionnaire (EBIQ), based on participants' responses in Phase 2 (N = 23).

Measure	Subscale	Number of items	Cronbach's alpha
EBIQ	Somatic	8	.628*
	Cognitive	13	.860
	Motivation	5	.787
	Impulsivity	13	.904
	Depression	9	.856
	Isolation	4	.398*
	Physical	6	.783
	Communication	4	.823
	Core Symptoms	34	.931
	Overall Total	*63*	*.951*

Note: Asterisked items fell below the acceptable internal consistency level of α ≥ .70 (Peterson, 1994).

The Functional Independence Measure (FIM; Granger, Hamilton, & Keith, 1986)

As with the EBIQ, this 22-item measure (Appendix 16) was administered by the author and completed by the person with ABI alongside their carer. The FIM assesses physical and cognitive disability, focussing on the level of assistance the person with ABI requires to complete different tasks. Higher FIM scores signify a greater level of functioning. Consent was sought (Appendix 22) and obtained for all participants to access their medical records for FIM scores recorded whilst on the rehabilitation unit[12]. Unfortunately, these data were only available for 11 of the 23 participants. For these individuals, internal consistency was $\alpha = .974$ for FIM scores at hospital admission and $\alpha = .978$ for FIM scores upon discharge. Cronbach's alpha was $\alpha = .946$ for the 23 participants' FIM data gathered at follow-up.

Procedure

Ethical approval was obtained from a local NHS ethics committee and relevant NHS Trust research and development departments before participants were contacted (Appendices 25 and 26).

Initially, those 51 participants who had consented to their details being kept on file were sent an information pack. This was between 12 and 18 months after they participated in Phase 1. The pack contained cover letters to carers and care recipients (Appendices 17 and 18), participant information sheets (Appendices 19 and 20), consent forms (Appendices 21 and 22), an opt-out form (Appendix 23), and a stamped addressed envelope for return of the opt-out form should they not wish to take part.

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[12] These data were collected by collaborators of the current author.

As detailed in the information pack, carers who did not opt out within 14 days were contacted by telephone to arrange questionnaire completion at a mutually convenient time and location. The ability and interest of the person with ABI to participate was also gauged at this time. In most cases, participants chose to be seen in their own homes[13].

Completion of the questionnaires generally took between 45 minutes and 1 ½ hours. The researcher was vigilant to signs of distress from participants, and it was clarified that questions could be omitted if desired. All participants were informed that they were free to withdraw their involvement at any point until completion of data analysis.

Data analysis

As in Phase 1, all data analyses were performed using SPSS version 17.0. Aside from a small number of entirely missing scores for certain measures[14], missing data represented 1.1% of the dataset. These were spread fairly evenly across the dataset and thus are not of concern (Tabachnick & Fidell, 2001). Nevertheless, as SPSS will not compute totals where there are missing data points, missing items were prorated using the mean score for that participant's responses on the questionnaire (Strube, 1985). The dataset was subsequently analysed for outliers, using the methods described in Phase 1. A small number of outliers were identified and adjusted as before.

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[13] In these instances, the author adhered to her employing NHS Trust's Lone Worker Policy.

[14] These are highlighted in Tables 9 and 10. In the case of the IRQ v.1 and v.2, certain participants had given several "not applicable" responses. Given the relatively small number of items on these scales, internal consistency was calculated for these measures if items were deleted. Where Cronbach's alpha dropped below $\alpha = .70$ (Peterson, 1994) with items deleted, that individual's responses were not used (Strube, 1985). This calculation allowed participants' responses to be included if six out of ten or six out of nine items on the IRQ v.1 and v.2 respectively were completed.

Hypothesis testing

The research hypotheses for Phase 2 were proposed and tested as follows:

1. A Pearson correlation was carried out to gauge whether better carer wellbeing at follow-up (WEMWBS, Phase 2) was associated with perceptions of less serious ABI consequences (CEQ-Consequences, Phase 2).

2. Pearson correlations were used to analyse whether greater carer involvement later in rehabilitation (IRQ, Phase 2) was linked to perceptions of better ABI controllability and treatability (CEQ-Patient Control; Carer Control; Treatability, Phase 2).

3. Pearson correlations were applied to test whether greater carer involvement earlier post-injury (FIAS Involved-Staff and IRQ, Phase 1) predicted better rehabilitation outcomes for the person with ABI as regards general functioning (EBIQ), life satisfaction (LiSat-11), and community integration (CIQ). Since degree of disability was a potential confound here (poorer functioning may necessitate greater carer involvement and entail poorer general outcomes), a Pearson correlation between carers' initial involvement (FIAS and IRQ, Phase 1) and improvement in relatives' FIM scores across study phases (FIM Phase 2 minus FIM Phase 1) was undertaken to test the hypothesis that greater early involvement would be associated with larger improvements in FIM scores.

4. A t-test was used to assess whether carers' illness perceptions at follow-up were more negative than their earlier expectations (higher CEQ subscale scores at Phase 2 than Phase 1). A Pearson correlation was carried out to gauge whether greater disappointment in expectations (more negative CEQ Phase 1 minus CEQ Phase 2 values) was associated with a greater decline in wellbeing at follow-up (higher WEMWBS Phase 1 minus WEMWBS Phase 2 values).

PHASE 2 RESULTS

Descriptive statistics for participants' responses on the Phase 2 measures are presented in Tables 9 and 10. In Table 9, data for carer- and staff-completed measures are displayed, to include data for up to 23 participants from the Phase 1 dataset who also took part in Phase 2. Table 10 shows questionnaire responses from participants with ABI. These data were gathered at Phase 2; FIM scores from archived data, corresponding roughly to the time of Phase 1 data collection, are also presented.

Table 9

Descriptive data pertaining to carers' and staff's questionnaire responses across Phases 1 and 2.

Measure and subscale	**N**	**Range of scores**[a]	**Mean score**	**Standard deviation**
Carer Expectations Questionnaire v.1				
Consequences Total	23	27-72 *(15-75)*	48.17	11.87
Patient Control Total	23	5-17 *(5-25)*	11.13	3.42
Carer Control Total	23	4-12 *(4-20)*	6.70	2.79
Treatability Total	23	5-14 *(5-25)*	10.65	2.25
Carer Expectations Questionnaire v.2				
Consequences Total	23	37-75 *(15-75)*	56.96	10.97
Patient Control Total	23	5-18 *(5-25)*	11.43	3.70
Carer Control Total	23	4-11 *(4-20)*	6.65	2.15
Treatability Total	23	6-19 *(5-25)*	12.26	3.20
Involvement in Rehabilitation Questionnaire v.1	21[b]	30-50 *(0-50)*	40.19	5.72
Involvement in Rehabilitation Questionnaire v.2	20[c]	26-36 *(0-36)*	32.25	3.52
Family Involvement Assessment Scale *Involved-Staff subscale*	22[d]	46-85 *(22-88)*	66.00	9.87
Warwick-Edinburgh Mental Wellbeing Scale: Phase 1 responses	22[e]	26-50 *(14-70)*	40.09	6.80
Warwick-Edinburgh Mental Wellbeing Scale: Phase 2 responses	23	23-62 *(14-70)*	44.61	1.98

Note: Higher scores on the CEQ signify more pessimistic expectations; higher scores on the IRQ and FIAS denote greater involvement; and higher scores on the WEMWBS indicate better wellbeing.

[a] First listed are obtained scores, adjusted for outliers; range in parentheses denotes full range of scores possible for the measure or subscale.

[b] One participant answered all questions with "not applicable"; one answered 5 out of 10 items as "not applicable".

[c] Two participants answered 6 out of 9 items as "not applicable"; one answered 5 out of 9 items as "not applicable".

[d] One questionnaire was not completed.

[e] One participant did not complete this measure.

Table 10

Descriptive data pertaining to care recipients' questionnaire responses in Phase 2.

Measure and subscale	**N**	**Range of scores**[a]	**Mean score**	**Standard deviation**
LiSat-11	22[b]	22-59 *(11-66)*	42.61	10.33
Community Integration Questionnaire				
Home Integration Total (5 items)	23	5-9.25 *(5-15)*	7.10	1.48
Social Integration Total (6 items)	23	8-15 *(6-18)*	12.65	1.90
Productivity Total (2 items)	23	2-8 *(2-14)*	4.17	1.70
Overall Total (13 items)	23	16-33 *(13-47)*	24.34	4.60
European Brain Injury Questionnaire				
Somatic Total (8 items)	23	1-2.25 *(8-24)*	1.63	0.37
Cognitive Total (13 items)	23	1-2.85 *(13-39)*	1.81	0.49
Motivation Total (5 items)	23	1-3 *(5-15)*	1.78	0.62
Impulsivity Total (13 items)	23	1-2.77 *(13-39)*	1.75	0.54
Depression Total (9 items)	23	1-2.89 *(9-27)*	1.61	0.50
Isolation Total (4 items)	23	1-3 *(4-12)*	1.72	0.47
Physical Total (6 items)	23	1-2.83 *(6-18)*	1.65	0.53
Communication Total (4 items)	23	1-3 *(4-12)*	1.80	0.63
Core Symptoms Total (34 items)	23	1.06-2.39 *(34-102)*	1.70	0.37
Overall Total (63 items)	23	75-147 *(63-189)*	107.70	22.07
Functional Independence Measure				
Admission Total[d]	11[c]	21-136 *(21-147)*	69.55	40.57
Discharge Total[e]	11	36-146 *(21-147)*	107.91	35.55
Follow-up Total[f]	11	49-146 *(21-147)*	115.00	31.35
Follow-up Total (all participants)	23	49-146 *(21-147)*	115.87	27.77

Note: Higher scores on the LiSat-11 signify better life satisfaction; higher scores on the CIQ denote greater community integration; higher scores on the EBIQ indicate increased symptom presence; and higher scores on the FIM indicate a greater level of independence.

[a] First listed are obtained scores, adjusted for outliers; range in parentheses denotes full range of scores possible for the measure or subscale.

[b] One participant did not complete this measure.

[c] Only 11 of the 23 participants' FIM scores were able to be obtained from clinical notes archives.

[d] This is participants' score on admission to the brain injury unit, as reported by the staff team.

[e] This denotes participants' scores upon discharge from the brain injury unit, as reported by staff.

[f] These are participants' responses obtained alongside the other Phase 2 measures by the current author.

Aim 1. Is wellbeing associated with perceptions of ABI consequences at follow-up?

No significant correlation was found between Phase 2 CEQ-Consequences scores and WEMWBS at follow-up ($r(19) = -.219$, $p = .341$).

Aim 2. Is involvement linked with perceptions of controllability and treatability at follow-up?

Carers' IRQ scores at follow-up were significantly associated with and CEQ-Carer Control at Phase 2 ($r(18) = -.517$, $p = .020$). IRQ follow-up scores were not significantly correlated with CEQ-Patient Control ($r(18) = -412$, $p = .071$) or CEQ-Treatability ($r(18) = -.239$, $p = .310$) at Phase 2.

Aim 3. Does initial involvement predict outcomes for the person with acquired brain injury?

