

VOLUME I
RESEARCH COMPONENT

BY
ANDREA HOUGH

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for the Degree of Clinical Psychology Doctorate

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OVERVIEW

This thesis is submitted in partial fulfillment of the requirements for the degree of Clinical Psychology Doctorate (Clin.Psy.D) at the University of Birmingham. It is comprised of a research component (Volume I) and five clinical practice reports (Volume II).

Volume 1 of the thesis consists of the research component in the form of two papers. The first paper in Volume I is a review of the literature, which examines the evidence for family involvement in acquired brain injury rehabilitation services and has been prepared for submission to Disability and Rehabilitation Journal. The second paper is an empirical study to investigate carers' expectations of recovery and their engagement in the rehabilitation process with individuals with Acquired Brain Injury. This paper has been prepared for submission to Neuropsychological Rehabilitation (see Appendix 1 for submission guidelines).

Volume II is comprised of five clinical practice reports that present work undertaken in the areas of adult mental health, older adults, child and Neurorehabilitation. The first report presents a cognitive and psychodynamic formulation of a man experiencing intrusive thoughts in an older adults mental health service. The second report describes a service evaluation to evaluate the outcome of the implementation of a recovery approach within an Older Adults Mental Health service. The third report presents a case study of cognitive-behaviour therapy with a 10 year- old girl with a fear of vomiting and anxiety. The fourth report is a single case experimental design to evaluate the use of compensatory strategies in a 35-year old man with unilateral spatial neglect as a result of acquired brain injury. An abstract for the fifth report presents a case study of a 26 year- old man with schizophrenia who experienced difficulties associated with persistent persecutory delusions. Cognitive-behavioural assessment, formulation and intervention with this client is presented.

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LITERATURE REVIEW

A REVIEW OF THE EVIDENCE TO SUPPORT THE EFFICACY OF FAMILY INVOLVEMENT IN ACQUIRED BRAIN INJURY REHABILITATION

ABSTRACT

Background: In recent years, there has been an emphasis on promoting family and carer involvement in rehabilitation services for individuals with Acquired Brain Injury. Research and government legislation advocate family involvement, and suggest that the family can help to promote recovery in their relatives. Although there is a perceived benefit of family involvement in rehabilitation, currently there is limited evidence to support the assertion that this involvement is beneficial. Furthermore, there is a need for understanding of factors that may facilitate or impede family involvement.

Content: This literature review is divided into two sections; one to evaluate research which has examined the effects of family involvement in rehabilitation activities on patient outcome. The other section reviews studies that have explored potential barriers and facilitators to family involvement. The findings of the studies are discussed and evaluated.

Conclusions: This review highlighted that there is low quality to evidence to support the assertion that family involvement can benefit their relatives and there is a need for well controlled, high quality research. The review also found evidence to support the existence of common barriers and facilitators of family involvement.

Key- words Family carers, acquired brain injury rehabilitation, involvement, patient outcome, literature review

INTRODUCTION

Recent government policy documents have called for more focus on recognising the expertise of the carer and have advocated greater involvement of the family in the rehabilitation process following acquired brain injury (ABI). The document, *Caring about Carers* (DOH, 1999) suggested that:

“helping carers is one of the best ways of helping people they are caring for”
(DOH, 1999, p6).

Furthermore, the National Carers Strategy (DOH, 2008) states that by 2018:

“carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role”
(DOH, 2008 p9).

Family involvement in acquired brain injury rehabilitation is a developing area and a number of anecdotal reports and opinion papers suggest ways that family involvement might improve the rehabilitation outcomes for patients (Tarvin, 1995). It has been suggested that families could help to determine the success of the transition phase from hospital to home and help to facilitate the carryover of rehabilitation strategies to compensate for cognitive difficulties Fleming, Shum, Strong & Lightbody, 2005; Turner et al., 2007). Involving families could also potentially reduce the length of time required in hospital and reduce costs of rehabilitation (Kalra et al., 2004). Furthermore, Evans, Matlock, Bishop, Stranahan and Pederson (1988) suggested that family involvement can help to resolve issues related to family adjustment to acquired brain injury, for example when a family member may have unrealistic expectations regarding their relatives’ recovery. Addressing expectations could therefore positively impact on the outcome of the individual with ABI (Levack, Siegart, Dean & McPherson, 2009). Importantly, Evans et al. (1988) acknowledged that the family can have a negative influence on the patients’ recovery if they are uninformed or uninvolved.

Despite these suggested benefits of family involvement, the evidence base for claiming that family involvement will improve patient outcomes in ABI remains uncertain.

Defining Family Involvement in Acquired Brain Injury Rehabilitation (ABI)

There is considerable variation in how family involvement in ABI rehabilitation is defined and described within the current research literature (Levack et al., 2009; Shaw & McMahon, 1990). Some of the ways in which families can be involved include: involvement in goal planning; acting as a co-therapist, or otherwise being involved, in therapeutic activities with the person with the ABI who is in receipt of rehabilitation; and involvement in discharge planning (Levack et al., 2009). Levack et al identified that there are few guidelines available on how clinicians should involve families in goal planning. A recent review of goal planning in the rehabilitation centres in the United Kingdom, found that carers were not always routinely involved despite national recommendations (Monaghan, Channell, McDowall & Sharma 2005).

Family Interventions

Family involvement has also been described as the provision of specific interventions to promote the skills of the carer in adopting their caring role and address their emotional adjustment (Evans et al., 1988). These could include psychosocial, educational programmes and training in rehabilitation activities. These studies of family interventions have tended to focus mainly on carer outcomes or both the carer and patient outcomes, but there appears to be a lack of studies, which have looked at the relationship between the two (i.e whether involving the family member in the intervention explicitly affects the recovery of the individual acquired brain injury).

AIM

The primary aim of this present paper is to review the research that has addressed the suggestion that family involvement in routine aspects of acquired brain injury rehabilitation leads to improvements in patient outcome. As will be seen, evidence relating to this question is very limited, therefore an additional issue will be addressed regarding suggestions/evidence about potential facilitators or obstacles to family involvement. This review is presented in two sections in order to address these two issues and relevant studies are described and evaluated below. Implications for clinical practice will then be considered in the light of these studies. For the purposes of this review, the term carer or family involvement refers to involvement or engagement in activities such as goal setting, decision-making, discharge planning and involvement as a co-therapist or receiving training in carrying out therapeutic activities with the person with ABI.

Search Strategy

A search for studies relevant to the primary aim of the study (i.e to review the evidence that family involvement improves patient outcome) was conducted using PsychINFO, Web Of Science, MEDLINE and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search terms used were (carer* or caregiver*, or family* or family member* or “spouse* or “relative* or informal carer *) and (involvement or participation or engagement or collaboration or intervention or professional-family relations) and (rehabilitation or discharge planning or goal-planning or neurorehabilitation or therapy or occupational therapy or physiotherapy or cognitive rehabilitation) and (patient or patient outcome or functional outcome). The titles, abstracts and the main text of studies were searched using these terms. The search was limited to studies published between 1988 and

2010 and written in the English language. This search generated 207 studies, which were then reviewed in relation to certain inclusion and exclusion criteria. Studies were included if they addressed family involvement and patient outcome and looked at the relationship between the two. Studies that related to a family intervention were only included if they explicitly addressed the relationship between family involvement and patient outcome. This review also excluded review papers, commentaries or opinion papers.

Using the above criteria, only three papers met the criteria for the primary review and a further six studies were identified by hand-searching the references of these papers and review papers related to the area of interest. This resulted in a total of nine studies, which include various methodologies such as a biographical report, three case studies, two single case experimental designs, a quasi-experimental design and two randomised controlled trials.

1. FAMILY INVOLVEMENT AND EFFECTS ON THE OUTCOME OF THE INDIVIDUAL WITH ABI

This section will review studies, which have investigated the effects of family involvement on the outcome of the individual with ABI within different aspects of the rehabilitation process. These include: involvement in cognitive rehabilitation with the individual, involvement in general rehabilitation and interventions designed to train the family member to carry out rehabilitation activities.

1.1 Involvement as a co-therapist in cognitive rehabilitation

A number of studies have investigated the efficacy of training relatives/significant others to deliver therapy or act as a co-therapist in acquired brain injury rehabilitation. As will be seen, various methodologies have been used to investigate this. This section will review the evidence that carer involvement in cognitive rehabilitation can facilitate the carryover of cognitive strategies and improve the outcomes/recovery of their relatives.

McKinlay and Hickox (1988) reported a multiple baselines across participants design to evaluate the role of the family as co-therapists in helping their relative to acquire strategies to manage memory difficulties or anger problems. Two clients had significant memory difficulties and two clients had anger control difficulties. These clients were randomly assigned a baseline period of 4,5,6,7 or 8 weeks. Relatives were involved in treatment sessions to prompt the client to use either memory and organisational strategies or anger control strategies. No stable baseline was obtained for anger outbursts so this not evaluated. Following an intervention period, there was a reduction in the number of memory failures recorded by the client and their relative. No changes however, were observed on neuropsychological testing with the logical memory test of the Wechsler Memory Scale (Wechsler, 1987) or the Rey Osterrieth complex figure test (Rey, 1959).

McKinlay and Hickox (1988) tentatively suggested that involving relatives in rehabilitation may have beneficial effects on the patient's outcome, however they acknowledged that this was a pilot study and it was too early to say. They described other benefits of involving families as having the opportunity to share information with professionals, which provided a clearer picture of the patient's difficulties. This was described as a multiple baselines

methodology, however the authors did not elaborate on the choice of this design. The authors acknowledge that these findings were preliminary and suggested a need for a larger evaluation study over a longer period of time. As this study had no control, it is not possible to say that the relatives had any impact on the clients' use of memory aids and strategies, therefore no firm conclusions can be drawn on the effectiveness of family involvement in this case.

Kime, Lamb and Wilson (1996) reported a case study to investigate a multi-disciplinary compensatory training programme of external cueing for memory difficulties with a 24 year old female with amnesia as a result of brain damage sustained during status epilepticus 20 months earlier. The client attended a day rehabilitation programme, which actively promoted family participation in therapies. The client and her family were taught to use external cueing techniques to remember to check a datebook and the family were involved in promoting the client's use of these. The client's outcomes were measured using scores on the Cambridge Behavioural Prospective memory test (unpublished at the time of the study) and Wechsler Memory Scale (Wechsler, 1987). During the first 21 days of the intervention, the client complied with the cues at a rate of 47.6%. After 64 days, this increased to 100% compliance with checking the datebook for 7 consecutive days. The authors found that the client continued to independently remember to check her datebook at 13 months follow-up. Evaluation with the outcome measures revealed that the client's scores improved on the Cambridge Behavioural Prospective Memory Test but not on the Wechsler Memory Scale.

The authors suggested that involving the family helped to generalise the patient's use of cueing strategies to the home environment and improve her ability to remember to use a datebook. However, this was a case study and there was no control condition. Consequently,

it is not clear that family involvement was necessary for the behaviour to become established in the home environment, or was better than alternative methods of establishing the behaviour. A more rigorous methodology would be necessary to determine the influence of family involvement, for example a single case experimental design. The evidence for the suggestion that family involvement was beneficial in improving the clients' ability to use an external memory aid in this study is therefore limited and inconclusive.

Fleming, Shum, Strong and Lightbody (2005) report the results of three case studies of individuals with traumatic brain injury (TBI) that involved family members in an 8 week compensatory training programme for prospective memory rehabilitation. The purpose of family involvement was to help the individual to generalise the use of strategies to the home and the community although this was not the main focus of the study. Only one relative fully engaged in the family aspects of the intervention, however all three participants improved on a measure of prospective memory, therefore no conclusions could be drawn that family involvement had been beneficial at all. Fleming et al concluded that including a significant other in training and practising compensatory skills, could have helped to generalise skills into the home and community for the person whose relative had been involved, however the other two participants improved without any family involvement. The methodology of this study is limited as there was no control condition that would allow one to infer an effect for family involvement. No reason is also given for why two of the families may have not participated in the study. This study is therefore speculative that family involvement could be beneficial in aiding strategy generalisation, given the right conditions and does not provide any evidence to support this assertion.