Neither IRQ Phase 1 total nor FIAS Involved-Staff significantly predicted functional (EBIQ), life satisfaction (LiSat-11), or community integration (CIQ) outcomes for the person with an ABI, according to a series of Pearson correlations. With regard to the hypothesis concerning improvement in FIM scores, it was anticipated that most or all participants' FIM scores would be obtainable. This was not the case, and only 11 participants' FIM scores could be acquired. Analyses of carer involvement and changes in function were therefore very limited. Unsurprisingly, Pearson correlations were non-significant for IRQ at Phase 1 and FIAS Involved-Staff with FIM difference scores (FIM at follow-up minus FIM at discharge). All Aim 3 results are displayed in Table 11.

Table 11

Pearson correlations for IRQ Total at Phase 1and FIAS Involved-Staff Total with functional, life satisfaction, and community integration outcomes for relatives with brain injury

Measure/subscale	**df**	***r* (IRQ Phase 1 total)**	***p* (2-tailed)**	**df**	***r* (FIAS Involved -Staff)**	***p* (2-tailed)**
LiSat-11	18	-.276	.239	19	.044	.851
Community Integration Questionnaire						
Home Integration Total (5 items)	19	-.116	.615	19	-.136	.557
Social Integration Total (6 items)	19	.275	.227	19	-.121	.602
Productivity Total (2 items)	19	.062	.788	19	-.021	.929
Overall Total (13 items)	19	.096	.679	19	-.129	.578
European Brain Injury Questionnaire						
Somatic Total (8 items)	19	.051	.827	19	.211	.359
Cognitive Total (13 items)	19	.094	.685	19	.381	.088
Motivation Total (5 items)	19	-.051	.826	19	-.041	.862
Impulsivity Total (13 items)	19	-.085	.714	19	.015	.950
Depression Total (9 items)	19	.183	.428	19	-.087	.709
Isolation Total (4 items)	19	.045	.846	19	.109	.637
Physical Total (6 items)	19	.003	.989	19	.009	.968
Communication Total (4 items)	19	-.014	.459	19	.031	.895
Core Symptoms Total (34 items)	19	.171	.882	19	.171	.458
Overall Total (63 items)	19	.034	.880	19	.155	.501
Functional Independence Measure						
FIM Difference (Discharge)[a]	9	.262	.437	9	-.176	.604

Note: Higher scores on the IRQ and FIAS denote greater involvement; higher scores on the LiSat-11 signify better life satisfaction; higher scores on the CIQ denote greater community integration; higher scores on the EBIQ indicate increased symptom presence; and higher scores on the FIM indicate a greater level of independence.

[a] This denotes participants' follow-up FIM scores (collected by the current author at Phase 2) minus their score upon discharge from the brain injury unit (as reported by the staff team). FIM at discharge, as opposed to at admission, was used as it corresponded most accurately with the time of carer participants' initial involvement in the research.

Aim 4. Have carers' initial expectations been realised? And are disappointed expectations related to a decline (less improvement) in wellbeing?

Since CEQ v.1 and v.2 differ only in the tense to which items refer, comparative analyses were possible to explore changes in carer expectations over time. T-tests, all two-tailed, were performed for the three CEQ subscales to investigate differences in scores between phases. Significant differences were revealed between carers' Phase 1 and Phase 2 CEQ-Consequences totals ($t(22) = -4.852$, $p < .001$) and Treatability totals ($t(22) = -2.716$, $p = .013$), indicating that expectations about the outcomes of the ABI and its treatability at an early stage of rehabilitation were more optimistic than their perceptions 12 to 18 months later. No significant difference was found between CEQ-Patient Control ($t(22) = -.390$, $p = .701$) or Carer Control ($t(22) = .063$, $p = .951$) totals between Phase 1 and Phase 2.

Carers' disappointed expectations as to the consequences of the ABI (Phase 1 CEQ-Consequences total minus Phase 2 CEQ-Consequences total) were significantly negatively correlated with WEMWBS differences (Phase 1 WEMWBS minus Phase 2 WEMWBS): $r(20) = -.521$, $p = .013$. However, WEMWBS difference was not significantly associated with CEQ-Patient Control difference ($r(20) = .173$, $p = .442$), Carer Control difference ($r(20) = .196$, $p = .382$), or Treatability difference ($r(20) = -.015$, $p = .947$).

Supplementary analyses

Several additional analyses were undertaken, which did not relate directly to the study aims. These are summarised in Appendix 24. One finding of note was that carers' emotional wellbeing was significantly better at Phase 2 than at Phase 1 ($t(19) = -4.060$, $p = .001$, two-tailed).

PHASE 2 DISCUSSION

The extent to which the results supported the four hypotheses is outlined below, before being examined further in the General Discussion.

The first hypothesis, that better carer wellbeing at follow-up would be associated with perceptions of less serious ABI consequences at Phase 2, was not supported.

The second hypothesis was that carers' greater involvement at Phase 2 would be correlated with perceptions of better controllability and treatability of the ABI at follow-up as it had previously. This was the case in terms of carers' perceptions of their own influence over their relative's recovery, but not in terms of perceived patient control or treatment effectiveness.

There was no support for the third hypothesis, that carers' greater initial involvement would predict outcomes for relatives in terms of general functioning, life satisfaction, and community integration. However, the analysis intending to control for the potentially-confounding influence of disability level was substantially under-powered: The correlations for FIM improvement with carer-reported and staff-reported involvement were in opposite directions, neither reaching significance.

The hypothesis that carers' initial expectations would be over-optimistic was supported by the analyses as regards perceptions about the consequences and treatability of the ABI, but not its perceived controllability. Finally, as hypothesised, unfulfilled optimism about the ABI's consequences was associated with less improvement in wellbeing by Phase 2. This association was not seen for carers' perceptions of ABI controllability or treatability.

GENERAL DISCUSSION

The overall purpose of this study was to examine carer expectations, wellbeing, and involvement, as regards acquired brain injury rehabilitation: issues neglected in previous research. Phase 1 of the study was an extension of a previous researcher's project (Hough, 2010a), whereby extra participants were added to the existing dataset. Phase 2 saw a subset of these participants followed up 12 to 18 months later, and changes in the variables over time and outcomes for the relative with ABI were examined.

On the basis of Hough's (2010a) findings, for Phase 1 it was hypothesised that carers' pessimistic expectations about the future consequences of the ABI for the person, carer, and family would be correlated with carers' reduced mental wellbeing, and that pessimistic expectations about the effectiveness of the rehabilitation over time (treatability) and perceived control over the recovery process (controllability) would be linked to carers' reduced rehabilitation involvement. Phase 2 aimed to answer four research questions:

1. Is carer wellbeing at follow-up associated with perceptions of the consequences of the ABI as it was in the original Hough (2010a) study?
2. Is carer involvement at Phase 2 linked to expectations about controllability and treatability, as found by Hough (2010a)?
3. Does carer involvement at Phase 1 predict rehabilitation outcomes for relatives with ABI at Phase 2?
4. Have carers' expectations been realised at follow-up, and what is the impact of unrealised expectations on carer wellbeing?

The findings from both phases will be discussed together below.

Carers' illness perceptions and wellbeing

In the Phase 1 sample, carers' pessimistic expectations earlier in the rehabilitation process, in terms of ABI consequences, were linked to their poorer mental wellbeing. This is in line with the first hypothesis and is consistent with the finding of Fortune et al. (2005) in carers of people with psychosis. This outcome might indicate that being optimistic about one's relative's prognosis acts as a protective factor for wellbeing in carers and is therefore a desirable initial coping strategy. This idea would extend the tentative proposals by Man (2002), Ruston (2007), and Verhaeghe et al. (2005) that carer expectations may be linked to their adjustment.

The results of Phase 2 demonstrated that carers' follow-up perceptions of their relative's recovery were not significantly linked to their wellbeing later in the rehabilitation process. However, the correlation was in the expected direction and it could be that the moderately low power of the Phase 2 analyses, due to the relatively small sample, explains the failure to obtain a significant correlation.

Carers' illness perceptions and involvement

In the wider literature, there is evidence that illness perceptions are associated with treatment engagement in both individuals with a health condition (Cooper et al., 1999; MacInnes, 2006; Phillips et al., 1984; Shah et al., 2009) and their carers (Ryan et al., 1996). The present study demonstrated that this association can also be found in ABI. In terms of carers' perceptions of their own influence over their relative's recovery, this was significantly linked to their level of involvement in both phases of the study in that carers who did not expect to play an important role in their relative’s rehabilitation were less engaged in the recovery process. This association was particularly strong in the early stages of rehabilitation, suggesting that this might be an important time for carers’ expectations about their role in the rehabilitation process to be identified and addressed.

Carer involvement and outcomes for relatives with acquired brain injury

The third aim considered the idea of early carer involvement being predictive of rehabilitation outcomes for relatives. Carer involvement in ABI rehabilitation is promoted as valuable (Department of Health, 2007, 2008; Turner-Stokes, 2003) but research evidence as to its clinical benefits is lacking. In this study, carers’ initial involvement was not significantly associated with physical, cognitive, psychological, or social functioning outcomes for relatives with ABI, nor was it related to their life satisfaction. Although not an intervention study, the lack of association between involvement and physical functioning outcomes found here is in line with Kalra et al.’s (2004) RCT findings on adults with stroke undergoing a family intervention, whilst being at odds with stroke patients’ improved physical functioning after family involvement in the Osawa and Maeshima (2010) study.

Researching the connections between carer involvement and patient outcomes is made difficult because of the potentially confounding effect of level of disability: A negative association between these variables might be expected since increased disability severity is probably linked to a need for greater carer involvement, and to poorer general outcomes. To address this problem, the present study intended to analyse whether early carer involvement predicted longitudinal improvement in disability levels using the Functional Independence Measure. Unfortunately, an inadequate number of participants had been given a FIM score during their in-patient stay. As such, the analysis was substantially underpowered and no significant findings were obtained. The correlation between initial carer-reported involvement and improvement in FIM scores suggested that greater involvement was weakly associated with better functional improvements, yet this finding was in the opposite direction according to staff-reported involvement. This issue therefore warrants further investigation.

Expectations over time and impact of unrealised expectations

For the carers in the present study, expectations as to their relative's rehabilitation from ABI were over-optimistic compared with the reported reality 12-18 months later, with respect to the consequences and treatability of the ABI. This is in line with Levack et al.'s (2009) report that staff considered many families to have unrealistically high expectations at the early stages of ABI rehabilitation. In contrast, Stein et al. (2003) found that stroke caregivers underestimated functional outcomes in their relatives. The present study offered some support for this latter finding, since demographic analyses revealed carers of individuals with stroke had more pessimistic expectations about treatability at Phase 1 than carers of those with traumatic brain injury.

According to the current study, the less carers' expectations about consequences of the ABI were realised, the greater decline in their mental wellbeing over time. Unrealised expectations about perceived controllability and treatability of the condition were not significantly associated with a difference in wellbeing over time. This is interesting in the context of the significant improvements in mental wellbeing at follow-up for carer participants as a whole, as it suggests that factors aside from expectations impact upon wellbeing over the recovery process. This is not altogether surprising, especially considering the relatively small, heterogeneous sample. It is also worth noting that the carers' wellbeing remained lower than the general population average at follow-up (Stewart-Brown & Janmohamed, 2008), reflecting the findings of Kumar and Kendrick (2009), whose participants' reports of poor mental wellbeing persisted to 15 months post-ABI.

Limitations

This study had a number of limitations. Firstly, although the sample size for Phase 1 was reasonable, the number of participants willing and able to take part in Phase 2 was fairly small, falling short of the calculated power requirements for the correlational analyses and thus increasing the risk of Type II errors. It was particularly regrettable that so few early FIM scores could be obtained, since this impeded evaluation of changes in relatives' function over time and precluded adequate exploration of involvement-outcome links. A further sampling issues was that participants were self-selected, and as such may not be representative of ABI carers as a population. For example, carers with very negative expectations or those with other caregiving responsibilities may not have taken part; the opt-out data suggested that couples whose relationship had broken down were less likely to be included. This study aimed to be inclusive of a range of ABI experiences, yet the sample's heterogeneity may have created difficulties. Certain demographic and injury-related variables were associated with differences in carer expectations, and it is possible that other differences not captured within these analyses may have influenced the results. For instance, the rehabilitation experiences of the parent of a young adult with TBI sustained in a motorcycle accident may differ in important ways from those of a spouse in her 70s caring for a husband with a stroke.

With regard to measurement, particular questionnaire subscales were found to have unacceptably low alpha levels, casting doubt on their reliability and validity. Additionally, the two measures designed for the current study and its precursor have not been used elsewhere, and thus evidence is limited as to their psychometric properties. It is also possible that social desirability bias affected some responses, particularly where measures were administered face-to-face.

Finally, there were certain limitations associated with the study design. Since almost all of the analyses were cross-sectional correlations, no causal inferences were possible. As such, the relationship between aspects of carer expectations, wellbeing, and involvement remains somewhat equivocal. The study's longitudinal design represents a strength of this piece of research and offered the potential to explore causal relationships. It is unfortunate that such analyses were hindered by the inadequate amount of data on participants' initial functioning post-injury.

Implications for research and clinical practice

The scope of theory and practice implications is to some extent restricted by the study findings. Fundamentally, there is a need for further research to address the limitations highlighted; the evidence base would particularly benefit from large-sample longitudinal research evaluating the impact of carers' expectations and involvement on rehabilitation outcomes in ABI.

This study offers tentative evidence for several ideas concerning brain injury rehabilitation, which may have important clinical implications given further empirical support. If family involvement does improve long-term patient outcomes, then according to previous research

(Lefebvre et al., 2005; Levack et al., 2009) there is a need for services to accommodate this in a more meaningful and realistic way. Encouraging carers' beliefs in the potential benefits of their involvement may help here, and may also contribute to their better wellbeing early in the rehabilitation process. It is important that services manage carers' illness perceptions sensitively, however, since this and previous research indicates that carers' early expectations can be unrealistic, impeding the rehabilitation process by creating staff-family tensions (Lefebvre et al., 2005; Levack et al., 2009). Furthermore, the current findings support an idea that the later disappointment that can arise from initially over-optimistic expectations may have a negative bearing on carers' wellbeing.

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PUBLIC DOMAIN BRIEFING PAPER

A FOLLOW-UP STUDY OF CARERS' WELLBEING, EXPECTATIONS, AND INVOLVEMENT IN THEIR RELATIVE'S REHABILITATION FROM ACQUIRED BRAIN INJURY

This study was carried out by Laura Meader (Trainee Clinical Psychologist) in partial fulfilment of the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham, UK. The work was supervised by Drs. Gerard Riley and Andrew Brennan.

BACKGROUND

When a person experiences an acquired brain injury (ABI)[15], their day-to-day functioning is often affected, which means that a family member typically takes on new tasks to help their relative when they leave hospital. Carers may play a significant role in their relative's recovery from ABI, and although there has been a great deal of research into the difficulties they experience (Oddy & Herbert, 2003), the links between carers' emotional wellbeing, rehabilitation involvement, and expectations for their relative's recovery are poorly understood. This study was a follow-up of a previous ClinPsyD project (Hough, 2010) which investigated these factors and found that carers' unrealistic expectations were associated with their poorer wellbeing and their reduced involvement in the rehabilitation process. This follow-up study aimed to explore these issues further, and also consider various rehabilitation outcomes for the relative with ABI. This is because carer involvement in rehabilitation is recommended (Department of Health 2007; 2008) but there is very little research into how it actually relates to aspects such as the physical and psychosocial functioning of the person with the brain injury.

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[15] Brain damage occurring after birth as a result of head trauma, stroke, infection, or tumour.

METHOD

Phase 1: This phase involved the 42 carers who participated in the original study of Hough (2010), with an additional 18 carers recruited soon afterwards. These 60 carers' expectations about their relative's recovery, emotional wellbeing, and involvement in their relative's rehabilitation were assessed with questionnaires. Rehabilitation staff also completed a questionnaire about how involved they felt the carers were in the rehabilitation process.

Phase 2: This was the follow-up phase, where 23 carers from Phase 1 were seen 12 to 18 months after the first phase and asked to complete further measures to assess the extent to which their earlier expectations had been met, their current wellbeing, and their current level of involvement in their relative's ongoing recovery. In this phase, relatives also completed questionnaires, to measure their physical, cognitive, and psychological functioning, life satisfaction, and engagement in social and community pursuits. Information on relatives' functioning during their inpatient stay was gathered, but this was only available for 11 people.

RESULTS

Phase 1: Carers who had more negative expectations about the consequences of their relative's brain injury and how well it would respond to treatment reported poorer emotional wellbeing. Carers who felt there was little that they, their relative, or the treatment could do to improve their relative's recovery were less involved in the rehabilitation process.

Phase 2: Carers' responses on the degree to which their expectations at Phase 1 had been met showed that for the most part, their expectations earlier in their relative's recovery had been over-optimistic. The consequences of the brain injury and the extent to which it could be treated were seen as more severe than the carers first thought. Carers' unfulfilled optimism as to the ABI's consequences was linked to less improvement in their wellbeing at follow-up. Carers were more involved in their relative's ongoing recovery at the follow-up stage if they believed they had played an important role in the rehabilitation process. Carers' involvement was not strongly linked to any of the rehabilitation outcomes for their relatives, but the small amount of data on relatives' earlier functioning made it harder to find meaningful results.

CONCLUSIONS AND SUGGESTIONS FOR RESEARCH AND PRACTICE

This study has demonstrated some interesting results in relation to the links between carers' expectations, wellbeing, and involvement. The findings suggest that carers of people with acquired brain injury tend to over-estimate how well their relative will recover in the longer term. Brain injury rehabilitation services could help carers by being as clear as possible as to what to expect after their relative's injury, especially at the early stages post-injury, where carers' expectations may have the strongest links with their level of rehabilitation involvement. This would need to be handled sensitively though, since early over-optimism may be linked to poorer wellbeing for carers in the longer term. Further research is needed, preferably with greater numbers of participants, to clarify the impact of carer involvement on rehabilitation outcomes for people with ABI.

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APPENDIX 1: NICE RESEARCH QUALITY GRADING CRITERIA

Criteria for evaluating research quality, as published by the National Institute Of Health and Clinical Excellence (NICE), 2004

Level of evidence	**Type of evidence**
1++	High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1+	Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
1-	Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias
2++	High-quality systematic reviews of case–control or cohort studies High-quality case–control or cohort studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal
2+	Well-conducted case–control or cohort studies with a low risk of confounding, bias or chance and a moderate probability that the relationship is causal
2-	Case–control or cohort studies with a high risk of confounding bias, or chance and a significant risk that the relationship is not causal
3	Non-analytic studies (for example, case reports, case series)
4	Expert opinion, formal consensus

APPENDIX 2: DEMOGRAPHIC QUESTIONNAIRE USED IN PHASE 1

Demographic Questionnaire

Part One : Information About You

The following questions require information about YOU as a relative. Please answer the following questions and tick which box applies to you.

1. Gender Male ☐ Female ☐

2. Age in Years ☐

3. Ethnicity

☐ white ☐ black ☐ asian ☐ other

4. Employed?

☐ Yes ☐ No

5. What relation are you to the person with the brain injury?

☐ Husband ☐ Wife ☐ Partner ☐ Father ☐ Mother

☐ Son ☐ Daughter ☐ Other (please specify)

☐

Part Two: Information about your Family Member

The following questions ask for information regarding your RELATIVE and their injury.

1. What kind of brain injury did your relative have?

☐ Head injury ☐ Stroke

☐ Other (please specify_

☐

2. How many months ago did their brain injury happen?

☐

3. What have you been told by doctors about the severity of your relative's brain injury/stroke?

☐ Mild ☐ Moderate ☐ Severe

4. Gender?

☐ Male ☐ Female

5. Your relative's age in years?

☐

Thank you for your time in completing this questionnaire.

APPENDIX 3: CARER EXPECTATIONS QUESTIONNAIRE VERSION 1 (CEQ v.1)

CEQ - Carer Expectations Questionnaire

Section 1 - Consequences for your family member

The following questions are about how you expect your relative's condition to be in 12 months' time. Please indicate to what extent you agree with the statements below by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Their condition will be serious					
2. Their condition will strongly affect the way others see them					
3. Their condition will be disabling					
4. My relative will get back to doing the things they enjoy in life.					
5. My relative will be able to manage their responsibilities (e.g. family and financial responsibilities)					

Section 2 - Consequences for you

The following questions are about how you expect your relative's condition to affect your own life over the next 12 months. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Their condition will strongly affect the way others see me					
2. My lifestyle will have to change					
3. My quality of life won't be the same					
4. I am worried that my relative will become completely dependent on me					
5. I won't be free to live my own life					

Section 3 - Consequences for the family

The following questions are about how you expect your relative's condition to affect the life of your family over the next 12 months. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. We won't be able to do a lot of the things we used to enjoy together					
2. Our relationship will be put under stress by what has happened					
3. Given time, we will settle back into our old way of life					
4. Life for us as a family is never going to be the same again					
5. Our quality of life will be every bit as good as it was before					

Section 4 - Improvement of Condition

These questions concern your expectations about treatment and rehabilitation. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. There is very little that can be done to improve their condition					
2. Their treatment will be effective in improving their condition					
3. My relative will regain full independence					
4. I'm confident that the therapy will help my relative improve					
5. Looking back at how much my relative has improved gives me hope for future improvement					

Section 5 - What influence your relative can have

The following questions are about how important a contribution you think your relative can make to their own recovery. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. There is a lot that my relative can do to improve their condition					
2. What my relative does determines whether their condition gets better or worse					
3. I doubt sometimes whether my relative puts 100% effort into getting better					
4. My relative will recover well if they think positively					
5. My relative has the strength of character to get back to being independent					

Section 6 - What influence you can have

The following questions are about how important your contribution to recovery is. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. I believe I have a really important role in helping my relative to make progress					
2 Family support is vital in overcoming many of the problems my relative has got					
3. My relative's recovery will be better the more information I have about their disabilities					
4. I need to have a high involvement with my relative for the good of their progress					

Section 7 - How the condition will change over time

The following questions are about how you see things changing in the longer term. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Their condition is likely to be permanent rather than temporary					
2. Changes I've noticed in my relative's mood are only temporary					
3. Most of my relative's problems will sort themselves out in time					
4. I am seeing aspects of my relative's personality returning as time goes by					
5. I expect that being a carer will get easier as time goes by					

Section 8 - Expectations of being a carer

These questions concern your expectations about being a carer. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
1. I'm confident in my ability to provide what my relative needs to progress					
2. I will be successful in adjusting to my new role as a carer					
3. I am confident about taking on my new role as a carer					
4. The caring role will be a challenge, but I'm prepared for it.					