Campbell, Wilson, McCann, Kernahan and Rogers (2007) carried out a multiple baseline single case experimental design to investigate carer facilitated errorless learning in a 24-year-old male with severe memory impairment following traumatic brain injury six years previously. The client's mother was involved in the intervention and was trained to apply errorless learning techniques in order to develop the client's use of a notebook and to respond to a prompt to take the dog for a walk. The carers also received support from the Occupational Therapist. A stable baseline was established of memory failures and lack of use of a notebook. In the intervention phase, which lasted three days, forward chaining was used to prompt the client to write in his notebook. The carer recorded errors that were made and provided verbal feedback to the Occupational Therapist. The authors found that there was a significant change in notebook use between the baseline period and three months later. The post intervention phase began when the client consistently used the notebook without prompting. A second intervention phase then began in which backward chaining was used to teach the client to respond to an external prompt i.e a mobile phone bleep to remember to take the dog for a walk. Prompts were reduced until the client needed no prompts to take the dog for a walk. The client's outcome was also measured by the Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley, 1985). This is a test of prospective memory and the clients' results on this test suggested improvements in his ability to remember to do things that he needed to do.

The authors suggested that this study demonstrated the role of the carers in helping to implement errorless learning strategies, however it is not clear whether it was the carer involvement that led to the changes or whether prompting from the therapist alone would have been as beneficial. The study aimed to demonstrate that carers can take on the role of

therapist within the home environment, which could potentially reduce the cost of rehabilitation in the community and increase the ecological validity of cognitive rehabilitation. There are biases present in this study as the author was the treating clinician and this may have influenced the results. The methodology used indicated that the client improved, however it did not allow strong conclusions to be drawn about whether the involvement of the family did actually influence the outcomes of the study.

Osawa and Maeshima (2010) investigated the effectiveness of family participation in improving the outcomes of twenty patients with unilateral spatial neglect as a result of stroke. Fourteen patients did not have any family involvement and underwent rehabilitation as usual. There were no significant differences between the groups in terms of demographics and scores on the Behavioural Inattention test (Wilson, Cockburn & Halligan, 1987), physical functioning measures and other neuropsychological measures. All patients received conventional therapy, including occupational and physiotherapy, five times a week and the family participation group received extra training in the gym on transfers, mobility and gait with a family member present. To compensate for the extra training that the family group received, the patients with no family involvement were encouraged to stay out of bed and spent time in the day area and were stimulated by listening to music or talking with doctors, nurses when the family involvement group were undergoing their additional therapy. The authors compared improvement at 3 weeks and used a two-way repeated measures ANOVA to analyse the results. They found that the patients in the family participation group scored significantly better on the Behavioural Inattention Test and on measures of physical functioning, for example the Barthel Index (Mahoney & Barthel, 1965) at post assessment

than did the non-family participation group. The authors concluded that family participation led to a reduction in unilateral spatial neglect and an improvement in mobility.

The results of this study however need to be viewed with caution, as the authors did not address biases associated with non-randomised samples or provide a comprehensive critique of their study. The study appears to be a quasi-experimental design as the participants were not randomly allocated to treatment groups and it is possible that the family participation group only improved because they were actually receiving more functional training rather than family involvement being a factor. On the other hand, the control group merely spent time in the day area and therefore did not have as much opportunity for functional recovery. This study is innovative in that it did find that there were perhaps some benefits of involving family members, however this does not appear to be strong enough evidence to support their claims that the family intervention was more superior to the control condition in improving the effects of unilateral spatial neglect in functional activities.

1.2 Family involvement as a co-therapist in general rehabilitation activities

This section reviews studies that have focused on more general aspects of rehabilitation.

McCormack and Liddiard (2009) carried out a case study of community-based rehabilitation with a 25 year old man who had a severe traumatic brain injury (TBI). The rationale for this was because the family and client were resistant to in-patient rehabilitation. Over a two -year period, three separated episodes of community rehabilitation were provided and cognitive, functional and physical goals were negotiated with the client and his mother who was the main carer. At 14 weeks, the client was reported to have made improvements in memory, functional and physical skills, however no statistical evidence is reported in this study, or

details of how outcomes these were measured. The second episode of intervention was delayed for three months as the client began to display verbal aggression and loss of motivation. Throughout this period, his mother continued the implementation of rehabilitation activities alone. At three months, the client maintained his level of functioning. The authors argued that the family support during the gap in rehabilitation maintained the clients' functioning, suggesting a role for the family and efficacy of a home based rehabilitation approach. The authors stated that this approach actively involved the family who helped with goal setting and carry over between sessions.

As this was a case study, it is not possible to attribute any improvements in the clients' outcome to family involvement in this context as there was no experimental control condition and other factors could have been responsible for this. The study is also limited by the fact that no standardised measures appear to have been used to demonstrate changes in the clients' outcome. This could be interpreted as meaning that outcomes were based on the therapists' clinical opinions and observation of functional gains and reduction in memory problems. The findings may therefore have been subject to observer biases. This study does suggest a potential role for the family, however the findings are limited by the methodology used and are therefore inconclusive.

Horwitz, Horwitz, Orsini, Antoine and Hall (1988) presented a biographical report of the outcome of the first author following a road traffic accident in which she sustained a brain injury. The second author was her mother. The narratives of the individual with ABI, her family and health professionals are presented to tell the story of the client's rehabilitation journey and the development of collaboration between the family and the staff in the hospital.

The authors report that the involvement of the family in the patient's rehabilitation resulted in a shortened length of stay in hospital, improved compliance with medication and a reduced need for sedating medication. The family provided emotional support when the client was distressed which therefore helped to engage the client in therapy. The family also acted as advocates for the client and assisted with rehabilitation therapies.

Horwitz et al. suggested that family involvement led to improved outcomes for the client, however this was not evaluated against any other variables and appears to be based on the opinions of all those involved in the study. The parents who were also co-authors did account for possible factors that may have influenced their involvement such as their professional background as a therapist and attorney, which may have led to greater respect from staff and facilitated their involvement. This study provided a rich account of the perceptions and lived experience of all those involved in the rehabilitation process. Due to the methodological limitations, this study is mainly speculative and based on subjective opinions, therefore no firm conclusions can be drawn regarding the impact of family involvement on the outcome of the first author.

1.3 Interventions to train family members

Braga, Paz Junior and Ylvisaker (2005) carried out a randomised controlled trial to examine the effectiveness of family involvement in the delivery of rehabilitation to children with moderate and severe traumatic brain injury after one year of outpatient treatment. Braga et al compared direct clinician-delivered rehabilitation (conventional rehabilitation) with indirect family-supported rehabilitation (family intervention). Eighty-seven children and their parents were randomly allocated to the two groups and were similar in terms of demographic

variables. Fifteen children over the two groups dropped out over the course of the study. The authors hypothesised that parents in the experimental group could be effectively trained to carry out rehabilitation activities with support and supervision, that their competence would be unrelated to their educational level and that the children in the experimental group would have more superior outcomes in terms of cognitive and physical outcomes as measured by the SARAH scale of motor development (Sarah Network of Rehabilitation Hospitals, 1989) and WISC-III (Wechsler, 1949). The parents' fidelity to the training was assessed every three months, which revealed consistency in the delivery of rehabilitation activities. The cognitive and physical outcomes of the children in each group, were evaluated by independent assessors who were blind to the treatment condition.

Following a year of intervention, a within groups analysis revealed that all children showed improvements on cognitive and physical functioning, however only the children in the family supported group showed statistically significant improvements. A between groups statistical analysis also indicated a significant difference between the childrens' outcomes with the family intervention group indicating more improvement. The authors suggested that this demonstrated the efficacy of the family delivered treatment, however they acknowledged that there were a number of biases that may have influenced the results. The children in the experimental group may have received more input when at home than the children in the control group, which may have led to improvements rather than the actual intervention. It is also possible that the children in the experimental group improved because of other factors than family involvement, for example reduction in family stress and changes in family functioning. The authors also did not control for the area of brain injury, for example damage to different lobes. They only matched the children in terms of severity as measured by the

Glasgow Coma Scale (Teasdale & Jennett, 1974). They also acknowledged that they did not measure outcomes of childrens' behavioural and social functioning which also may have been influenced by the intervention.

Despite acknowledgement of these biases, the authors still inferred that this study demonstrated evidence for the efficacy of the intervention. The authors also acknowledged that the study was not generalisable as it took place in one setting. They suggested that a multi-centre RCT would be the next step. Nevertheless this was a reasonable quality research study, which was adequately described in order to promote its replicability. This study can be classified as level 1- (NICE 2004) due to the high risk of bias, which may have influenced the results and provides some evidence to support family involvement in rehabilitation.

Kalra et al. (2004) conducted a single blind randomised controlled trial to evaluate the effectiveness of training carers of relatives with stroke to undertake basic nursing tasks and facilitate personal care activities. Three hundred carers and patients were randomly assigned to the experimental and control group and they were assessed at 3 months following the intervention and again at 12 months. The comparison group received conventional care only, which also included family involvement in goal planning and attending meetings, although the amount of involvement was not clearly stated. The experimental group received conventional care and structured caregiver training in basic rehabilitation activities. There were no significant differences between demographic variables in the two comparison groups.

Patients' and carers' quality of life and psychological wellbeing were assessed with the Hospital and Anxiety Depression Scale (HADS) (Zigmond & Snaith, 1983) and the Visual

analogue scale of the EuroQol instrument (EuroQol Group, 1992). The patients' functional outcome was assessed using standardised measures including the Barthel index (Mahoney & Barthel, 1965) and the Frenchay Activities Index (Holbrook & Skilbeck, 1983). At 12 months' follow-up, regression analyses indicated that the patients in the caregiver-training group improved on psychosocial outcomes on mood and wellbeing, however no effect was observed on their functional outcome. The study also found support for improving carer psychosocial outcomes and reducing the cost of overall stroke rehabilitation through involvement of a family member.

The authors discuss the limitations of this study and reported that it was not possible to fully blind the assessors as to which condition the participants were in, as the families may have inadvertently disclosed whether they were receiving training. They also discuss the generalisability of the findings in that the sample was recruited from a rehabilitation unit in a predominantly middle class suburban area in the UK and so factors such as education, finances and cultural beliefs may have influenced carers' willingness to engage in rehabilitation activities. Despite these limitations, the study clearly demonstrated that caregiver involvement can have beneficial effects on the patient in terms of psychosocial outcome, however it does not support the efficacy of family training for improving patients' functional outcomes. The study was a good example of a randomised controlled trial and they used validated and objective outcome measures at pre and post assessment. It can therefore be classified as level 1- due to the high risk of biases (NICE, 2004), which may have influenced the results and a more rigorous methodology is needed in order to replicate this study.

2. TO WHAT EXTENT ARE FAMILIES INVOLVED IN ACQUIRED BRAIN INJURY REHABILITATION: A REVIEW OF THE POTENTIAL BARRIERS AND FACILITATORS.

It has been suggested that family involvement does not always happen in practice and services may only pay lipservice to this despite the recommendations in guidelines and government policies (Levack et al., 2009; Brereton & Nolan, 2002; Monaghan et al., 2005). It is therefore important to determine what factors may facilitate or prevent families' engagement or involvement in acquired brain injury rehabilitation in order for rehabilitation services to address these and improve the consistency across services. This section will discuss and evaluate eight studies, which have examined professional and family experiences and perceptions regarding the extent of family carer involvement in rehabilitation in order to identify suggestions and evidence regarding potential facilitators and obstacles to involving carers in ABI rehabilitation.

Search Strategy

These studies were selected using the search terms and criteria described earlier. As the papers were examined for their relevance to the primary aim of the review (i. e whether family involvement improves patient outcome), note was taken of studies that related to potential barriers and facilitators to family involvement. Six studies were identified and a further two were found through looking at the reference lists of the selected papers, giving a total of eight studies.

2.1 Staff and family perceptions of Family Involvement

One study aimed to examine staff and family perceptions of family involvement in order to clarify what types of involvement are preferred by families and professionals, to identify the ways that families would like to be involved and to identify areas of agreement. Shaw, Chan and Lam (1997) developed a questionnaire to measure family involvement (FIQ) in 67 family members of individuals with severe TBI who were in-patients in one of four post-acute rehabilitation facilities and 67 rehabilitation professionals. This questionnaire included four subscales, which measured information sharing, direct participation, counselling/support and empowerment. Shaw et al. (1997) found that the staff and family members differed in their opinions regarding family involvement. They agreed that information should be shared, but differed in opinions regarding family involvement in treatment planning and involvement in therapies. They also differed on views regarding education and families felt that the education given should be more specific to their relative's condition rather than more general information.