Section 9 - Views about the service received

The following questions ask about what you think about the service you and your relative have received. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
1. I feel my relative's progress has already proved a lot of people wrong					
2. My relative will make more progress than the professionals say					
3. I think that the professionals exaggerate the level of difficulties my relative has					
4. My relative has already achieved things that we were told they would never be able to do again					
5. I've had to push a lot to make sure my relative receives the right treatment					

Thank you for completing this questionnaire

APPENDIX 4: INVOLVEMENT IN REHABILITATION QUESTIONNAIRE VERSION 1 (IRQ v.1)

Involvement in Rehabilitation Questionnaire (IRQ)

These questions are about your involvement in your relative's rehabilitation. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree	Not applicable
1. I take an active part in therapy sessions (with the occupational therapist, physiotherapist etc.)						
2. Outside therapy sessions, I do activities with my relative that I think will help their recovery						
3. I carry out treatment recommendations made by the staff						
4. I regularly ask staff how I best can help my relative						
5. I tell staff my own ideas about what I think will help my relative's recovery						
6. I have regular discussions with the therapists and other staff about my relative's progress						
7. I am actively involved in decisions about the rehabilitation programme for my relative						

8. I ask staff if there are other ways in which I can help my relative’s progress						
9. I seek out information and advice about my relative’s condition from sources outside the hospital (e.g. from the internet, or from charities like Headway or the Stroke Association).						
10. I try to motivate my relative to get the best out of their rehabilitation programme, e,g by encouraging him/her to do the exercises the therapists have recommended, or by praising him/her when s/he does well.						

APPENDIX 5: FAMILY INVOLVEMENT ASSESSMENT SCALE (FIAS) FULL VERSION

Family Involvement Assessment Scale (FIAS)

Instructions

Below is a list of items that describe behaviours that family members sometimes display when their relative is receiving rehabilitation services. Please indicate the frequency with which the family member demonstrates each behaviour, by circling the appropriate response. Please answer all the items

Behaviour of Family Member	**Frequency the Behaviour is displayed**			
1. This family member maintains regular contact with staff	**Never**	**Occasionally**	**Often**	**Always**
2. Attempts to dictate patient's therapy	**Never**	**Occasionally**	**Often**	**Always**
3. Makes themselves available to attend meetings and/or appointments with staff	**Never**	**Occasionally**	**Often**	**Always**
4. Complains about inadequate care or treatment	**Never**	**Occasionally**	**Often**	**Always**
5. Attends meeting and/or appointments with staff	**Never**	**Occasionally**	**Often**	**Always**
6. Expresses anger/hostility towards the patient	**Never**	**Occasionally**	**Often**	**Always**
7. Contacts staff for updates on patient's progress	**Never**	**Occasionally**	**Often**	**Always**
8. Expresses negative feelings that the family may feel towards staff or the rehabilitation programme	**Never**	**Occasionally**	**Often**	**Always**
9. Actively engages in decision making with staff	**Never**	**Occasionally**	**Often**	**Always**
10. Criticises patient for making poor progress	**Never**	**Occasionally**	**Often**	**Always**
11. Asks for or seeks additional education regarding head injury	**Never**	**Occasionally**	**Often**	**Always**
12. Criticises either staff or rehabilitation programme for poor patient progress	**Never**	**Occasionally**	**Often**	**Always**
13. Asks questions of staff about the patient's treatment	**Never**	**Occasionally**	**Often**	**Always**
14. Offers praise or positive reinforcement to a patient	**Never**	**Occasionally**	**Often**	**Always**
15. Asks staff how they or other family members can be involved in patient's treatment	**Never**	**Occasionally**	**Often**	**Always**

16. Verbally contradicts staff	**Never**	**Occasionally**	**Often**	**Always**
17. Participates in establishing patient's treatment goals	**Never**	**Occasionally**	**Often**	**Always**
18. Remains calm while with patient	**Never**	**Occasionally**	**Often**	**Always**
19. Participates in meetings at which patient's progress is discussed	**Never**	**Occasionally**	**Often**	**Always**
20. Expresses unrealistic goals or expectations for recovery	**Never**	**Occasionally**	**Often**	**Always**
21.Discusses family issues or dynamics with staff	**Never**	**Occasionally**	**Often**	**Always**
22. Requests a second opinion about rehabilitation treatment recommendations	**Never**	**Occasionally**	**Often**	**Always**
23. Works with the patient independently on therapeutic activities	**Never**	**Occasionally**	**Often**	**Always**
24. Sabotages efforts made by staff to treat the patient	**Never**	**Occasionally**	**Often**	**Always**
25. Emphasises the patient's physical deficits as a focus of treatment while ignoring or minimising cognitive and behavioural problems	**Never**	**Occasionally**	**Often**	**Always**
26. Provides encouragement and emotional support to motivate patient's engagement in the rehabilitation programme	**Never**	**Occasionally**	**Often**	**Always**
27. Describes patient's behaviour to staff	**Never**	**Occasionally**	**Often**	**Always**
28. Checks that staff are providing patient with quality care/treatment	**Never**	**Occasionally**	**Often**	**Always**
29. Follows through on treatment recommendations made by staff	**Never**	**Occasionally**	**Often**	**Always**
30. Does not respond to staff's attempts to incorporate them into the therapeutic process	**Never**	**Occasionally**	**Often**	**Always**
31. Encourages patient to perform tasks that the patient cannot do	**Never**	**Occasionally**	**Often**	**Always**
32. Involved in rehabilitation process only when there is a crisis	**Never**	**Occasionally**	**Often**	**Always**
33. Communicates opinions to staff about the effectiveness of specific therapies	**Never**	**Occasionally**	**Often**	**Always**
34. Interrupts patient's treatment sessions	**Never**	**Occasionally**	**Often**	**Always**
35. Asks staff for help in understanding patient's behaviour	**Never**	**Occasionally**	**Often**	**Always**
36. Observes therapy sessions	**Never**	**Occasionally**	**Often**	**Always**
37. Participates in therapy sessions	**Never**	**Occasionally**	**Often**	**Always**

APPENDIX 6: FAMILY INVOLVEMENT ASSESSMENT SCALE (FIAS) INVOLVED-STAFF SUBSCALE

Behaviour of Family Member	Frequency Behaviour is Displayed			
1. This family member maintains regular contact with staff	**Never**	**Occasionally**	**Often**	**Always**
3. Makes themselves available to attend meetings and/or appointments with staff	**Never**	**Occasionally**	**Often**	**Always**
5. Attends meeting and/or appointments with staff	**Never**	**Occasionally**	**Often**	**Always**
7. Contacts staff for updates on patient's progress	**Never**	**Occasionally**	**Often**	**Always**
9. Actively engages in decision making with staff	**Never**	**Occasionally**	**Often**	**Always**
11. Asks for or seeks additional education regarding head injury	**Never**	**Occasionally**	**Often**	**Always**
13. Asks questions of staff about the patient's treatment	**Never**	**Occasionally**	**Often**	**Always**
14. Offers praise or positive reinforcement to a patient	**Never**	**Occasionally**	**Often**	**Always**
15. Asks staff how they or other family members can be involved in patient's treatment	**Never**	**Occasionally**	**Often**	**Always**
17. Participates in establishing patient's treatment goals	**Never**	**Occasionally**	**Often**	**Always**
19. Participates in meetings at which patient's progress is discussed	**Never**	**Occasionally**	**Often**	**Always**
21.Discusses family issues or dynamics with staff	**Never**	**Occasionally**	**Often**	**Always**
23. Works with the patient independently on therapeutic activities	**Never**	**Occasionally**	**Often**	**Always**
26. Provides encouragement and emotional support to motivate patient's engagement in the rehabilitation programme	**Never**	**Occasionally**	**Often**	**Always**
27. Describes patient's behaviour to staff	**Never**	**Occasionally**	**Often**	**Always**
29. Follows through on treatment recommendations made by staff	**Never**	**Occasionally**	**Often**	**Always**
30. Does not respond to staff's attempts to incorporate them into the therapeutic process	**Never**	**Occasionally**	**Often**	**Always**
32. Involved in rehabilitation process only when there is a crisis	**Never**	**Occasionally**	**Often**	**Always**

33. Communicates opinions to staff about the effectiveness of specific therapies	**Never**	**Occasionally**	**Often**	**Always**
35. Asks staff for help in understanding patient’s behaviour	**Never**	**Occasionally**	**Often**	**Always**
36. Observes therapy sessions	**Never**	**Occasionally**	**Often**	**Always**
37. Participates in therapy sessions	**Never**	**Occasionally**	**Often**	**Always**

APPENDIX 7: WARWICK-EDINBURGH MENTAL WELL-BEING SCALE (WEMWBS)

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)

APPENDIX 8: PHASE 1 ANALYSES OF DEMOGRAPHIC AND INJURY-RELATED VARIABLES

1. Independent t-tests

Carer gender

T-test results for carer gender with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 1 participants.

Variables analysed	df	*t*	*p*
Carer gender & WEMWBS total	57	1.378	.174
Carer gender & CEQ Consequences total	58	.063	.950
Carer gender & CEQ Patient Control total	58	-2.734**	.008
Carer gender & CEQ Carer Control total	58	-1.675	.099
Carer gender & CEQ Treatability total	58	-.664	.509
Carer gender & IRQ Total	56	1.119	.268
Carer gender & FIAS Involved-Staff subscale	51	-1.253	.216

Note: Results are two-tailed, equal variances assumed.

** Significant at the .01 level

Injury severity

T-test results for ABI injury severity[a] *with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 1 participants.*

Variables analysed	df	*t*	*p*
Injury severity & WEMWBS total	53	.443	.660
Injury severity & CEQ Consequences total	54	-.509	.613
Injury severity & CEQ Patient Control total	54	.900	.372
Injury severity & CEQ Carer Control total	54	.838	.406
Injury severity & CEQ Treatability total	54	1.112	.271
Injury severity & IRQ Total	52	-1.621	.111
Injury severity & FIAS Involved-Staff subscale	47	-.542	.590

Note: Results are two-tailed, equal variances assumed.

[a] "Moderate" or "severe", according to carers' understanding of the severity of their relative's ABI. More accurate information was not available, as consent from relatives was not part of the ethical approval agreement.

Type of injury

T-test results for type of injury (stroke or traumatic brain injury) with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 1 participants.

Variables analysed	df	*t*	*p*
Type of injury & WEMWBS total	50	.433	.667
Type of injury & CEQ Consequences total	51	-1.859	.069
Type of injury & CEQ Patient Control total	51	-1.653	.104
Type of injury & CEQ Carer Control total	51	-.099	.951
Type of injury & CEQ Treatability total	51	-2.192*	.033
Type of injury & IRQ Total	49	.587	.560
Type of injury & FIAS Involved-Staff subscale	45	1.957	.057

Note: Results are two-tailed, equal variances assumed.

*Significant at the .05 level

2. Spearman Correlations

Carer age

Spearman correlation results for carer age with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 1 participants.

Variables analysed	N	*rho*	*p*
Carer age & WEMWBS total	59	-.118	.374
Carer age & CEQ Consequences total	60	.016	.906
Carer age & CEQ Patient Control total	60	-.049	.709
Carer age & CEQ Carer Control total	60	-.047	.720
Carer age & CEQ Treatability total	60	.022	.869
Carer age & IRQ Total	58	-.184	.167
Carer age & FIAS Involved-Staff subscale	53	-.058	.680

Note: Results are two-tailed.