This study therefore highlighted potential barriers to family involvement based on inconsistency in staff and families' perceptions of how they should be involved. This study used an opportunistic sampling strategy and there was some attrition due to the use of a postal questionnaire method. It is therefore possible that those who valued family involvement may have been more likely to return the questionnaires. This was a pilot study to evaluate a questionnaire and it could be for this reason that the authors do not discuss the methodological limitations of the study. The strengths of this study are related to the fact that participants were from four different facilities. This therefore improves the representativeness of the results albeit within the limitations of a pilot study. This study found some important

findings regarding the variation in views of families and staff which can be used to further develop the knowledge base of potential barriers and facilitators to family involvement.

2.2 Acknowledgement of Family Carers' Expertise

Brereton and Nolan (2002) identified the relationship and communication between staff and families as a potential barrier or facilitator to family involvement. This also includes recognition of or lack of recognition of the carers' expertise and knowledge. Brereton and Nolan carried out a grounded theory qualitative study with 14 carers of relatives with stroke who were in-patients on a rehabilitation ward in the United Kingdom. The interviews were developed from the themes from the first seven interviews that they conducted. The carers expressed a wish to be more involved in their relatives' care and reported that they actively made attempts to form partnerships with health professionals in order to gain confidence and acquire skills to be able to carry out care activities with their relatives. This created a theme of "seeking activities". However they felt that these attempts were not always acknowledged or were rebuffed and some carers reported that they felt they were intruding on professional territory when they tried to get involved. The carers also expressed a need for their knowledge to be recognised and valued.

This study used a qualitative methodology and the authors fully described the process and included quotes from participants, which increased the credibility and transferability of this study. This study provided rich qualitative information regarding carers' perceptions of involvement on which further studies could be built. This study was conducted in England and so is very relevant to carers' experiences of stroke services in the UK.

2.3 Family Involvement In Rehabilitation Therapies

One study investigated physical therapists'¹ perceptions of family involvement in the rehabilitation process. Ryan et al. (1996) carried out a structured interview survey with a convenience sample of 40 physical therapists, from 35 rehabilitation facilities in eastern USA to investigate perceptions of family involvement in physiotherapy. All of the participants reported that they encouraged families to participate in therapy sessions which included observation of the treatment session, demonstration and training in exercises, written information on home exercise programme and home visits to work with family in their environment.

Ninety three percent of the participants stated that they involved families through teaching functional activities to promote the transition from hospital to home. They found that four major factors could potentially impede or facilitate family involvement. These included issues related to the family, the therapist, the healthcare organisation and the patient. In relation to the family, physical therapists identified potential barriers or facilitators such as the family members' flexibility and availability, cognitive skills, financial status, relationship with the patient and emotional state. They also saw carers' unrealistic expectations as a barrier. A potential barrier or facilitator was also the experience and confidence of the health professional in providing opportunities for involvement. More experienced physiotherapists were more likely to incorporate family involvement into their everyday practice. The healthcare organisation was also seen as a barrier for example restrictions on involvement due to visiting times and shift patterns.

¹ Physical Therapy is the American equivalent of the profession of Physiotherapy. This study was conducted in the United States

Limitations of this study include the fact that the sample appeared to be self-selecting by responding to a request for participants, and so they may have been more interested in family involvement and therefore more likely to engage families in rehabilitation. Furthermore they were all physical therapists whose opinions may have differed from other health professionals in their service. Nevertheless this was a useful way of obtaining the opinions of a large number of staff from different rehabilitation settings in America.

Galvin, Cusack and Stokes (2008) investigated the views of 75 people with stroke and 100 family/friends in Ireland. A questionnaire design was used to identify current family involvement and to ascertain whether the family/friends of the individuals with stroke would be willing to engage in training to learn how to carry out physiotherapy exercises when the person was discharged. Seventy nine percent of the individuals with acute stroke reported that their family members had not been invited to be involved in their physiotherapy sessions and 87% expressed an interest in family/friend involvement and training in carrying out physiotherapy exercises. Those individuals who did not wish their family members to be involved, reported reasons including; a perception that it was not an appropriate role for their family/friend, not feeling confident in their relatives' abilities to undertake rehabilitation activities and perceiving that family members could express unrealistic expectations during rehabilitation and put pressure on the individual. The potential barriers to family involvement therefore consisted of concerns as to the appropriateness of the involvement of their family member/friend, confidence in family/friend abilities and concerns about potential conflict in the relationship due to differences between the expectations of the person with stroke and their family members/friends' expectations of the rehabilitation process.

The family/friends of the person with stroke also completed the questionnaire survey and reported that they were not routinely involved in physiotherapy and most stated that they would like to be more involved. Barriers to involvement were identified as work commitments, lack of confidence and unsuitable therapy times. The authors also explored the views of 10 expert physiotherapists on the role of the family using a qualitative focus group methodology. The physiotherapists reported that involving families could benefit the patient through carry over of treatment. They identified factors related to the family member that could influence their involvement. These included their level of interest and motivation, their educational level and their availability. The physiotherapists did not identify any service barriers to family involvement. This study highlighted that the majority of the participants in this study perceived family involvement to be beneficial.

The findings of the study were then used to inform the development of a randomised controlled trial to evaluate the effectiveness of family delivered exercise in improving patients' lower limb function. This study has not yet been published. The authors acknowledge the strengths and limitations of the methodology and provide quotes from the focus groups to enhance the transferability of the study. The study also used a mixed qualitative and quantitative methodology in order to obtain a large sample of family members and people with stroke, however the authors acknowledge that this made it difficult to compare the opinions of the three types of participants. Nevertheless this study provided some evidence to support the existence of barriers and facilitators to family involvement and identified the potential for a randomised controlled trial to test the efficacy of this.

2.4 Family Involvement in Goal Planning

According to Levack, Dean, Siegert & McPherson (2009), involving family members in decision-making processes such as goal planning can make the family more willing to engage in the rehabilitation process. Reasons for this include helping to identify expectations regarding the outcome for the patient, helping with transfer of knowledge and skills from hospital to home (Levack et al., 2009). Levack et al. (2009) investigated the beliefs and experiences of nine health professionals regarding family involvement in goal planning in acquired brain injury using a grounded theory qualitative approach. The authors justify the use of this approach in order to explore an area where relatively little is known and new perspectives are sought. In this study, clinicians described the family as being an integral part of the goal planning process and they saw family involvement as providing an opportunity to educate families about rehabilitation principles. They also identified that early discussion of goals could help to prevent conflict from arising at the stage of discharge and to aid the development of realistic expectations of recovery and emotional adjustment.

Barriers to family involvement included when family members had their own agendas and their expectations were unrealistic. Clinicians therefore felt they had to limit family involvement, or avoid engaging with the family at all to protect the patient. Levack et al. (2009) concluded that this study found that clinicians were more oriented to addressing the needs of patients rather than the family. This qualitative study provided a valuable insight into potential factors that may prevent or facilitate family involvement such as unrealistic expectations and conflict between staff and families when they do not agree on treatment, which then leads to avoidance. The authors also acknowledge the methodological limitations of the study. This study was perhaps limited as it only focused on the perspectives of staff and

it would have been interesting to look at staff and family perceptions of experiences of involvement in goal planning.

Lefebvre, Pelchat, Swaine, Gelinas and Levert (2005) carried out a qualitative study to explore the views of eight individuals with ABI, eight families, nine physicians and twenty two health professionals regarding their perspectives of the care provided from the acute critical care stage to the rehabilitation phase. Families reported that information sharing was dependent on the phase of care and lack of information led to uncertainty. Family members also reported that they did not feel supported in their uncertainty, which affected their relationship with staff. Furthermore, relations with family and staff were compromised and more negative when families felt that their expertise and knowledge of their relative, was not recognised or ignored by staff. Positive relations on the other hand were fostered when carers' expertise was acknowledged and they were given opportunities to share information.

The professionals in this study endorsed this view that conflict between staff and families can occur when there is a perceived lack of communication. Physicians and professionals reported several barriers to positive relations such as conflicting family dynamics, differences in values and opinions and families' high expectations regarding the recovery of the individual with ABI. Professionals and physicians also varied in their views on the family involvement in decision making and most felt that family members did not have the skills to be seen as an integral member of the care team.

The individuals with ABI also expressed a need to be included in the care process and to have their views acknowledged. Lefebvre et al. (2005) identified that relations with staff could be

improved if the individuals with ABI were informed and involved in decision-making. The authors however did not explicitly explore the perspectives of the individuals with ABI regarding the involvement of their family members in their rehabilitation. The authors concluded that this qualitative study identified a need to include families and individuals with ABI in the care process, however there is a need to address the barriers before this could be fully achieved. Lefebvre et al suggested that these findings highlight a need to educate professionals and development of confidence in liaising with relatives.

This study explored the perceptions of family members and staff involved in rehabilitation regarding family involvement, however did not obtain the perspectives of individuals this area. Despite this limitation, this study is a useful and informative study regarding potential barriers and facilitators to family involvement in acquired brain injury rehabilitation. The authors acknowledge the limitations of the study in terms of generalisability and the potential biases of the professionals who may not have been fully open about their experiences and practice of family involvement.

Doig, Fleming, Cornwell and Kuipers (2009) explored the perspectives of 12 people with traumatic brain injury (TBI) and their relatives regarding their involvement in occupational therapy goal planning in the community. Three Occupational Therapists were also interviewed regarding their perspectives on goal setting. The authors found that the family members generally wanted to be involved in goal setting and rehabilitation with their relative and some acknowledged the role of the family as a support to the person with TBI and as a source of knowledge that could assist with the goal planning process. Other family members recognised, however that their involvement in initial goal planning could be a challenge due

to limited knowledge and uncertainty regarding the types of difficulties that their relatives would experience following TBI. Some of the clients with TBI agreed that it was helpful to have their relatives involved in their rehabilitation as they could provide additional information on improvements and progress in goal achievement. One client with TBI, however, reported that his mother did not really know what he found difficult. This suggested that family involvement could be potentially unhelpful to the person with TBI. The three Occupational Therapists reported that the goal planning process could provide clarity of goals for both the individual and the family member, however the authors did not explicitly explore the therapists' perspective regarding the potential benefits of family involvement in goal setting.

The authors concluded that this study identified that family members and individuals felt that family involvement was positive for goal planning and that they should be included in the process. This study did not identify any barriers as such to family involvement and did not gain the Occupational Therapists' perspectives of family involvement, but did however suggest that a potential barrier could be when an individual does not want their relative to be involved in their rehabilitation or perceives that their relative does not have the knowledge to assist. The generalisability of this study is limited due to a small sample size and participants were from the same site, however the perspectives of family members and individuals with TBI on the benefits of involvement were obtained.

2.5 Family Involvement in Discharge Planning

Almborg, Ulander, Thulin and Berg (2009) carried out a cross-sectional study of 152 relatives of acute stroke patients who were admitted to a stroke unit in Sweden over a period of two years. A questionnaire methodology was used to investigate relatives' perceptions of their participation in discharge planning and to identify factors that correlate with perceived participation. The authors defined perceived participation in discharge planning as 'receiving sufficient information regarding stroke, care, medication, rehabilitation and support, and as participation in discussions on care, goals and treatment'. Relatives' perceptions were measured using the 'Relative's Questionnaire about Participation in Discharge Planning' which had reasonable internal consistency and construct validity. A visual analogue scale was also used to measure relatives' overall rating of perceived participation in rehabilitation and the Barthel Index (Mahoney & Barthel, 1965) was used as a measure of patient outcome. Relatives were interviewed two to three weeks after discharge. 80% of relatives reported that they did not participate in discussions related to planning and goals of their relatives' care and treatment. The interviews were conducted by the first author. Using multiple regression, the authors found that a longer length of stay in hospital and a higher education level of the patient was positively associated with relatives' higher perceived participation on all scales of the questionnaire. The authors also suggested that some of the relatives may not have wanted to be involved or were not invited. The relatives were also dissatisfied with the amount of participation in discussions regarding goal setting.

The findings suggest that relatives and health professionals may have different expectations regarding goal setting. The findings of the study highlighted a need to develop more effective discharge planning procedures to include provision of information so that they can be more

involved in the rehabilitation process. The authors suggested that services may lack effective practice for involving families. This study was of a reasonable quality and identified a way of quantitatively measuring carers' perceptions of family involvement in discharge planning in order to identify and address barriers.

3. DISCUSSION

3.1 Family Involvement and Patient Outcome

The literature reviewed since 1988 has demonstrated that there is limited evidence to support the assertion that involving the family in rehabilitation activities and therapy sessions can lead to beneficial outcomes. The findings from the biographical report, case studies and single case designs were inconclusive, as they did not explicitly control for other factors, which may have influenced the improvement of clients' difficulties. An additional limitation was that the amount of family involvement was not always quantified. Only two studies were of level 1-evidence with risk of bias (Braga et al., 2005; Kalra et al., 2004). Furthermore, only Braga et al.'s study reported the measurement of family/carers fidelity with the rehabilitation protocols so it is not clear whether the family interventions in the other studies may have been diluted over time.

The case studies and single case designs were generally carried out by clinicians who were involved in rehabilitation with the patient and families and so the methodologies used perhaps were more feasible in everyday practice. Research in healthcare settings can be constrained by service limitations, funding and ethical issues that make it difficult to carry out well-designed rigorous studies whilst also engaging in clinical work as a full time health professional.

Nevertheless, the ideas from the case studies and single case designs although inconclusive, do

provide scope for further more rigorous methodologies and demonstrated that families can be involved in a myriad of ways.

It is also difficult to make comparisons between the studies due to differences in methodologies, age of the person with ABI and variations in stages of rehabilitation, client group and the social and cultural context. Comparing family involvement in adult and children's rehabilitation services is not possible given the fact that parents have the right to be involved whereas adults have the right to decline family involvement.

This review highlighted the fact that only studies could be found that included family involvement in non-routine aspects of rehabilitation and may not actually be part of routine rehabilitation practices. Government policies and NHS guidelines state that carers should be involved in goal planning and decision making activities, however there appears to be a lack of studies which have actually examined the effects of family involvement in terms of benefits to patients with acquired brain injury. A pertinent question that needs to be addressed is why there is such a limited range of high quality studies in this area. One possible answer may be that it is difficult and ethically questionable to carry out a randomised controlled trial to compare lack of family involvement with family involvement. The studies, which have addressed this, have compared treatments as usual which will inherently involve some form of family involvement with an enhanced form including training (e.g. Kalra et al., 2005; Braga et al., 2005). In conclusion, the limited research evidence in this area indicates a need for more high quality studies that are methodologically rigorous, generalisable, use valid outcome measures and that are replicable to gain further understanding of how family involvement may affect outcome.

3.2. Barriers and facilitators to family involvement

This review found evidence to support the existence of a number of barriers, principally related to characteristics of the family member/carer, for example their cognitive ability and motivation. There were also organisational barriers to family involvement for example access and opportunities to be involved in rehabilitation. Barriers identified also included attitudes of staff, their experience and their openness to forming partnerships with family members.

Barriers to family involvement were also identified from the perspectives of individuals with ABI. These included a suggestion that family involvement may be potentially unhelpful due to the family member's lack of knowledge.

Individuals with ABI also expressed limited confidence in the abilities of their family members to undertake rehabilitation and a view that involvement in some rehabilitation activities may not be an appropriate role for the family member and could affect their relationship. An important barrier was also related to potential differences between family members' and patients' expectations during the rehabilitation process. These factors were consistently found in all the studies reviewed which suggest they are a common concern for all parties involved in the rehabilitation process worldwide. All the studies reviewed indicated that families did want to be involved in their relatives' care however they often felt that they were not provided with opportunities to do so. The professionals in the studies also acknowledged the importance of involvement although there was considerable variation in how this was practised in reality. Individuals with acquired brain injury also acknowledged the benefits of family involvement.

Relations between staff and families were seen as a significant barrier to family involvement as families felt that their expertise went unrecognised and that their opinions were not always heard. This could lead to conflict, which led to staff avoiding the family. Other barriers included service limitations such as the timing of therapy sessions, which did not fit with the working patterns of the family, their other commitments and the workload of the staff. Professionals also viewed their training and experience of working with families as factors that could influence family involvement. This included confidence in their clinical role and knowledge.

The majority of these studies adopted a qualitative methodology which is a useful method for exploring an area where little is known, however the types of qualitative methodologies were variable and the process not always fully described, therefore this limited the credibility and transferability of the studies. Furthermore the perspectives of all parties regarding family involvement were not always sought. These limitations make it difficult to compare the findings of the studies although similar themes were apparent. Also, as the studies were carried out worldwide, there could be barriers that are specific to that healthcare context, for example, funding and local service policies on family involvement. The literature suggests that addressing such barriers could facilitate family involvement and improve patient and carer outcomes, however no correlational or intervention studies have been carried out which have looked at whether specific barriers do actually impede or prevent family involvement.

4. IMPLICATIONS

This review has highlighted that there is some evidence, albeit limited, regarding the effectiveness of family involvement in improving the outcomes of their relatives. There is a need for more high quality research to prove its effectiveness and to ensure that family involvement is seen as important by all parties and incorporated into routine care. The review of barriers and facilitators has highlighted a need for services to address staff and organisational barriers. There is a need for training and education to change attitudes and practice in working with families and accountability for ensuring family involvement in routine aspects of rehabilitation. Barriers to carer involvement could also focus on addressing the needs of families, who may feel that they lack the skills to make a meaningful contribution, which could therefore limit their engagement and involvement in their relative's rehabilitation.

5. FUTURE RESEARCH

It appears that the current status of family involvement is perhaps influenced by the lack of an evidence base to support it and the existence of barriers. There is a need for more rigorous, high quality research using validated measures and well designed qualitative and quantitative methods to increase the evidence base for family involvement and its effects on their relatives' recovery. There is also a need for more high quality research to understand more about barriers to involvement. This knowledge could positively influence the future involvement of families in acquired brain injury rehabilitation and have positive effects on all parties involved. Furthermore there appears to be a gap in the literature that looks at when family involvement may not be so helpful, for example when there are relationship difficulties

within families. This would provide a broader understanding of the factors that promote the efficacy of family involvement.

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EMPIRICAL PAPER

**AN INVESTIGATION OF CARERS' EXPECTATIONS
OF RECOVERY AND PROGRESS IN THEIR RELATIVES
WITH AN ACQUIRED BRAIN INJURY**

ABSTRACT

Background: Little is known about the factors that may influence the psychological wellbeing of family carers of individuals with Acquired Brain injury (ABI) and their engagement in the rehabilitation process. Carers' illness perceptions and expectations of recovery may be a potential factor.

Aims: This study aimed to investigate whether carers' expectations of recovery in their relatives are associated with their emotional wellbeing and involvement/ engagement in the rehabilitation process.

Method: A measure of carers' expectations of recovery and a self report measure on involvement in rehabilitation were developed and evaluated in a pilot study. The revised questionnaires were administered to 42 family carers of relatives with ABI along with measures of emotional wellbeing and staff perceptions of engagement/involvement in rehabilitation.

Results: Carers with more pessimistic expectations of recovery had lower levels of wellbeing and were less engaged in rehabilitation. No association was found between measures of emotional distress and expectations or engagement in the rehabilitation process. A tentative model of a relationship between carers' expectations, psychological wellbeing and engagement is suggested.

INTRODUCTION

The role of the family Carer in Acquired Brain Injury Rehabilitation

The role of the family carer in supporting individuals with acquired brain injury is gaining increasing recognition within health and social care policy in the United Kingdom. These policies acknowledge the impact that acquired brain injury can have upon the carer in terms of emotional distress and advocate the early detection of carers' needs and involvement in the rehabilitation process. This is also reflected within the Long-term (Neurological) Conditions National Service Framework (Department of Health, DOH, 2005) and the National Clinical Guidelines for Rehabilitation following Acquired Brain Injury (British Society of Rehabilitation Medicine, 2003). These documents call for rehabilitation services to include carers as partners and support them in carrying out the caring role. Emphasis is placed on involving carers in planning and decision making activities in relation to their relative's care. (DOH, 2005; British Society of Rehabilitation Medicine, 2003).

Acquired Brain Injury (ABI)

Acquired brain injury (ABI) refers to a brain injury that has occurred as a result of traumatic brain injury (closed or open), vascular accident (stroke or subarachnoid haemorrhage), cerebral anoxia or infection, for example encephalitis (British Society of Rehabilitation Medicine, 2003). Individuals can experience cognitive, emotional and physical difficulties following ABI, and rehabilitation is focused on helping the individual to regain skills or to learn compensatory strategies to facilitate independent living and quality of life (Ponsford, 1999).

The Psychological impact of caring for someone with an Acquired Brain Injury

ABI occurs suddenly and family members may have little time to prepare or adjust to the role of carer and can be left in a state of shock, uncertainty and distress (Oddy & Herbert, 2003; Man, 2002). The impact of ABI can therefore dramatically alter the trajectory and expectations of life for carers and their relatives (Ruston, 2007) as well as change family relationships (Lezak, 1986). This could potentially affect carers' wellbeing and research with carers has shown consistent findings that they are at risk of experiencing high levels of stress, anxiety and depression (Stebbins & Pakenham, 2001; Riley 2007). The emotional wellbeing of carers has also been found to be associated with the level of difficulties that the person with ABI has. Anderson, Parmenter and Mok (2002) found that spouse/caregivers who reported high levels of behavioural, communication and social problems in their partners, experienced higher levels of psychological distress. More recently, Kreutzer et al. (2009) found distress in carers was associated with poorer functional outcomes in their relatives.

Reviews based on clinical experience, however, have highlighted that not all carers experience stress and depression, (Oddy & Herbert, 2003), and there is some variation in how carers cope with and adjust to their relative's condition (Weinman, Heijmans, & Figueiras, 2003). Some carers have actually reported positive experiences of caring and maintain their psychological well-being (Oddy & Herbert, 2003). Relatively little is known about what factors may be responsible for these differences in carers' adjustment and wellbeing, as research in this area has tended to focus predominantly on negative aspects of care-giving, including subjective burden and distress (Perlesz, Kinsella & Crowe, 1999). Perlesz et al. (1999) recommended a need to gain understanding of factors that may promote the resilience

of families and their ability to work towards positive outcomes with their relatives. This could explain why some carers adjust better than others.

Carers' Engagement and Involvement in Rehabilitation

It has been suggested that engaging family carers in acquired brain injury rehabilitation can potentially lead to positive outcomes for family carers (Levack, Siegert, Dean & McPherson 2009). Levack et al. suggested that involving families in rehabilitation activities for example goal planning, could help rehabilitation staff to identify any unrealistic expectations of recovery, which may contribute to emotional distress when these expectations are not met. It is likely that this emotional distress could potentially have a negative impact on the carers' ability and motivation to become involved in their relative's rehabilitation. (Kreutzer, Gervasio & Camplair, 1994).

There is also some evidence to support the assertion that rehabilitation can have a positive impact on the recovery of the individual with ABI (Braga, da Paz Junior & Ylvisaker, 2005), however the evidence base for the efficacy of family involvement is considerably limited by studies that lack methodological rigour². Furthermore, the development of the evidence base has perhaps been constrained by the lack of tools in existence, that allow the measurement of the construct of family involvement (McNeil, Schuyler & Ezrachi, 1997).

Illness perceptions and Expectations of Recovery

Carers' illness perceptions of ABI and expectations about the future progress and recovery of their relatives are potential factors that may play a key role in influencing the emotional reactions and psychological adjustment of carers, and their engagement in rehabilitation. It

² A literature review conducted by the author of the present study, identified a lack of methodologically sound studies in this area.

has been suggested that carers develop unrealistic optimistic or pessimistic expectations about their family member's recovery, which may fluctuate over time (Ruston, 2007). Stein, Shafquat, Doherty, Frates and Furie (2003) investigated family members' knowledge of stroke and expectations of recovery and found that 60% of carers overestimated the functional abilities of their relatives when making predictions of recovery. It is possible that such expectations of outcome, could be driven by the carers' cognitive representation or illness perceptions of their relatives' condition, to help them to make sense of their situation (Leventhal, Brissette & Leventhal, 2003).

The Self- Regulation Model Of Illness Perceptions

In this section, the concept of illness perceptions is explained, and research relating them to coping, distress, well-being and engagement with treatment is described. Leventhal's self-regulation or common sense model of illness perceptions /representations (SRM), suggests that individuals form cognitive and emotional representations of a health condition from prior information and cultural knowledge of the condition, and information gained from health providers (Leventhal, Brissette & Leventhal, 2003) and current experience with the illness (Hagger & Orbell, 2003).