Time since injury

Spearman correlation results for time since ABI (range: 1-14 months) with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 1 participants.

Variables analysed	N	*rho*	*p*
Time since injury & WEMWBS total	58	.131	.327
Time since injury & CEQ Consequences total	59	.364**	.005
Time since injury & CEQ Patient Control total	59	.324*	.012
Time since injury & CEQ Carer Control total	59	.134	.312
Time since injury & CEQ Treatability total	59	.287*	.028
Time since injury & IRQ Total	57	-.107	.428
Time since injury & FIAS Involved-Staff subscale	52	.208	.139

Note: Results are two-tailed.

**Significant at the .01 level

*Significant at the .05 level

APPENDIX 9: ANALYSES OF DEMOGRAPHIC AND INJURY-RELATED DIFFERENCES BETWEEN OPT-IN AND OPT-OUT GROUPS

1. Chi-square tests of independence

Carer gender

There was no significant difference between participants who opted into Phase 2 (N = 23) and individuals who opted out (N = 28), on the basis of carer gender:
χ^2 (1, N = 23) = .032, p = .858.

Severity of injury

There was no significant difference between participants who opted into Phase 2 (N = 23) and individuals who opted out (N = 28), on the basis of severity of the relative's brain injury ("moderate" or "severe"): χ^2 (1, N = 21) = 1.868, p = .172.

Type of injury

There was no significant difference between participants who opted into Phase 2 (N = 23) and individuals who opted out (N = 28), on the basis of the type of brain injury (stroke or traumatic brain injury): χ^2 (1, N = 17) = .016, p = .901.

2. Independent t-test

Carer age

There was no significant difference between participants who opted into Phase 2 (N = 23) and individuals who opted out (N = 28), on the basis of carers' age: $t(49)$ = -1.149, p = .256 (two-tailed; equal variances assumed).

APPENDIX 10: CARER EXPECTATIONS QUESTIONNAIRE VERSION 2 (CEQ v.2)

CEQ - Carer Expectations Questionnaire

Section 1 - Consequences for your family member

The following questions are about how you perceive your relative's condition at the moment. Please indicate to what extent you agree with the statements below by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Their condition is serious					
2. Their condition strongly affects the way others see them					
3. Their condition is disabling					
4. My relative has got back to doing the things they enjoy in life					
5. My relative is able to manage their responsibilities (e.g. family and financial responsibilities)					

Section 2 - Consequences for you

The following questions are about how your relative's condition affects your own life at the moment. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Their condition strongly affects the way others see me					
2. My lifestyle has changed					
3. My quality of life isn't the same					
4. My relative is very dependent on me					
5. I'm not free to live my own life					

Section 3 - Consequences for the family

The following questions are about how your relative's condition affects the life of your family at the moment. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. We're not able to do a lot of the things we used to enjoy together					
2. Our relationship has been put under stress by what has happened					
3. We have settled back into our old way of life					
4. Life for us as a family has never been the same					
5. Our quality of life is every bit as good as it was before					

Section 4 - Improvement of Condition

These questions concern your ideas about treatment and rehabilitation. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. Not much has been done to improve their condition					
2. Their treatment has been effective in improving their condition					
3. My relative has regained full independence					
4. The therapy has helped my relative improve					
5. Looking back at how much my relative has improved gives me hope for even more improvement in the future					

Section 5 - What influence your relative can have

The following questions are about how important a contribution you think your relative can make to their own recovery. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. My relative has been able to do a lot to improve their condition					
2. My relative's actions had an influence on how much progress they made					
3. I don't think my relative put 100% effort into getting better					
4. Positive thinking has helped my relative recover					
5. Strength of character helped my relative regain their independence					

Section 6 - What influence you can have

The following questions are about how important your contribution to recovery is. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

STATEMENTS	Strongly Agree	Agree	Don't know	Disagree	Strongly Disagree
1. I've played an important role in helping my relative make progress					
2. Family support has been vital in overcoming many of the problems my relative has faced					
3. Being given information about their disabilities was an important in helping me to aid my relative's recovery					
4. My close involvement has helped my relative's recovery					

Thank you for completing this questionnaire

APPENDIX 11: INVOLVEMENT IN REHABILITATION QUESTIONNAIRE VERSION 2 (IRQ v.2) MALE VERSION

Involvement in Rehabilitation Questionnaire (Participation) - Male

These questions are about your involvement in your relative’s rehabilitation. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

		Often	**Sometimes**	**Rarely**	**Never**		**Not applicable**
1	I encourage him to do as much as he can around the house (e.g. cooking, cleaning, DIY)						
2	I encourage him to keep himself busy during the day (e.g. reading, using a computer, gardening)						
3	I encourage him to keep up the exercises recommended by the physiotherapist						
4	I encourage him to take part in social activities and events (e.g. going out with friends, keeping in touch by phone)						
5	I encourage him to do as much personal care for himself as he can (e.g. dressing, bathing)						
6	I encourage him to keep physically active (e.g. exercises, swimming, walking)						
7	I encourage him to take part in leisure activities outside the home (e.g. days out, going to a sports event or the cinema)						
8	I encourage him to deal with other people himself, rather than relying on me (e.g. in shops, during meetings with therapists)						
9	I encourage him to use the skills and strategies recommended by his therapists (e.g. memory aids, relaxation techniques)						

APPENDIX 12: INVOLVEMENT IN REHABILITATION QUESTIONNAIRE VERSION 2 (IRQ v.2) FEMALE VERSION

Involvement in Rehabilitation Questionnaire (Participation) - Female

These questions are about your involvement in your relative's rehabilitation. Please indicate to what extent you agree with the following statements by ticking the appropriate box.

		Often	**Sometimes**	**Rarely**	**Never**		**Not applicable**
1	I encourage her to do as much as she can around the house (e.g. cooking, cleaning, DIY)						
2	I encourage her to keep herself busy during the day (e.g. reading, using a computer, gardening)						
3	I encourage her to keep up the exercises recommended by the physiotherapist						
4	I encourage her to take part in social activities and events (e.g. going out with friends, keeping in touch by phone)						
5	I encourage her to do as much personal care for herself as she can (e.g. dressing, bathing)						
6	I encourage her to keep physically active (e.g. exercises, swimming, walking)						
7	I encourage her to take part in leisure activities outside the home (e.g. days out, going to a sports event or the cinema)						
8	I encourage her to deal with other people herself, rather than relying on me (e.g. in shops, during meetings with therapists)						
9	I encourage her to use the skills and strategies recommended by her therapists (e.g. memory aids, relaxation techniques)						

APPENDIX 13: THE LISAT-11 CHECKLIST

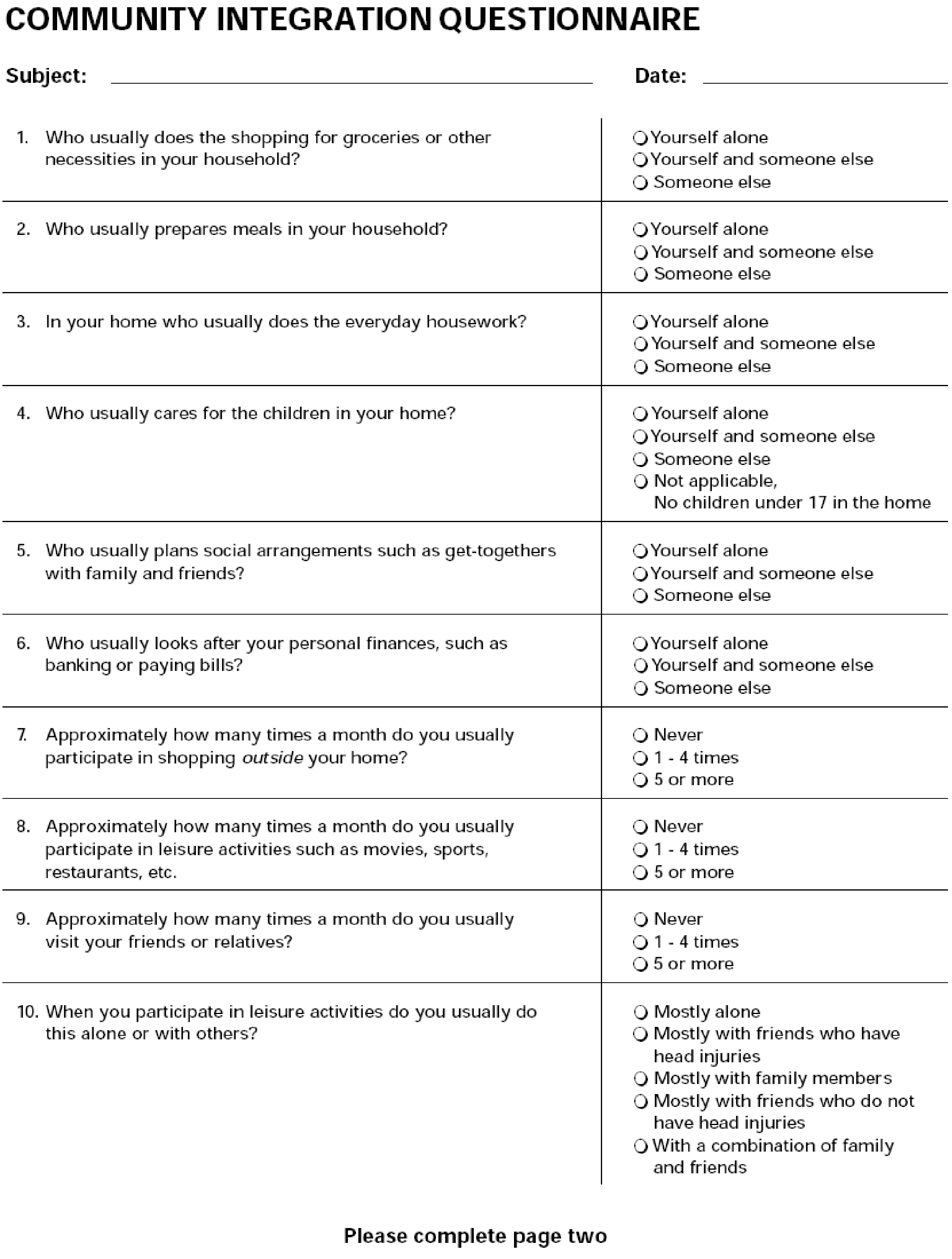
☐The LISAT-11 checklist (in English translation)

Fugl-Meyer (2002)

Here are a number of statements concerning how satisfied you are with different aspects of your life. For each of these statements please mark a number from 1 to 6, where 1 = very dissatisfying 2 = quite dissatisfying 3 = a bit dissatisfying 4 = a bit satisfying 5 = quite satisfying 6 = very satisfying

1	My life as a whole is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
2	My vocational situation (employment or voluntary work) is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
3	My financial situation is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
4	My leisure situation (how I spend my leisure time) is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
5	My contact with friends and acquaintances is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
6	My sexual life is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
7	My ability to manage my self-care (dressing, hygiene, transfers etc.) is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
8	My family life is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
	I have no family ☐						
9	My relationship with my partner (wife, husband etc.) is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
	I have no steady partner ☐						
10	My physical health is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying
11	My psychological health is	very dissatisfying	quite dissatisfying	a bit dissatisfying	a bit satisfying	quite satisfying	very satisfying

APPENDIX 14: COMMUNITY INTEGRATION QUESTIONNAIRE (CIQ)