The self regulation model defines illness perceptions as consisting of five dimensions. These include, illness identity (beliefs about symptoms or diagnosis), cause (beliefs related to factors implicated in aetiology of the condition), consequences (beliefs related to the effects on physical, social and psychological well-being), control and cure (beliefs about how much the person can control the condition and beliefs about how much treatment can control the health threat) and timeline (beliefs related to the expected duration and/or cyclical nature of

the condition) (Leventhal et al. 2003). The Illness Perceptions Questionnaire (IPQ), was developed by Weinman, Petrie, Moss-Morris and Horne (1996) to measure these dimensions of the self regulation model. The IPQ was revised by Moss- Morris et al in 2002.

Illness representations have been shown to influence the individual's use of coping strategies and emotional adjustment (Broadbent, Ellis, Thomas, Gamble & Petrie, 2009). A recent meta-analysis found a strong negative correlation between the five dimensions of the SRM model and psychological wellbeing in twenty illness conditions (Hagger & Orbell, 2003). Illness perceptions have also been linked with engagement in treatment. Cooper, Lloyd, Weinman and Jackson (1999) studied factors that influence attendance at cardiac rehabilitation appointments and found non-attenders were less likely to believe that their condition was controllable than those who were involved in rehabilitation.

Illness perceptions of carers

Acquired brain injury has effects on all members of the family, particularly those who provide care for their relative (Lezak, 1986). Weinman, Heijmans and Figueiras (2003) suggested that family carers vary in how they may respond to the needs of their relatives, for example, some carers may be indifferent, avoidant or critical, whereas others may be involved and supportive. Weinman et al. suggested that this variation could be due to the relationship between family members, prior to the illness, or could in fact be influenced by the carers' perceptions of their relatives' illness. Such illness perceptions could also influence the psychological wellbeing of the carer as well as the patient (Weinman, Heijmans & Figueiras, 2003). Research applying the self-regulation model to carers is now gaining momentum and there are studies, which have explored the illness perceptions of spouses of individuals with

myocardial infarction (Figuieras & Weinman, 2003) and rheumatoid arthritis (Sterba & DeVellis, 2009) and relatives of individuals with schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001; Fortune, Smith & Garvey, 2005).

No published studies of the investigation of carers' illness perceptions in acquired brain injury are currently available within the research literature and only one study has investigated the illness perceptions of individuals with mild head injury in influencing post-concussional syndrome (Whittaker, Kemp & House, 2007). The original version of the Illness Perception Questionnaire by Weinman, Petrie and Moss-Morris (1996), was modified by Barrowclough, Lobban, Hatton and Quinn (2001). The purpose of this modification was to produce a carer version of the IPQ in order to explore the illness perceptions of carers of relatives with schizophrenia (IPQ-SCV). In this study, Barrowclough et al. found associations between different components of illness perceptions and distress in carers and expressed emotion within the family. The authors demonstrated the clinical utility of the IPQ with carers and suggested that gaining understanding of their perceptions and evaluations of the illness experience will help to guide appropriate intervention procedures if they experience any difficulties. Fortune, Smith and Garvey (2005) also used the IPQ-SCV and found a relationship between carers' distress and strong beliefs in chronicity, illness identity, severity of consequences and weaker beliefs in treatment control.

The revised version of the IPQ (IPQ-R) was recently adapted to investigate the illness perceptions of husbands of wives who had rheumatoid arthritis (Sterba & DeVellis, 2009). Evidence was found to support an association between illness perceptions and wellbeing. The

husbands who had more pessimistic beliefs regarding the consequences of the condition showed higher levels of negative affect.

The current research on carers' illness perceptions in conditions such as psychosis, rheumatoid arthritis and myocardial infarction, has looked predominantly at the association between illness perceptions and carer wellbeing. There appears to be a lack of research studies that look specifically at the influence of carers' illness perceptions on their involvement in treatment/rehabilitation, however there have been studies on interventions in spouses of individuals with myocardial infarction (Weinman, Petrie, Sharpe & Walker, 2000) which have addressed their illness perceptions. The findings of these studies suggest that the level of support provided by carers may be influenced by their perception of their relatives' illness or condition (Weinman et al., 2000). For example if the carer believes their relative has little control over their condition, they may try to help by providing higher levels of support and assistance. Benyamini, Medalion and Garfinkel (2007) found that spouses who had more pessimistic illness perceptions were also found to provide more support to their relatives with heart disease.

The majority of research studies, which have utilised Leventhal's self-regulation model, have focused on the perceptions of the current impact and characteristics of the illness or condition. However, the emotional status of carers and their willingness to engage in treatment or rehabilitation may also depend on their beliefs about the future impact and characteristics of the illness or condition. Carers' expectations of recovery, whether optimistic or pessimistic, may influence their emotional well-being and their level of engagement within the rehabilitation process. Those with more pessimistic expectations (i.e. who expect that the

consequences will more severe; that the timeline will be chronic; that the condition is not treatable; and that they have little control over the outcome) may experience lower emotional well-being as a result; and may be less willing or motivated to engage in the treatment or rehabilitation process. Some support for these ideas comes from a study by Bellamy (2008). This was a qualitative study involving five people who expected to be the primary carer for a family member with an ABI who was, at the time, still an in-patient on a post-acute rehabilitation unit. The study explored the expectations of the participants about their relative's future recovery. Bellamy (2008) reported that most of the participants had very positive expectations and were highly engaged in the rehabilitation process; however one participant who had more negative expectations, experienced low mood and was less engaged in the rehabilitation process.

This review has presented the research evidence that supports the links between carers' perceptions of a condition/illness and their emotional adjustment. There is also evidence to suggest that illness perceptions may influence adherence/engagement with treatment for the individual with the condition, however little is known about the links between carers' illness perceptions and engagement/involvement in the rehabilitation process in ABI. There is therefore a need for greater understanding of and research into the factors that influence carers' emotional well-being and engagement in rehabilitation. Understanding more about these factors could assist services to recognise carers' needs at an early stage and provide effective support in order to improve outcomes for both the carer and the individual with an acquired brain injury.

The present study

The present study aimed to explore the links between carers' expectations of recovery and progress in their relatives, their psychological wellbeing and their engagement in rehabilitation using a quantitative approach and through the application of Leventhal's self-regulation model. The first phase of the research involved the development and evaluation of a questionnaire to measure family carers' expectations about the future impact and characteristics of brain injury. The questionnaire was based on the Illness Perceptions Questionnaire for family carers of relatives with schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001) and was modified to be appropriate to acquired brain injury. This first phase also involved the development and evaluation of a self-report measure of carers' engagement in the rehabilitation process. The second phase of the research involved administering these questionnaires to a sample of family carers in the earlier stages of their relative's recovery from an acquired brain injury, along with other measures of their engagement in rehabilitation and of their emotional status. It was hypothesised that those with more pessimistic expectations would have lower levels of emotional well-being, and would be less engaged in the rehabilitation process.

METHODOLOGY

Phase One- Development of the Questionnaires

Phase one of this study aimed to develop and evaluate a quantitative measure of carers' expectations and beliefs regarding the future progress and recovery of their relatives with an acquired brain injury (i.e. expectations of the consequences for the patient, the carers and the family; carers and patients control, expectations of treatment and the timeline of the condition). A further aim was to develop a measure of carers' perceptions of their involvement in rehabilitation. This phase of the study was necessary because of the lack of existing tools in the research literature.

Questionnaires

Carer Expectations Questionnaire (CEQ)

The initial version of the carer expectations questionnaire (CEQ) was developed from the Illness Perception Questionnaire for carers of individuals with schizophrenia (IPQ-SCV) (Barrowclough, Lobban, Hatton & Quinn, 2001). According to French and Weinman (2008) the IPQ should be adapted for use with a particular population and it had been modified in a study by Barrowclough et al. (2001) to investigate the illness perceptions of carers. During the initial conceptualisation of the present study, the IPQ-SCV was the only published adaptation of the original IPQ that was available. Other studies by Weinman et al. (2000) had looked at the illness perceptions of spouses of individuals with myocardial infarction but had not actually published an adapted version of the IPQ for family members. A modified version of the IPQ for spouses of individuals with Rheumatoid Arthritis (Sterber & DeVellis, 2009) was recently published but was not available during the initial stage of the present study.

Barrowclough et al. (2001) modified the original IPQ by removing the cause scale, which refers to perceptions regarding the aetiology of the illness or condition as they felt that this was not relevant to the condition (see Appendix 7). The authors also replaced the identity scale, which refers to physical symptoms, with the Family Questionnaire (FQ; Barrowclough & Parle, 1997), which assesses the carers' perception of the frequency of symptoms of schizophrenia. The IPQ-SCV comprised of 23 items, which were incorporated into the remaining original IPQ scales of timeline, consequences, control/cure. Additional scales were included to capture the episodic nature of schizophrenia and to provide a measure of the consequences for the carer and their perceptions of control over the condition and treatment (control/cure).

In the present study, version one of the CEQ included all items from the six scales of the IPQ-SCV (see Appendix 8). In line with Barrowclough et al.'s (2001) modification of the IPQ, it was also viewed as not appropriate to include the cause and identity scale from the original IPQ in the present study due to the nature of ABI. In light of the suggestion that the IPQ can be adapted to suit the needs of the population being studied (French & Weinman, 2008) the questions on the CEQ were re-worded to refer to "condition" rather than "illness" in order to be more relevant to the ABI population. Furthermore, the tense of the questions was changed so that "their illness is serious" became "their condition will be serious" so that they would be interpreted as future-related questions. Additional questions were then included in the scale, which related to expectations regarding the future impact of ABI and recovery of their relatives' condition. These questions were considered to be more specific to a population with ABI and the process of rehabilitation in this setting. Two Psychologists with experience of working with carers in ABI rehabilitation generated the additional questions. The researcher

and a Masters of Research student were also involved in this. Potential questions for the CEQ were then shown to a sample of five carers in a series of individual interviews with carers, whose relatives were currently in-patients on a post acute neuro-rehabilitation ward. This was part of an earlier project by another researcher³. The carers were asked to provide an opinion regarding the items in terms of the relevance of the items to their situation and to identify any ambiguous items.

Version One of the CEQ (see Appendix 8)

Version one of the CEQ consisted of 68 questions, which included the 23 items from the IPQ-SCV and additional items more specific to acquired brain injury. On each item of the CEQ, respondents were asked to indicate the extent to which they agreed or disagreed with a statement on a 5-point scale (*1 = Strongly Disagree, 2 = Disagree, 3 = Don't Know, 4 = Agree, 5 = Strongly Agree*). The items, which referred to positive expectations, were reverse-scored so that high scores on the CEQ would indicate more pessimistic expectations of recovery. Previous studies using the IPQ with carers have followed the scoring guidelines for the original IPQ (Weinman et al., 1996) and have looked at the subscales separately so that high scores indicate severe consequences, chronic timeline and strong belief in controllability. Other studies have totalled these items to provide an overall score. As the present study was concerned with investigating overall negative expectations, it was considered to be more appropriate to use the total score on the questionnaire in the analysis.

³ The pilot study to test the face validity of the items and posting of the web based questionnaire was carried out by a researcher who was undertaking a Masters in Research at the University of Birmingham. Her role also involved assisting with the construction of items for the two questionnaires.

Involvement in Rehabilitation Questionnaire

A self-report measure of carers' perceptions of involvement in ABI rehabilitation was also developed, as no such measure was available in the research literature. The same procedure was followed as in the development of the CEQ. This produced an initial questionnaire of 12 items. On each item of the IRQ, respondents were asked to indicate the extent to which they agreed or disagreed with a statement on a 5-point scale

(1 = *Strongly Disagree*, 2 = *Disagree*, 3 = *Don't Know*, 4 = *Agree*, 5 = *Strongly Agree*). The main score used for analysis was the total sum of the items. Higher scores indicated perceptions of high involvement and engagement in the rehabilitation process (see Appendix 11).

Procedure

Ethical Approval (see Appendix 2)

Ethical Approval was sought from the NHS Ethics committee and conditional approval was granted to allow the execution of the pilot phase of study that aimed to develop and evaluate a measure of carers' expectations of recovery and a measure of carers' perceptions of their involvement in rehabilitation.