COMMUNITY INTEGRATION QUESTIONNAIRE

Subject: ________________________ **Date:** ______________

1. Who usually does the shopping for groceries or other necessities in your household?	○ Yourself alone ○ Yourself and someone else ○ Someone else
2. Who usually prepares meals in your household?	○ Yourself alone ○ Yourself and someone else ○ Someone else
3. In your home who usually does the everyday housework?	○ Yourself alone ○ Yourself and someone else ○ Someone else
4. Who usually cares for the children in your home?	○ Yourself alone ○ Yourself and someone else ○ Someone else ○ Not applicable, No children under 17 in the home
5. Who usually plans social arrangements such as get-togethers with family and friends?	○ Yourself alone ○ Yourself and someone else ○ Someone else
6. Who usually looks after your personal finances, such as banking or paying bills?	○ Yourself alone ○ Yourself and someone else ○ Someone else
7. Approximately how many times a month do you usually participate in shopping *outside* your home?	○ Never ○ 1 - 4 times ○ 5 or more
8. Approximately how many times a month do you usually participate in leisure activities such as movies, sports, restaurants, etc.	○ Never ○ 1 - 4 times ○ 5 or more
9. Approximately how many times a month do you usually visit your friends or relatives?	○ Never ○ 1 - 4 times ○ 5 or more
10. When you participate in leisure activities do you usually do this alone or with others?	○ Mostly alone ○ Mostly with friends who have head injuries ○ Mostly with family members ○ Mostly with friends who do not have head injuries ○ With a combination of family and friends

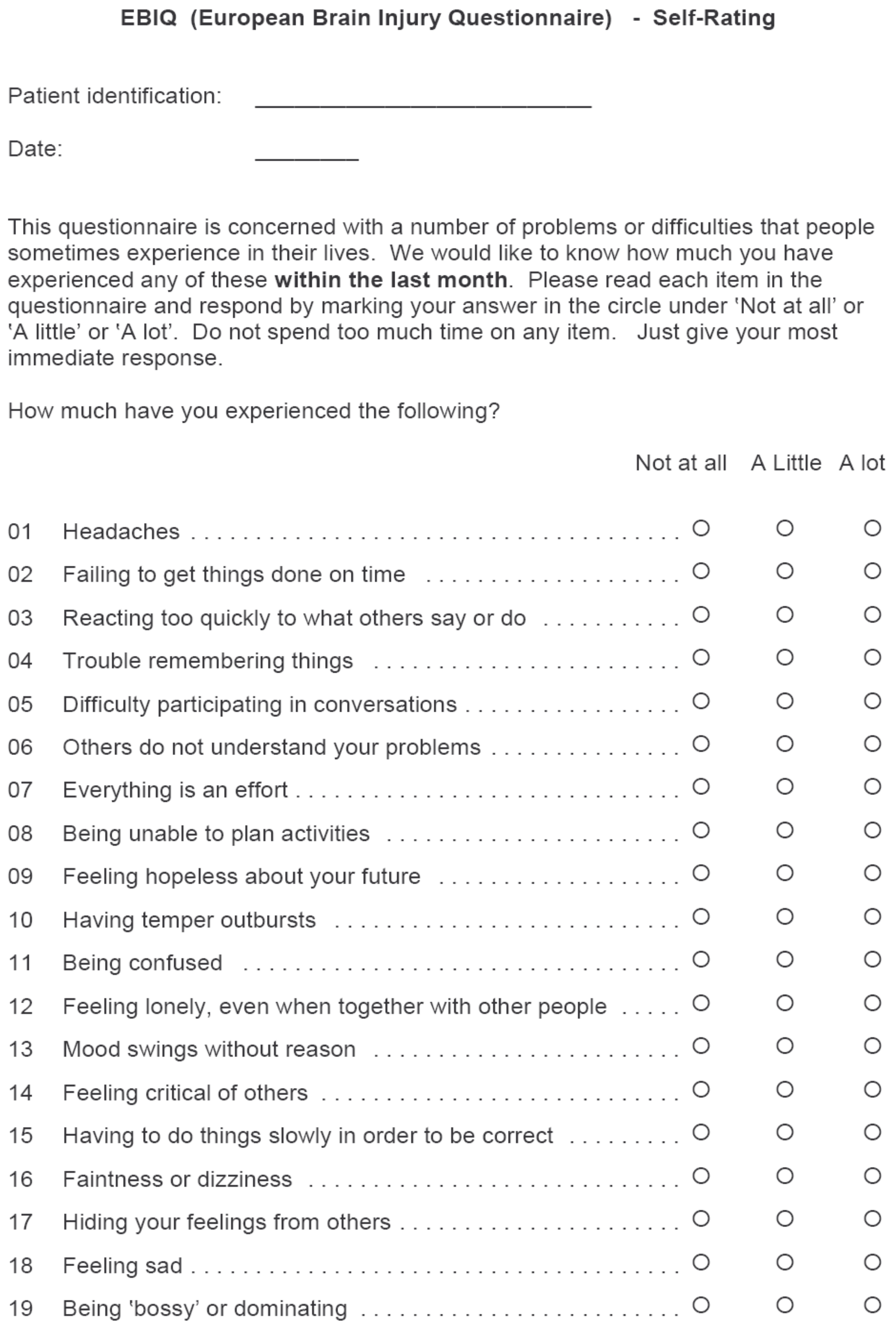
Please complete page two

COMMUNITY INTEGRATION QUESTIONNAIRE (Page 2)

11. Do you have a best friend with whom you confide?	○ Yes ○ No
12. How often do you travel outside the home?	○ Almost every day ○ Almost every week ○ Seldom/never (less than once per week)
13. Please choose the answer that best corresponds to your current (during the past month) work situation:	○ Full-time (more than 20 hours/week) ○ Part-time (less than or equal to 20 hrs/week) ○ Not working, but actively looking for work ○ Not working, not looking for work ○ Not applicable, retired due to age
14. Please choose the answer that best corresponds to your current (during the past month) school or training program situation:	○ Full-time ○ Part-time ○ Not attending school, or training program ○ Not applicable, retired due to age
15. In the past month, how often did you engage in volunteer activities?	○ Never ○ 1 - 4 times ○ 5 or more

Comments:

APPENDIX 15: THE EUROPEAN BRAIN INJURY QUESTIONNAIRE (EBIQ)



EBIQ (European Brain Injury Questionnaire) - Self-Rating

Patient identification: ___________________________

Date: ________

This questionnaire is concerned with a number of problems or difficulties that people sometimes experience in their lives. We would like to know how much you have experienced any of these **within the last month**. Please read each item in the questionnaire and respond by marking your answer in the circle under 'Not at all' or 'A little' or 'A lot'. Do not spend too much time on any item. Just give your most immediate response.

How much have you experienced the following?

		Not at all	A Little	A lot
01	Headaches	○	○	○
02	Failing to get things done on time	○	○	○
03	Reacting too quickly to what others say or do	○	○	○
04	Trouble remembering things	○	○	○
05	Difficulty participating in conversations	○	○	○
06	Others do not understand your problems	○	○	○
07	Everything is an effort	○	○	○
08	Being unable to plan activities	○	○	○
09	Feeling hopeless about your future	○	○	○
10	Having temper outbursts	○	○	○
11	Being confused	○	○	○
12	Feeling lonely, even when together with other people	○	○	○
13	Mood swings without reason	○	○	○
14	Feeling critical of others	○	○	○
15	Having to do things slowly in order to be correct	○	○	○
16	Faintness or dizziness	○	○	○
17	Hiding your feelings from others	○	○	○
18	Feeling sad	○	○	○
19	Being 'bossy' or dominating	○	○	○

		Not at all	A Little	A lot
20	Needing to be reminded about personal hygiene	○	○	○
21	Difficulty managing your finances	○	○	○
22	Trouble concentrating	○	○	○
23	Failing to notice other people’s moods	○	○	○
24	Feeling anger against other people	○	○	○
25	Having your feelings easily hurt	○	○	○
26	Feeling unable to get things done	○	○	○
27	Annoyance or irritation	○	○	○
28	Problems with household chores	○	○	○
29	Lack of interest in hobbies at home	○	○	○
30	Feeling lonely	○	○	○
31	Feeling inferior to other people	○	○	○
32	Sleep problems	○	○	○
33	Feeling uncomfortable in crowds	○	○	○
34	Shouting at people in anger	○	○	○
35	Difficulty in communicating what you want to say	○	○	○
36	Being unsure what to do in dangerous situations	○	○	○
37	Being obstinate	○	○	○
38	Lack of interest in your surroundings	○	○	○
39	Thinking only of yourself	○	○	○
40	Mistrusting other people	○	○	○
41	Crying easily	○	○	○
42	Difficulty finding your way in new surroundings	○	○	○
43	Being inclined to eat too much	○	○	○
44	Getting into quarrels easily	○	○	○
45	Lack of energy or being slowed down	○	○	○
46	Forgetting the day of the week	○	○	○
47	Feeling of worthlessness	○	○	○
48	Lack of interest in hobbies outside the home	○	○	○

		Not at all	A Little	A lot
49	Needing help with personal hygiene	○	○	○
50	Restlessness	○	○	○
51	Feeling tense	○	○	○
52	Acting inappropriately in dangerous situations	○	○	○
53	Feeling life is not worth living	○	○	○
54	Forgetting appointments	○	○	○
55	Leaving others to take the initiative in conversations	○	○	○
56	Loss of sexual interest or pleasure	○	○	○
57	Throwing things in anger	○	○	○
58	Preferring to be alone	○	○	○
59	Difficulty in making decisions	○	○	○
60	Losing contact with your friends	○	○	○
61	Lack of interest in current affairs	○	○	○
62	Behaving tactlessly	○	○	○
63	Having problems in general	○	○	○

If you have a close relative who is also completing this questionnaire, then please answer the following questions about that person.

64	Do you think that his/her life has changed after you had the injury?	○	○	○
65	Do you think that he/she is having problems due to your present situation?	○	○	○
66	Do you think that his/her mood has changed due to your present situation?	○	○	○

Any other comments?

Thank-you for your cooperation

APPENDIX 16: THE FUNCTIONAL INDEPENDENCE MEASURE (FIM)

		Admission	**Goal**	**Discharge**
	Date of admission/goal/discharge			
	Date of FIM/FAM Assessment			
1	**Eating**			
2	**Grooming**			
3	**Bathing**			
4	**Dressing Upper Body**			
5	**Dressing Lower Body**			
6	**Toileting**			
Score both level of assistance and frequency				
7.1	**Bladder – Level of assistance**			
7.2	**Bladder – Frequency of accidents**			
8.1	**Bowel – Level of assistance**			
8.2	**Bowel – Frequency of accidents**			
9	**Bed, Chair, Wheelchair transfer**			
10	**Toilet Transfer**			
11	**Tub, Shower transfer**			
12.1	**Locomotion – Walking (“w”)**			
12.2	**Locomotion – Wheelchair (“c”)(0 score allowed 6 max)**			
Indicate most frequent mode of locomotion (w or c)				
13	**Stairs**			
14	**Comprehension**			
15	**Expression**			
16	**Social Interaction**			
17	**Problem Solving**			
18	**Memory**			

Scoring criteria:

Level	*Description*
7 Complete independence	Fully independent
6 Modified independence	Requiring the use of a device but no physical help
5 Supervision	Requiring only standby assistance or verbal prompting or help with set-up
4 Minimal assistance	Requiring incidental hands-on help only (subject performs > 75% of the task)
3 Moderate assistance	Subject still performs 50-75% of the task
2 Maximal assistance	Subject provides less than half the effort (25-49%)
1 Total assistance	Subject contributes < 25% of the effort or is unable to do the task

APPENDIX 17: COVER LETTER CARER VERSION (PHASE 2)

UNIVERSITY OF
BIRMINGHAM
School of Psychology

Dear [*carer's name*],

Re. Study on client recovery and family involvement in brain injury rehabilitation

Approximately a year ago, you took part in a study about your expectations of recovery following a brain injury that happened to your [*relative*]. The study was based at the University of Birmingham. At the time, you met with Andrea Hough (the researcher) and agreed to be contacted some time later with a view to participating in the second part of this study.