The two questionnaires were posted onto an internet-based survey site⁴ and access to this site was gained via links from the Brain Injury Association of Canada website and the Headway National website in the United Kingdom.⁵ Information regarding the nature and purpose of the research study was displayed on the host sites together with a link to the questionnaire. No approaches in any form were made to any individual requesting their participation. When the links were activated to the survey site, visitors were provided with further details regarding

⁴ This was completed by a researcher undertaking a Masters of Research project at the University of Birmingham

⁵ The researchers' clinical supervisor made contact with the associations responsible for the website.

the study and information regarding relevant organisations that could be contacted if support was required. Visitors were asked to verify that they had a family member with an acquired brain injury within the last 12 months, and that they provided (or expected to provide) a significant amount of care and support for that person. Those who did not fulfill these criteria were asked not to complete the questionnaire. Visitors were also asked to provide demographic information.

Participants

During a five-month period, there were 62 visitors to the website, however not all participants completed every item on the questionnaires. Each reliability analysis for the subscales of the CEQ and IRQ automatically omitted the missing data (see Table 1 and 2). The participants indicated that they were family members who expected to be or were primary caregivers of clients with an acquired brain injury. Some data were also missing from the demographic items, however the participants were still included in the study if they had completed the CEQ and IRQ. This may have been due to a wish to remain anonymous.

Table 1: Demographic Data of Visitors to the website

Demographic Variable	Total (%)
<i>Gender</i>	
Male	14 (23)
Female	34 (54)
Missing data (N)	14 (23)
Mean age in years (SD)	41.5 (SD = 12.73)
<i>Relationship to Patient</i>	
Mother	16 (25.8)
Father	1 (1.6)
Husband	6 (9.7)
Wife	8 (12.9)
Partner	3 (4.8)
Son	6 (9.7)
Daughter	2 (3.2)
Other inc sister, brother	7 (11.3)
Missing data	13 (21)
<i>Employment Status</i>	
Employed	30 (48.4)
Not employed	19 (30.6)
Missing data	13 (21)
<i>Ethnic Origin (%)</i>	
White	47 (75.8)
Asian	1 (1.6)
Other	1 (1.6)

Table 2: Demographic details of the relative with ABI

Demographic Variable	N (%)
Gender	
Male	14 (23)
Female	34 (23)
Missing (N)	14 (21)
Mean age in Years (SD)	40 (SD = 18.14)
Missing	15
<i>Patient Status</i>	
In-patient	24 (39.3)
Outpatient	37 (60.7)
Missing (N)	1
<i>Type of Brain Injury</i>	
Traumatic Brain Injury	29 (46)
Stroke	7 (11.5)
Other	12 (19.7)
Missing (N)	14 (21.3)
<i>Mean Time since brain injury</i> (months)	6.25 (4.235)
Missing (N)	14

RESULTS

The data was analysed using SPSS Version 17.0 and a reliability analysis was carried out.

Psychometric properties of the Questionnaires

Carer Expectations Questionnaire (CEQ)

The aim was to produce a questionnaire of reasonable length (by having a maximum of 5 items for each subscale), discriminative power and internal consistency (at least 0.7, Kline, 2000). Cronbach's alpha for each subscale was calculated, together with the correlations between each item and the subscale total. Items, which had low or negative item-total correlations were removed. So, too, were questions that lacked discriminative power (i.e. statements with which few, if any, participants agreed or disagreed). Of the items that remained, those 5 items that correlated most highly with the total were retained. For the

control-carer subscale, only four items performed well enough to be retained. Thirty-four items were removed in this way from the original pool of questions (see Appendix 10). This produced a questionnaire of 34 items (which included 11 items from the IPQ-SCV).

The final version of the CEQ (see Appendix 10) consisted of 7 subscales which were grouped together to correspond with three dimensions of the self regulation model (Leventhal), namely consequences (3 subscales), control (3 subscales) and timeline (1 subscale) dimensions.

Cronbach's alpha was calculated for the 34 items, which provided a reasonable level of internal consistency ($\alpha = .94$). Table 3 shows the Cronbach's alpha for the sub-scales of the CEQ.

Table 3: Reliability coefficients of the Questionnaires

Questionnaire	Version One			Version Two		
	N	No of items	Cronbach's Alpha	N	No of items	Cronbach's Alpha
CEQ						
Consequences						
Patient	57	13	.91	59	5	.86
Carer	47	13	.91	56	5	.88
Family	55	9	.79	56	5	.84
Control						
Treatment	53	11	.89	54	5	.83
Patient	53	9	.66	54	5	.72
Carer	53	4	.81	53	4	.81
Timeline	47	9	.82	47	5	.82
Total Score	29	68	.96	39	34	.94
IRQ	31	12	.82	41	10	.85

Involvement in Rehabilitation Questionnaire (IRQ)

Two items were removed from this questionnaire due to low or negative item correlations.

Following removal of these items, Cronbach's alpha was calculated, which provided a

reasonable level of internal consistency ($\alpha = .85$). Table 3 shows the Cronbach's alpha and number of items for both questionnaires.

DISCUSSION

Two questionnaires were developed and evaluated in order to use in a further study to test the hypothesis that carers' expectations about their relative's condition are associated with emotional wellbeing and engagement in the rehabilitation process. Despite 62 visitors to the website, not all items were completed on the two questionnaires suggesting that these questions were possibly irrelevant to their situation, or that the questionnaires were too lengthy and so items were missed. When items with low or negative item total correlations were removed to create version two of the questionnaires, this increased the number of completed subscales of the questionnaires that could be analysed. This suggests that version one of the CEQ and IRQ included a number of irrelevant and invalid questions. The removal of these items therefore appeared to increase the face validity of the questionnaires. The final versions were found to have good internal consistency and were of a reasonable length. It was beyond the scope of the study to further examine the psychometric properties of the questionnaires for example, test retest reliability. It was expected that the main phase of the study would provide further information regarding the internal reliability of the items.

Methodological Evaluation

The main limitation of the internet survey method of evaluating a questionnaire is that there was no way of checking that the respondents were, in fact, family carers of people who had had an ABI within the previous 12 months. This method is possibly vulnerable to the influence of sampling and self selection biases, as only those who utilised the internet to

actively search for information regarding their relatives' condition would have seen the link to the survey website. This motivation to acquire information may have been a factor influencing the development of their expectations of recovery from ABI. Furthermore, it is also possible that these participants were supporting relatives who may have had more severe head injuries or stroke and therefore they may have had expectations of more severe consequences than perhaps a more general population of carers.

The two host websites were based in the United Kingdom and Canada and it is possible that visitors to each of these two sites may have had very different experiences of ABI services. The websites, however could be accessed when using a search engine⁶ from anywhere in the world so it was not known how many respondents were actually from the United Kingdom, Canada or from other countries. Despite these limitations, the use of the Internet survey method provided a useful means of gaining access to a particular group of interest in order to evaluate the questionnaire.

⁶ An internet search using a well-known search engine (google) was carried out by the researcher in May 2009 using the keywords: carers, expectations, acquired brain injury, recovery, research. A link to the website was available.

PHASE TWO: INVESTIGATION OF CARER' EXPECTATIONS OF RECOVERY IN RELATIVES WITH ACQUIRED BRAIN INJURY

Aims and Hypotheses

The aim of the second phase of the study was to investigate whether carers' expectations about their relative's condition are associated with the carers' emotional wellbeing and engagement in the rehabilitation process. The main hypothesis of the study was that: Carers who have pessimistic expectations of recovery in their relatives with an acquired brain injury will have lower levels of emotional well-being and will have lower levels of engagement in the rehabilitation process.

METHODOLOGY

Following the initial phase of the study, the two revised questionnaires (CEQ and IRQ) were sent to the NHS ethics committee. Once ethical and local research and development approval for the study had been obtained, (see Appendix 2), three Neuro-rehabilitation units, which provided in-patient multi-disciplinary rehabilitation services for people with acquired brain injury were contacted.

Recruitment Strategy

Potential participants, who expected to be the primary caregiver upon discharge for their relative with an acquired brain injury and involved in their relatives' care, were identified by members of the clinical team in each unit. For ethical reasons, family members were only approached if they were viewed as being not significantly distressed by a member of staff. The member of staff gave an Information Sheet (see Appendix 3) to the family member, advising them to contact the Chief Investigator if they were interested in taking part or to

indicate consent to be approached via the member of staff. Those family members who expressed an interest in taking part were then contacted either face to face or by telephone to arrange a convenient time to meet in order to explain the study in more detail.

Procedure

An initial meeting was arranged with potential participants to provide further details regarding the study. Written consent was obtained (see Appendix 5) and a further appointment was made at least 24 hours after the initial contact to administer five questionnaires relevant to the purposes of the study. Participants were also asked to provide consent to allow a member of staff to complete a questionnaire regarding their perceptions of the carers' involvement in rehabilitation. If they did not consent to this, this did not preclude them from taking part in the study. Three participants did not consent to the completion of the staff questionnaire.

The researcher met with participants on NHS premises where their family member was being treated. In circumstances where it was not feasible to meet on NHS premises, the participant was seen in their own home⁷. The researcher was present to answer any questions the participant had; and to monitor their emotional state and take action should this give cause for concern. All participants were able to withdraw from the study at any time, up to the stage of data analysis.

Participants

Carers of individuals with an Acquired Brain Injury who were in-patients or had recently been in-patients within a neurorehabilitation service were invited to take part in the study. The aim of the research was to recruit only carers whose relatives were in-patients, however there was

⁷ In this instance, the NHS Trust's lone worker policy was adhered to

a delay in recruiting some carers. This meant that their relative had already been discharged by the time that the carer took part in the study, however the longest period at home was six weeks.

Participants were included in the study if they expected to be the primary caregiver for the person once they left hospital and if their ABI had occurred within the last 12 months and at least six weeks prior to contact with the researcher. The rationale for this was that it was considered to be unethical to approach carers during the very early stages post-injury due to the distress and shock that they may have been experiencing. Furthermore, including carers whose relative had sustained their head injury over a year ago would mean that expectations would have been affected and perhaps shaped by time and experience in providing care.

Carers under the age of 21 were excluded as it was felt that their expectations might differ from those over the age of 21. It was also necessary to exclude participants who did not speak English, as it was not feasible to translate the questionnaires. Carers of individuals with progressive neurological conditions were also excluded. Forty-two carers were recruited for the study and their demographic details are displayed in table 4. Participants were asked to complete a brief questionnaire that provided information on their age, gender, relationship with the relative with ABI, employment status, type of brain injury, time since the occurrence, gender and age of their relative.

Table 4: Demographic details of the Carer Participants

Demographic Variable	Total n=42 (%)
Mean age in Years (SD)	49.7 (SD =11.09)
Gender (%)	
Male	10 (24)
Female	76 (76)
Ethnicity (%)	
White	39 (92.9)
Black	1 (2.4)
Asian	1 (2.4)
Other	1 (2.4)
Employed (%)	
Employed	28 (66.7)
Unemployed	6 (14.3)
Retired	7 (16.7)
Student	1 (2.4)
Relationship (%)	
Husband	15 (11.9)
Wife	13 (31)
Partner	4 (9.5)
Father	4 (9.5)
Mother	6 (14.3)
Son	2 (4.8)
Daughter	3 (7.1)
Other (inc sister, sister-in law)	5 (11.9)

Carers were also asked to provide an approximate indication of what they had been told about the severity of their relatives' ABI. No further information was collected regarding the individual with an acquired brain injury, for example severity as measured by the Glasgow Coma Scale (Teasdale & Jennett, 1974) or the extent of their cognitive, physical and functional difficulties as this would have required obtaining consent from the person with the acquired brain injury. Table 5 shows the demographic information regarding the individual with ABI.

Table 5: Demographic Details of the Individual with ABI

Demographic Variable	Total (N=42)
Mean age in Years (SD)	48.7 (18.4)
Gender (%)	
Male	33 (79)
Female	9 (21)
Type of Brain Injury (%)	
Traumatic Brain Injury	26 (62)
Stroke	14 (33)
Other (subdural haematoma)	2 (5)
Mean time in months since occurrence of ABI (SD)	5.4 (2.7)
Severity of ABI (%)	
Mild	1 (2.4)
Moderate	11 (26.2)
Severe	28 (66.7)
Status (%)	
In-patient	29 (69)
Discharged	13 (31)

Staff Participants

Staff Participants who completed the Family Involvement Assessment Scale (see Appendix 15) consisted of occupational therapists (N=7), speech and language therapists (N= 1), qualified nurses (N= 2) and Psychologists (N= 3). Staff were provided with an information sheet and consent form for the study (see Appendix 6).

Questionnaires

Carer Expectations Questionnaire (CEQ)

Carers' expectations of recovery in their relatives were measured using the revised version of the Illness Perception Questionnaire for Carers (IPQ-SCV) that had been developed during the initial phase of the study (see phase one for more detail). The score used in the analysis of the CEQ was the total score for the whole scale. Higher scores indicated more pessimistic

expectations of recovery (i.e. expectations of more severe consequences for the patient, the carers and the family; expectations that treatment will be ineffective and that the carer and patient have little control over the outcome of the condition; and lower expectations regarding whether the patient's difficulties will improve with time). The internal consistency of the CEQ as assessed in phase one of the study ranged from $\alpha = .72$ to .88 for each subscale (See Appendix 9) and ranged from .76 to .91 in the second phase. Table 6 displays the internal consistency of the CEQ in both phases of the study.

Table 6: Reliability Coefficients for all subscales on the CEQ in the first and second phases of the study.

CEQ Subscale	Number of Items	Cronbach's Alpha α (Phase One Version 2)	Cronbach's Alpha α (Phase Two)
1.Consequences-patient	5	.86	.80
2. Consequences-carer	5	.88	.89
3.Consequences-family	5	.84	.76
4. Control- Treatment	5	.83	.91
5. Control- patient	5	.72	.78
6. Control- carer	4	.81	.87
7. Timeline	5	.82	.77
<i>Total Score on the CEQ</i>	34	.94	.95

Measures of Emotional Distress and Wellbeing

1. Anxiety and Depression

The presence of anxiety and depression in carers was measured using the Hospital and Anxiety Depression Scale (HADS) (Zigmond & Snaith, 1983). This is a 14 -item questionnaire (see Appendix 18) with seven items relating to depression and seven to anxiety

symptoms. The HADS provides an individual anxiety and depression score or an overall total score. Items are rated on a 4-point scale and a total score of 21 can be obtained for each subscale. According to Zigmond and Snaith (1983) a score of 0 to 7 falls within the normal range, 8 to 10 suggests mild symptoms and a score of 11 or above indicates caseness of moderate and severe symptoms of anxiety or depression. Crawford, Henry, Crombie and Taylor (2001) suggested however, that scores of 11 or above should be used as a cut off for caseness to increase the utility of the HADS in differentiating between those with mild and those with more clinical levels of depression and anxiety. Crawford et al also suggest that a total score can be calculated to give an overall level of distress.

The HADS has established normative data for use with a non-clinical population such as carers (Crawford, Henry, Crombie & Taylor 2001). It has also previously been used in studies with carers of individuals with ABI (Kalra et al., 2004). Cronbach's alpha for the HADS in the present study was .85 for the depression subscale and .78 for the anxiety scale and .88 for the total. These are reasonably similar to reliability coefficients found in a study of a non-clinical population by Crawford et al. (2001), which were .77 for anxiety, .82 for depression and .86 for the total scale.

2. Wellbeing

The wellbeing of carers was also measured using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS, Tennant et al., 2007) (see Appendix 17). This questionnaire was developed to measure the positive aspects of mental health and capture affective-emotional aspects, cognitive-evaluative dimensions and psychological functioning (Tennant et al., 2007). The 14- item scale is scored out of 70, with 70 representing a high level of wellbeing. The lowest possible score is 14, which represents a low level of wellbeing. This scale was

validated on a student and a general population sample. Cronbach's alpha on a student sample was .89 and .91 with a population sample. Tennant et al. found that the WEMWBS was highly correlated with eight other measures of physical and mental health and well being including the EUROQOL (Euroqol Group, 1992) and the WHO-5 wellbeing index (Bech, 2004). The authors also confirmed the test-retest reliability of the questionnaire one week later (.83). No ceiling effects were found in a population sample. The WEMWBS has not been used with a carer population, however was chosen due to the lack of availability of other suitable well-being measures to use with this population. In the present study, Cronbach's alpha was .89.

Engagement in Rehabilitation

Carers' engagement in rehabilitation was measured from the perspective of the family member and from a member of staff who was involved in the patient's care. The rationale for this was to obtain a more valid picture of the carers' involvement and therefore avoid difficulties associated with response bias and social desirability (Robson, 2002).

1. Carers' perceptions of involvement in rehabilitation

Carers' perceptions of their involvement in rehabilitation with their relative, was measured using the Involvement in Rehabilitation Questionnaire (IRQ), which was developed in phase one of this study (see phase one for more details). In both phases of the study, this 10 item-questionnaire showed reasonable internal consistency ($\alpha = .82$ for phase one and $\alpha = .85$ for phase two, see Appendix 11). Participants were asked to indicate the extent to which they agreed that they participated in rehabilitation whilst their relative was an in-patient on the unit. The questionnaire was amended in this phase to include a "not applicable" option as the first participant indicated that some of the questions were not applicable to them. The scoring

was amended and the “not applicable” option was given a score of zero. Higher scores on the questionnaire indicated a higher self-reported involvement in rehabilitation.

2. Health Professionals’ perceptions of carers’ involvement in rehabilitation.

A member of staff who was involved with the patient also completed a questionnaire regarding their perceptions of the carer’s level of engagement and involvement in the rehabilitation process. Staff completed the Family Involvement Assessment Scale (FIAS, McNeil, Schuyler & Ezrachi, 1997) if carers had given consent to this. The FIAS consists of 37 items and was developed to provide a clinical measure of family involvement in rehabilitation (see Appendix 15). The psychometric properties of the questionnaire were tested on clinicians working in a brain injury unit who rated the carers of in-patients that they were working with. Items on the questionnaire are grouped into three categories and each scored accordingly to give three scores of family involvement.

In the present study, only the Involvement-staff scale score was used in the analysis (see Appendix 16). The rationale for only analysing responses on this scale was because it measured carer engagement/involvement in rehabilitation, which was the main focus of the study. The other two scales however (involved- patient and support) focused on potential conflict with staff and the relationship with the patient. The scale used in the analysis included 21 items related to family involvement. High scores indicated a high level of involvement in rehabilitation. The reliability coefficient for this scale in McNeil et al’s study was .93 (McNeil et al., 1997). In the present study, the internal consistency was .89.

RESULTS OF PHASE TWO

The data in the second phase of the study were checked for errors and then analysed using SPSS version 17.0. The mean scores and standard deviations of the data are displayed in Table 7.

Table 7: The mean scores and standard deviations of the Questionnaires

Questionnaire	N	Possible Range of scores	Actual range of scores	Mean	Standard Deviation
Carer Expectations Questionnaire (CEQ)	42	34 - 170	62-162	93	20.09
Involvement in Rehabilitation Questionnaire (IRQ)	41	0-50	11- 50	34.6	8.85
Family Involvement Assessment Scale (Involved-staff subscale)	39	27-78	40-75	60.3	9.75
Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)	42	14-70	25-65	42.63	8.2
HADS- Anxiety Scale	42	0-21	3-20	11	3.98
HADS- Depression Scale	42	0-21	0-18	7.4	4.70

Table 7 indicates that all participants completed the CEQ and measures of emotional wellbeing. Three participants did not consent to a member of staff completing a questionnaire regarding their engagement. One participant chose not to complete the self -report involvement in rehabilitation scale.

Measures of Emotional Wellbeing and Distress

Using the scoring method suggested by Crawford et al. (2001), table 8 indicates that 52% of the carers reported anxiety symptoms that were above the cut off score of 11 (i.e scores which

indicate moderate to severe symptoms) and 31% of the carers reported symptoms of depression that fell within the moderate to severe range.

Table 8: Carers' scores on the Hospital Anxiety and Depression Scale

HADS Scale	Below cut off score (11)	Above Cut off score (11) Moderate to Severe range
HADS Anxiety	20(47.6%)	22 (52.4%)
HADS Depression	29 (69%)	13 (31%)

Statistical Analysis

Data were analysed using SPSS version 17.0 and correlational analyses were carried out to test the hypotheses of the study. Prior to analysis, the distribution of the data was examined to see if parametric assumptions could be met in order to reduce the risk of a type II error. This inspection of the data indicated the presence of outlier scores on several variables, which if left unaltered in a parametric analysis would have distorted the results. These outliers were substantially different from the rest of the scores. Rather than altering the scores using a method where the scores are altered to the next score plus or minus one unit (Tabachnick & Fidell, 2001), the data were analysed using a non-parametric correlation (Spearman's Rho). This type of statistical test prevents outliers from distorting the results.

Expectations of Recovery (CEQ) and Emotional Wellbeing

The results indicate that there was no significant correlation between family members' pessimistic beliefs about recovery in their relatives and levels of depression ($\rho = -.025$ $p = .875$ or anxiety ($\rho = .151$ $p = .341$). The results do however indicate that there was a

significant negative correlation between the CEQ and WEMWBS scores ($\rho = -.365$ $p = .017$). This indicates that carers who had higher scores on the CEQ (i.e. pessimistic expectations), reported lower levels of wellbeing.

Carers' Expectations and Engagement in Rehabilitation

A significant negative correlation was found between CEQ scores and scores on the FIAS ($\rho = -.320$ $p = .047$) and IRQ ($\rho = -.413$ $p = .007$). This indicates that the family carers who had more pessimistic expectations of recovery were less engaged in the rehabilitation process.

Other Findings

Involvement in Rehabilitation and Emotional Wellbeing

The results indicate that there was no significant correlation between staff perceptions of involvement and the emotional wellbeing or distress of family members ($\rho = .252$ $p = .112$) (see Appendix 19). There was also no evidence to support an association between family perceptions of involvement and emotional wellbeing or distress. A significant positive correlation was also found between family perceptions and staff perceptions of involvement ($\rho = .454$ $p = .004$). This suggests that the questionnaires were measuring what they purported to measure and that staff and family members had similar perceptions about what constituted involvement.

Influence of demographic variables

1. Age, Gender and Time since Injury

Analysis was also carried out to investigate whether there was a difference between the various demographic variables in relation to the measures. The age and gender of the carer

did not influence their expectations, emotional wellbeing or involvement in rehabilitation, however time since injury (i.e. six weeks to twelve months) was associated with pessimistic expectations as displayed in table 9. This suggests that the carers' expectations became more pessimistic over time. The length of time since the onset of the acquired brain injury did not influence carers' emotional wellbeing or involvement in rehabilitation.

Table 9: Time since ABI and relation with the questionnaires

Questionnaire	N	Spearman's RHO Correlation	Sig (2-Tailed)
CEQ	42	.338	.034
WEMWBS	42	.143	.366
HADS-Depression	42	-.077	.628
HADS- Anxiety	42	-.227	.147
IRQ	41	.084	.603
FIAS	39	.121	.462

2. Influence of the Type of Acquired Brain Injury

An independent groups t-test was carried out to investigate whether carers' expectations, emotional wellbeing and engagement in rehabilitation, were influenced by the type of acquired brain injury that their relatives had. The results from the t-tests (see Appendix 20) indicated that the carers of relatives who had a stroke, had significantly more pessimistic expectations than carers whose relatives had sustained a traumatic head injury ($t = -2.36$ $df = 19$ $p = .029$). No significant differences were found between the two groups in relation to the HADS Anxiety scale ($t = 1.18$ $df = 30$ $p = .248$), HADS Depression scale ($t = 1.23$ $df = 29$ $p = .227$), wellbeing measure ($t = .30$ $df = 31$ $p = .766$), staff reported engagement/involvement in rehabilitation ($t = .85$ $df = 15$, $p = .409$), or self reported engagement/involvement ($t = 1.03$ $df = 23$ $p = .314$).

3. Influence of in-patient and discharge status of relatives with ABI

As 31% of the relatives with ABI had already been discharged at the time that their family member took part in the study, it was important to determine whether their patient status had any influence on their family members' expectations of recovery, wellbeing and involvement in rehabilitation. The results of independent groups t-tests showed that there were no significant differences between the in-patient and discharged groups on any of the measures, thus indicating that the patient status of the relative did not have any influence on carers' expectations, wellbeing and involvement in rehabilitation (see Appendix 20).

Analysis of the sub-scales of the Carer Expectations Questionnaire

Further analysis was carried out to look more closely at the relationship between the seven subscales of the CEQ and carers' wellbeing and engagement in rehabilitation. The correlations for each of the seven subscales and the WEMWBS, HADS, IRQ and FIAS are displayed in Appendix 21.

Consequences Subscales

1. Consequences and Emotional wellbeing

No support was found for an association between the consequences for the patient or for the carer scores on the CEQ and emotional distress or wellbeing. A significant negative correlation was however found, between consequences for the family and wellbeing ($\rho = -.324$ $p = .037$). This finding suggests that carers who expected more severe consequences for the family, experienced lower levels of wellbeing. A significant negative correlation was also found between the total consequences score and wellbeing ($\rho = -.349$ $p = .023$).