I am a colleague of Andrea's and am leading this second phase of the study. Full details of what will be involved are enclosed to help you decide whether or not you wish to take part in this phase of the study. Essentially, you would be asked to complete some further questionnaires about yourself and, possibly, your [*relative*]'s progress.

IF YOU DO NOT WANT TO TAKE PART:

We appreciate that you may no longer wish, or be able, to take part in this follow-up phase of the study. If this is the case, please complete the enclosed "opt-out" form and return it to me in the pre-paid envelope, by [*day, month, year: date 14 days after date at top of letter*]. You do not need to explain your reasons for opting out, and choosing to opt out will not affect any services you receive, now or in the future. Please ignore the enclosed letter addressed to your [*relative*]: We would only ask your [*relative*] to take part if you wanted to take part yourself.

You will not receive any further contact from this research team. We would like to take this opportunity to thank you for taking part in the first phase of the study.

IF YOU MIGHT BE INTERESTED IN TAKING PART:

If you might be interested in taking part, you do not need to do anything at this point. If I do not receive the enclosed „opt-out' form within 14 days, I will be in touch with you by telephone after [*day, month, year stated in previous paragraph*] to answer any questions you may have about the project. If you are still interested in taking part, I will then arrange a convenient time and place to meet with you. I have enclosed a consent form which we would complete if we met.

INVOLVING YOUR [RELATIVE]:

In this second phase of the study, we would also like to involve your [*relative*]. I have enclosed a letter for your [*relative*] to read about this. If you are interested in taking part yourself, I would be grateful if you could pass on this letter and discuss its contents with [*him/her*]. If [*s/he*] is interested in taking part, [*s/he*] would be asked to complete some questionnaires about [*his/her*] progress. We would also ask for permission to obtain from [*his/her*] medical records information about how [*s/he*] scored on one of the assessments that was completed when [*s/he*] was still in hospital. I have also enclosed a consent form for your [*relative*] which we would complete if we met.

It is important that your [*relative*] is able to understand and reply to the items on the questionnaires. If you think that [*s/he*] may not be able to do this, then we would not involve [*him/her*] in the study. Please think about this, and I will discuss it with you when I phone you.

If your [*relative*] does not wish to take part, or you think that [*s/he*] would not be able to take part, we would still like you yourself to take part. It is not necessary that both of you take part.

Thank you for your time. Please contact me on the number given below if there is anything you wish to discuss with me about the contents of this letter.

Laura Meader (Psychologist in Clinical Training)
School of Psychology
Frankland Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Tel: or
Email:

Dr Andrew Brennan (Clinical Psychologist)
[address details removed]

APPENDIX 18: COVER LETTER CARE RECIPIENT VERSION (PHASE 2)

UNIVERSITY OF
BIRMINGHAM

School of Psychology

Dear [*care recipient's name*],

Re. Study on client recovery and family involvement in brain injury rehabilitation

Approximately a year ago, your [*relative*] took part in a research study looking at their expectations about recovery following a brain injury. At the time, they met with one of my colleagues, Andrea Hough, and completed some questionnaires. They also agreed to be contacted later about participating in the second part of this study. This second part of the study would involve your [*relative*] filling in some more questionnaires.

We would like to invite you to take part in this second phase of the study as well. You would be asked to complete some questionnaires about your progress. I would be able to assist you with completing the questionnaires if you have any difficulties with reading or writing. More details about what you would be asked to do are enclosed.

Please discuss with your [*relative*] whether you would like to take part or not. You are not obliged to take part. If you decide you are not interested, this will not affect the services you receive. If you have any questions about it, please let your [*relative*] know and [*s/he*] can ask me these questions when I contact [*him/her*] by phone in a few weeks' time. Alternatively, you can phone me on the number given below.

Thank you for your time,

Laura Meader (Psychologist in Clinical Training)
School of Psychology
Frankland Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Tel: or
Email:

Dr Andrew Brennan (Clinical Psychologist)
[address details removed]

APPENDIX 19: PARTICIPANT INFORMATION SHEET CARER VERSION (PHASE 2)

Participant Information Sheet for Carers

Study on client recovery and family involvement in brain injury rehabilitation

I, Laura Meader, am a trainee clinical psychologist. My training is run by the University of Birmingham, and this project is being conducted as part of the requirements for trainees completing this degree course.

Before you decide whether to take part in this study, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are interested in the following questions:

- Do people with a brain injury make better progress if their family are actively involved in their rehabilitation?
- What happens over time to the family's expectations about recovery after brain injury?
- Does the family's current involvement in rehabilitation depend on whether their expectations have been met, and on their general sense of well-being?

Why have I been contacted?

You have been contacted to take part in this research because approximately 12 months ago you took part in an earlier study, conducted by Andrea Hough. At the time, you agreed to have your contact details kept on file so that you could be contacted at this point with a view to participating in this second study.

Do I have to take part?

Participation in this study is entirely voluntary and you have the opportunity to think about it before you decide whether to take part. If you decide not to take part, please fill in the enclosed "opt-out" form. This will not affect the services you receive in any way. If you do not return this form I will assume that you would like to take part and will contact you, as explained below. I would like to make it clear that if you decide to take part, you are free to withdraw from the study at any time and you do not have to give a reason.

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

If you decide to take part, you will receive a telephone call from me to arrange a date and place to meet. This may be at a hospital, or at your own home if this is preferred. You will be asked to complete two questionnaires about your general wellbeing and your involvement in your relative's rehabilitation. You will also be asked about your responses to the questionnaire about expectations that you completed in the earlier study: We would like to know if your expectations about recovery at that time have been met. This process should take approximately 10-15 minutes.

If your relative also takes part, you and your relative, in discussion with the researcher, would complete two measures of how well your relative is functioning. This should take approximately 20-30 minutes. Your relative would also be asked to complete two questionnaires looking at life satisfaction and participation in activities they value. This should take approximately 10-15 minutes.

In total, there are seven questionnaires and you will be completing five out of the seven, although two of these will be completed jointly with your relative. Your relative will likely complete the remaining two questionnaires on their own, unless they request or require your assistance. For mutual convenience, I will aim to complete all of the above in one sitting. However, a second session can be arranged if this is not possible for any reason.

What are the possible disadvantages and risks of taking part?

It is possible that you and/or your relative may find some of the questions distressing if they bring up some difficult memories for you. If this does happen, then you are free to skip those questions. You are also free to withdraw from the study at any time. In the event that you do feel distressed, advice will be given about where you can seek further support. Information about support services are contained at the end of this leaflet. With your permission, we might also contact your G.P. or other health professional about your support needs.

What are the possible benefits of taking part?

It is hoped that the findings from the study will help us to understand more fully the needs of people with a brain injury and their families.

What happens when the research study stops?

The information from the questionnaires will be analysed to see whether they answer the questions listed earlier (under „What is the purpose of the study?'). The results of this study will then be submitted to an academic journal. A summary of the findings will also be produced for people involved in the study. A copy will be sent to you upon completion of the study if you request this on the consent form.

What if there is a problem?

You are free to withdraw from the study at any time. In the event that you may require further sources of support, the researcher will provide you with information regarding this. If you wish to complain about the way in which the study is conducted, you should contact the academic supervisor (contact details are given below) or your local PALS service (details below).

Will my taking part in the study be kept confidential?

Yes, all information that is collected will be kept confidential. Your name and address will not be written on any of the questionnaires. Instead, your questionnaires will be identified by a code number only. Access to the questionnaires and to your consent forms will be given only to the members of the research team listed below and to personnel authorized by the University to conduct audits of research. Paperwork will be stored in locked filing cabinets, and the data analysis on password-protected computers. No record of your name or address will be kept on computers. However, if you disclose any information that raises concerns about possible criminal activity or serious threat to someone's health and well-being, the researcher cannot ensure confidentiality and would need to discuss openly such concerns with Dr Andrew Brennan, Clinical Supervisor.

Contact Details:
If you would like any further information about the study, please do not hesitate to contact:

> Laura Meader, Psychologist in Clinical Training, School of Psychology, The University of Birmingham, Edgbaston, Birmingham, B15 2TT. Telephone: or , Email:
>
> Or
>
> Dr Andrew Brennan, Clinical Psychologist. *[address details removed]*

If you wish to raise any concerns about this project, please contact the academic researcher (Dr Gerry Riley) on or by writing to Dr G. Riley *[address details removed]*

Should you have any issues or concerns about your involvement in this research, please contact PALS (Patient Advice and Liaison Service) in your area. Telephone numbers:

There are also agencies in your area that offer a range of support to carers and people who have had a brain injury, should you require this input.

Contact details for your local branch of Headway are as follows:
[details removed]

There are many services provided by The Stroke Association, who have a free (national) helpline where you can find out about services in your area:

Thank you for your time,

Laura Meader (Psychologist in Clinical Training)

Dr Andrew Brennan (Clinical Psychologist)

APPENDIX 20: PARTICIPANT INFORMATION SHEET CARE RECIPIENT VERSION (PHASE 2)

Participant Information Sheet for care recipient

Study on client recovery and family involvement in brain injury rehabilitation

I, Laura Meader, am a trainee clinical psychologist. My training is run by the University of Birmingham, and this project is being conducted as part of the requirements for trainees completing this degree course.

Before you and your [*relative*] decide whether to take part in this study, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
We are interested in the following questions:

- Do people with a brain injury make better progress if their family are actively involved in their rehabilitation?
- What happens over time to the family's expectations about recovery after brain injury?
- Does the family's current involvement in rehabilitation depend on whether their expectations have been met, and on their general sense of well-being?

Why has my [*relative*] been contacted?
Your [*relative*] has been contacted to take part in this research because approximately 12 months ago they took part in an earlier study, which just looked at rehabilitation from the carer's perspective. At the time, your [*relative*] agreed to have *[his/her]* contact details kept on file so that *[s/he*] could be contacted again with a view to participating in this second study.

Do I have to take part?
Participation in this study is entirely voluntary and you have the opportunity to think about it before you decide whether to take part. If you decide not to take part, this will not affect the services you receive in any way. If you do not wish to or do not feel able to take part in this study, your [relative] can still take part if they wish. I would like to make it clear that if you do decide to take part, you are free to withdraw from the study at any time and you do not have to give a reason.

What will I be asked to do if I take part?
If you and your [relative] decide to take part, your [relative] will receive a telephone call from me to arrange a date and place to meet. This may be at a hospital, or at your own home if this is preferred. You will be asked to complete two questionnaires about your satisfaction with life and your participation in activities that are important to you. This should take approximately 10-15 minutes. There will be a further two questionnaires that you and your [relative] would complete with my assistance, which should take around 20-30 minutes to

complete. If you require assistance due to a particular impairment, I would discuss this with you or your carer before we meet, so that I can make arrangements to assist you.

For mutual convenience, I will aim to complete all of the above questionnaires in one sitting. However, a second session can be arranged if this is not possible for any reason.

So that we can look at any changes over time, I will also be seeking your permission to access a questionnaire that was completed while you were in hospital. This would involve a member of hospital staff accessing your medical records to obtain the questionnaire, which is called the Functional Independence Measure (FIM). I will also be asking you to complete the FIM when we meet.

In total, you would be completing four questionnaires, with assistance from your [relative] on at least two of these measures. Your [relative] will be completing two additional measures by themselves.

What are the possible disadvantages and risks of taking part?
It is possible that you and/or your carer may find some of the questions distressing if they bring up some difficult memories for you. If this does happen, then you are free to skip those questions. You are also free to withdraw from the study at any time. In the event that you do feel distressed, advice will be given about where you can seek further support. Information about support services are contained at the end of this leaflet. With your permission, we might also contact your G.P. or other health professional about your support needs.

What are the possible benefits of taking part?
It is hoped that the findings from the study will help us to understand more fully the needs of people with a brain injury and their families.

What happens when the research study stops?
The information from the questionnaires will be analysed to see whether they answer the questions listed earlier (under „What is the purpose of the study?'). The results of this study will then be submitted to an academic journal. A summary of the findings will also be produced for people involved in the study. A copy will be sent to you upon completion of the study if you request this on the consent form.

What if there is a problem?
You are free to withdraw from the study at any time. In the event that you may require further sources of support, the researcher will provide you with information regarding this. If you wish to complain about the way in which the study is conducted, you should contact the academic supervisor (contact details are given below) or your local PALS service (details below).

Will my taking part in the study be kept confidential?
Yes, all information that is collected will be kept confidential. Your name and address will not be written on any of the questionnaires. Instead, your questionnaires will be identified by a code number only. Access to the questionnaires and to your consent forms will be given only to the members of the research team listed below and to personnel authorized by the University to conduct audits of research. Paperwork will be stored in locked filing cabinets,

and the data analysis on password-protected computers. No record of your name or address will be kept on computers. However, if you disclose any information that raises concerns about possible criminal activity or serious threat to someone's health and well-being, the researcher cannot ensure confidentiality and would need to discuss openly such concerns with Dr Andrew Brennan, Clinical Supervisor.

Contact Details:
If you would like any further information about the study, please do not hesitate to contact:

Laura Meader, Psychologist in Clinical Training, School of Psychology, The University of Birmingham, Edgbaston, Birmingham, B15 2TT. Telephone: or , Email:

Or

Dr Andrew Brennan, Clinical Psychologist. *[address details removed]* Telephone:

If you wish to raise any concerns about this project, please contact the academic researcher (Dr Gerry Riley) on or or by writing to Dr G. Riley, *[address details removed]*

Should you have any issues or concerns about your involvement in this research, please contact PALS (Patient Advice and Liaison Service) in your area. Telephone numbers:

There are also agencies in your area that offer a range of support to carers and people who have had a brain injury, should you require this input.

Contact details for your local branch of Headway are as follows:

There are many services provided by The Stroke Association, who have a free (national) helpline where you can find out about services in your area:

Thank you for your time,

Laura Meader (Psychologist in Clinical Training)

Dr Andrew Brennan (Clinical Psychologist)

APPENDIX 21: CONSENT FORM CARER VERSION (PHASE 2)

CONSENT FORM: CARER VERSION

Study on client recovery and family involvement in brain injury rehabilitation

Name of Researcher: Laura Meader

I confirm that I have read and understand the Participant Information Sheet dated 1st February 2011 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my relative's medical care or legal rights being affected.

I agree to take part in the above study.

Name _________________ Signature___________ Date ___________

Researcher___________ Signature ___________ Date___________

I would like to receive a summary of the results of the study when it is finished (please tick):

Yes ☐

No ☐

If you would like to receive the summary, please write your address here:

____

APPENDIX 22: CONSENT FORM CARE RECIPIENT VERSION (PHASE 2)

CONSENT FORM: RELATIVE VERSION

Study on client recovery and family involvement in brain injury rehabilitation

Name of Researcher: Laura Meader

I confirm that I have read and understand the information sheet dated 1st February 2011 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my relative's medical care or legal rights being affected.

I do / do not [please delete] give permission for an authorized member of hospital staff to consult my medical records in order to provide the researcher with information about my scores on a rating scale (called the "Functional Independence Measure") that was filled in by staff while I was still in hospital.

I agree to take part in the above study.

Name _________________ Signature___________ Date ___________

Researcher___________ Signature ___________ Date___________

I would like to receive a summary of the results of the study when it is finished (please tick):

Yes ☐

No ☐

If you would like to receive the summary, please write your address here:

____

APENDIX 23: OPT-OUT FORM (PHASE 2)

OPT-OUT FORM

Study on client recovery and family involvement in brain injury rehabilitation

Name of researcher: Laura Meader

I do not wish to take part in this study. I understand that this decision will not in any way affect my legal or medical rights. Please do not contact me about this research again.

Carer’s name _________________ Signature _________________ Date_________

Please return this form in the envelope provided.

APPENDIX 24: PHASE 2 SUPPLEMENTARY ANALYSES

Analyses of demographic and injury-related variables

No significant findings were revealed for carer age or gender, time since injury, severity of injury, or type of injury when analysed alongside carer wellbeing, expectations, and involvement. These results are illustrated in the following tables.

1. Independent t-tests

Carer gender

T-test results for carer gender with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 2 participants.

Variables analysed	df	*t*	*p*
Carer gender & Phase 2 WEMWBS total	21	1.567	.132
Carer gender & Phase 2 CEQ Consequences total	21	1.285	.213
Carer gender & Phase 2 CEQ Patient Control total	21	.174	.863
Carer gender & Phase 2 CEQ Carer Control total	21	-1.092	.287
Carer gender & Phase 2 CEQ Treatability total	21	-1.293	.210
Carer gender & Phase 2 IRQ Total	18	-.338	.739
Carer gender & FIAS Involved-Staff subscale	19	-.335	.741

Note: Results are two-tailed, equal variances assumed.

Injury severity

T-test results for ABI injury severity[a] *with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 2 participants.*

Variables analysed	df	*t*	*p*
Injury severity & Phase 2 WEMWBS total	20	.093	.927
Injury severity & Phase 2 CEQ Consequences total	20	-.469	.644
Injury severity & Phase 2 CEQ Patient Control total	20	-.777	.446
Injury severity & Phase 2 CEQ Carer Control total	20	.239	.814
Injury severity & Phase 2 CEQ Treatability total	20	1.288	.213
Injury severity & Phase 2 IRQ Total	18	1.313	.206
Injury severity & FIAS Involved-Staff subscale	18	-.050	.961

Note: Results are two-tailed, equal variances assumed.

[a] “Moderate” or “severe”, according to carers’ understanding of the severity of their relative’s ABI. More accurate information was not available, as consent from relatives was not part of the ethical approval agreement.

Type of injury

T-test results for type of injury (stroke or traumatic brain injury) with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 2 participants.

Variables analysed	df	*t*	*p*
Type of injury & Phase 2 WEMWBS total	15	1.430	.173
Type of injury & Phase 2 CEQ Consequences total	15	-1.418	.177
Type of injury & Phase 2 CEQ Patient Control total	15	-.420	.680
Type of injury & Phase 2 CEQ Carer Control total	15	-.235	.818
Type of injury & Phase 2 CEQ Treatability total	15	-1.200	.249
Type of injury & Phase 2 IRQ Total	12	-.257	.801
Type of injury & FIAS Involved-Staff subscale	14	.439	.668

Note: Results are two-tailed, equal variances assumed.

2. Spearman Correlations

Carer age

Spearman correlation results for carer age with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 2 participants.

Variables analysed	N	*rho*	*p*
Carer age & Phase 2 WEMWBS total	23	.066	.763
Carer age & Phase 2 CEQ Consequences total	23	-.119	.590
Carer age & Phase 2 CEQ Patient Control total	23	.253	.245
Carer age & Phase 2 CEQ Carer Control total	23	.057	.795
Carer age & Phase 2 CEQ Treatability total	23	.166	.449
Carer age & Phase 2 IRQ Total	20	-.082	.730
Carer age & FIAS Involved-Staff subscale	21	-.140	.544

Note: Results are two-tailed.

Time since injury

Spearman correlation results for time since ABI (range: 1-14 months) with measures of carer wellbeing, expectations, and involvement in rehabilitation, for Phase 2 participants.

Variables analysed	N	*rho*	*p*
Time since injury & Phase 2 WEMWBS total	23	.142	.519
Time since injury & Phase 2 CEQ Consequences total	23	.180	.412
Time since injury & Phase 2 CEQ Patient Control total	23	.334	.120
Time since injury & Phase 2 CEQ Carer Control total	23	.044	.844
Time since injury & Phase 2 CEQ Treatability total	23	.126	.568
Time since injury & Phase 2 IRQ Total	20	-.209	.376
Time since injury & FIAS Involved-Staff subscale	21	.078	.735

Note: Results are two-tailed.

Carer wellbeing over time

Carers' responses on the WEMWBS were analysed using a t-test to investigate differences between Phase 1 and Phase 2. There was a significant difference in participants' scores ($t(19) = -4.060$, $p = .001$, two-tailed), demonstrating that carers' reported their emotional wellbeing upon follow-up as being significantly better than that closer to the time of their relative's brain injury.

Carer involvement over time

Pearson correlations were undertaken with the FIAS Involved-Staff Totals and IRQ data to clarify the association between carers' involvement in Phases 1 and 2. Carers' IRQ totals were not correlated across the two phases, yet this just failed to reach statistical significance ($r(17) = .451$, $p = .053$, two-tailed). The staff-reported FIAS (Involved-Staff subscale) was significantly associated with carers' IRQ totals at Phase 1 ($r(18) = .453$, $p = .045$, two-tailed) and at follow-up ($r(17) = .498$, $p = .030$, two-tailed).

Correlations between IRQ at Phase 2 and outcomes for relatives with ABI

Pearson correlation results for IRQ at Phase 2 with the functional, life satisfaction, and community integration outcomes for relatives with brain injury.

Measure/subscale	**df**	***r***	***p* (2-tailed)**
LiSat-11	17	-.079	.772
Community Integration Questionnaire			
Home Integration Total (5 items)	18	.120	.613
Social Integration Total (6 items)	18	.085	.721
Productivity Total (2 items)	18	-.075	.753
Overall Total (13 items)	18	.069	.772
European Brain Injury Questionnaire			
Somatic Total (8 items)	18	.433	.057
Cognitive Total (13 items)	18	.250	.288
Motivation Total (5 items)	18	.132	.579
Impulsivity Total (13 items)	18	.220	.351
Depression Total (9 items)	18	-.104	.662
Isolation Total (4 items)	18	.260	.268
Physical Total (6 items)	18	.024	.919
Communication Total (4 items)	18	-.248	.292
Core Symptoms Total (34 items)	18	.112	.640
Overall Total (63 items)	18	.134	.574
Functional Independence Measure			
Follow-up Total	18	.353	.132