2. Consequences and Involvement/Engagement in Rehabilitation

A significant negative correlation was found between the consequences for the family scores and staff reported involvement (FIAS) ($\rho = -.324$ $p = .044$) but not for self reported involvement (IRQ). This suggests that those carers who had expectations of more severe consequences for the family, were less engaged in the rehabilitation process as reported by staff. No support was found for an association between the consequences for the patient and carer subscales and measures of family involvement.

Control Sub-scales

3. Control and Emotional Well-being

No support was found for an association between the control-treatment, patient-control or carer- control subscale scores and wellbeing, anxiety or depression.

4. Control and Engagement

A low significant negative correlation was found between carers' expectations of treatment (control-treatment) and their involvement in rehabilitation as measured by the IRQ ($\rho = -.651$ $p = .000$) and FIAS ($\rho = -.425$, $p = .007$). This suggests that carers who had more pessimistic expectations regarding the outcome of treatment and therapy, were less engaged and involved in the rehabilitation process than carers who had more optimistic expectations. Furthermore, the control-carer subscale was associated with the IRQ ($\rho = -.641$ $p = .000$) and the FIAS ($\rho = -.432$ $p = .006$). This suggests that those carers who perceived that they had less control in regards to influencing their relative's recovery, were less engaged in the rehabilitation process. A significant negative correlation was also found

between carers' scores on the control-patient subscale and scores on the IRQ ($\rho = -.337$ $p = .031$) but not on the FIAS.

5. Expectations regarding the timeline of Acquired Brain Injury

No significant correlations were found between carers' expectations regarding the timeline of their relatives' condition and emotional distress, wellbeing or engagement/involvement in rehabilitation.

DISCUSSION

The second phase of the study aimed to investigate whether carers' expectations of recovery were associated with their emotional wellbeing and engagement in the rehabilitation process. It was hypothesised that carers who had more pessimistic expectations would show lower levels of emotional wellbeing and be less engaged in rehabilitation. The findings of the study are summarised below and will be discussed in relation to previous research in this area.

Hypothesis 1

Carers' Expectations and Emotional Wellbeing

This study found support for an association between carers' expectations and positive emotional wellbeing, however there was no support for the hypothesis that expectations and negative emotional wellbeing are associated. The correlation between expectations and positive well-being is consistent with the idea, suggested in the Introduction, that expectations will have an impact on well-being. Although previous research studies have found evidence to suggest that carers' illness perceptions impact on their emotional wellbeing, these studies have tended to focus on measuring aspects of emotional distress (Sterba & Devellis, 2009).

The present study is the first study to have quantitatively measured carers' future expectations and to have found an association between such expectations and positive well-being. This addresses the gap identified in the literature on positive adjustment in carers (Perlez et al., 1999). The idea that expectations impact on positive well-being was developed on the assumption, which drives much of the research on illness perceptions, that they influence the person's reaction to the illness. However, the design does not allow conclusions to be drawn about the direction of the causality. It could be that well-being influences perceptions/expectations, or, more likely, that the influence is mutual.

In this study, 52% of carers reported clinical levels of anxiety above the cut-off score of 11 and 31% reported clinical levels of depression, however no significant association was found between carers' expectations and depression or anxiety. The hypothesis about negative emotional states was therefore not supported. This is inconsistent with earlier research that has reported an association between illness perceptions and anxiety and depression (e.g. Barrowclough et al., 2001; Sterba & DeVellis, 2009). There are a number of reasons why this might be the case. The rates of depression on the HADS in this sample were fairly low, and it may be that they were too low for any relationship between depression and expectations to occur. It is also possible that some the carers in this sample were resilient to experiencing low mood and anxiety. As Oddy and Herbert (2002) have suggested, not all carers experience distress. This discrepancy could be explained by the fact that in the current sample, the person with the ABI was still in hospital or had recently been discharged, and it may be that depression at this stage is fairly low and only increases later. In the studies that have reported an association between illness perceptions and depression (Barrowclough et al., 2001; Sterba

& DeVellis, 2009), the person with the condition was living at home with the carer, which may influence expectations.

The carers in this study did experience higher levels of anxiety than depression and it is likely that this may have been due to the fact that the initial stages of rehabilitation were a fairly stressful time for carers, regardless of whether they had positive or negative expectations about future recovery. The anxiety scale of the HADS may have measured a general feeling of being under stress from conflicting demands, and adjustment to the rehabilitation environment after acute care, rather than anxiety about the future.

Hypothesis 2

Carers' Expectations and Engagement in Rehabilitation

The hypothesis that carers with more pessimistic expectations of progress and recovery in their relatives would be less engaged/involved in rehabilitation was also confirmed. Carers' and staff perceptions of involvement were both significantly associated with carers' expectations. This finding is similar to what was found by Bellamy (2008) in which a relationship was suggested between positive expectations and higher engagement in rehabilitation. These findings also resonate with previous studies, which have looked at the influence of illness perceptions on engagement with treatment (Cooper et al., 1999). No studies however have previously examined carers' expectations and involvement in rehabilitation using a quantitative methodology, therefore it is not possible to make direct comparisons between studies. The design used in this study did not provide confirmation that one factor causes the other but only an indication of an association between these two factors. As with the association between expectations and positive well-being, illness perceptions

research generally assumes that the perceptions influence the reaction to the illness, but the influence could run in the reverse direction, or be bi-directional. Expectations may influence engagement, but it may also be that those who engage more in the rehabilitation process also develop more positive expectations as a result.

Engagement and Emotional Distress and Wellbeing

No significant relationship was found between the two measures of engagement and measures of emotional distress and wellbeing. This is an important finding because another possible explanation of the association between expectations and engagement is that both are the product of a third variable. Mood and well-being are possible candidates for this third variable and may mediate the association between expectations and engagement. For example, emotional distress might make a person feel more pessimistic about the future which could then lead to them feeling less motivated to engage in rehabilitation with their relatives. However, the study provided no evidence to support this idea. This hypothesis could be investigated in future research.

Other Findings

Support was also found for an association between time since injury and pessimistic expectations, suggesting that carers' expectations became more pessimistic over time. This is an interesting finding and could be explained by the fact that the carers' expectations were shaped by the amount of knowledge they gained over time regarding the prognosis of their relatives' condition and their levels of impairment. Those whose relatives had sustained a brain injury earlier may have had more optimistic expectations that kept them going through the initial stages of adjusting to their relative's condition. This finding resonates with previous

studies on fluctuations in expectations by Ruston (2007). It is also possible that those with more optimistic expectations earlier in rehabilitation could have been experiencing denial (Lezak.,1986) and hence unrealistic expectations of recovery.

Analysis of the Subscales of the Carer Expectations Questionnaire

Post-hoc analysis of the seven subscales of the CEQ found support for an association between consequences for the family subscale and wellbeing, suggesting that more pessimistic expectations were associated with lower levels of wellbeing. No support was found for an association with consequences - carer or consequences- patient subscales and wellbeing. No association was also found between emotional wellbeing and the control-patient, control-carer, control-treatment and timeline subscales of the CEQ. Furthermore, no associations were found between any of the subscales and levels of distress, as measured by the HADS.

In regards to involvement in rehabilitation, only the consequences –family subscale and the control-treatment and control-carer subscales were significantly correlated with both the IRQ and FIAS. This suggests that more pessimistic expectations of control of treatment, carers - control and consequences for the family were associated with lower levels of carer involvement in rehabilitation. These results are limited by the small sample size and as such only tentative conclusions can be drawn about the association between the consequences, control and timeline expectations and carers’ wellbeing and involvement in rehabilitation.

Methodological Evaluation

Limitations relating to the sample:

Representativeness of the sample:

The carers who participated in the study were an opportunistic sample and they were recruited for the study via health professionals who worked with them. It is likely that this method of sampling may have resulted in biases in the selection process. Carers who had more contact with staff, a good relationship or appeared to be adjusting well may have been more likely to have been approached by staff. Conversely those who were less engaged in rehabilitation may not have been selected due to limited opportunities to approach them. This could potentially have resulted in missing those carers who had more pessimistic views, were less engaged and had lower levels of emotional wellbeing. The recruitment strategy used in this study meant that the researcher could not determine the attrition rate. These selection biases may have influenced the findings of the study and could possibly explain why carers were less likely to experience clinical levels of depression and anxiety as measured by the HADS than has been found in other samples.

The aim of the research was to recruit families whose relatives were in-patients at the time of recruitment, but this was not always possible due to the pressure on in-patient beds in the service. Some patients had already been discharged by the time their family member took part in the study but, due to limited availability of time to undertake the study, it was necessary to include these participants. It is possible that this may have biased the carers' scores on the questionnaires as a few weeks at home may have influenced the development of carers' expectations. Furthermore, including families whose relative had already been discharged may have affected their response on the Involvement in Rehabilitation Questionnaire. In order

to ensure that the measure retained its validity, those discharged were provided with additional instructions related to completing the questionnaire, for example, “*these questions relate to your involvement in rehabilitation when your relative was an in-patient on Ward X*”. Nevertheless, there was still the potential for carers not to pick up on this and to answer with reference to their current situation, which could possibly have led them to under-report their engagement. Further analysis however, found no differences between the carers whose relatives were in-patients and those whose relatives had been discharged. This suggests that carers’ expectations, wellbeing and engagement in rehabilitation were not influenced by the patient status of their relatives.

Homogeneity of the sample

The homogeneity of the sample was reduced by the fact that carers were recruited whose relatives had different conditions including stroke, traumatic brain injury and subarachnoid haemorrhage. Clearly these conditions have very different causal factors and mechanisms of injury and so carers’ expectations about potential recovery may therefore be diverse.

Traumatic brain injury is typically a one-off event where neurological damage is sustained, for example, a blow to the head and once the person has been medically stabilised, the person is unlikely to experience further deterioration in functioning unless another TBI occurs.

When a person has a stroke, however, it is possible that they may have another stroke in the future, leading to further deterioration in physical and cognitive functioning. In this study, carers of stroke survivors were found to have significantly more pessimistic expectations regarding recovery than the carers of relatives with TBI. There were no differences however between carers of relatives with stroke and traumatic brain injury on the measures of emotional wellbeing and engagement in rehabilitation.

The diversity of age in the sample may also have had an impact on the results. For example, older adults may have been more accepting of what had happened due to expectations of ill health in older age. The results did not show any association between the age of the carer and expectations or engagement in rehabilitation, but this may have been due to the relatively small sample size. There were also more female carers in this study who may have had different experiences and expectations to male carers. Furthermore, the type of relationship with the individual with ABI was not limited to spouses or partners but included offspring, parents and siblings which may have influenced carers expectations of recovery, their engagement in the rehabilitation process and their emotional wellbeing, however due to the low numbers in each group it was not possible to conduct an analysis of this.

The majority of the sample (86%), were recruited from two neuro-rehabilitation wards within the same hospital that were all treated by the same multi-disciplinary team. This may have improved the homogeneity of the sample, but at the same time may have reduced the generalisability of the findings.

Measures

The initial phase of the study established the internal reliability of the CEQ and IRQ for use with a carer population in ABI and similar levels were obtained in both phases. However, it was beyond the scope of study to complete further evaluations of the measures (such as test-retest reliability and validity). The study also utilised a measure of wellbeing (WEMWBS) that has not been validated for use with a carer population. Other wellbeing measures were considered, for example the General Health Questionnaire (Goldberg & Williams, 1988), however these include items related to physical health as well. A number of participants

indicated that some of the items on the IRQ were not applicable to their situation, for example one participant stated that they were not asked to be involved in Occupational Therapy or Physiotherapy sessions. Rehabilitation sessions generally took place between 9 and 5 pm and some participants could only visit their relative in the evenings, perhaps due to work, family or other commitments. This therefore may have limited their opportunities to be involved with all professionals on the wards. On the other hand, some support for the validity of the IRQ comes from the fact that it was significantly correlated with the FIAS.

The staff who took part in the study were all Health Professionals who had a high patient-to-staff ratio and busy workload, and therefore they were not always able to complete the questionnaire at the most opportune time or, perhaps, to give the questionnaire their full attention. This may have led to biases in memory recall or fast completion without fully considering the items. This also meant that the questionnaires for both staff and carers were not completed at the same time, which may have led to discrepancies between staff and carers' perceptions of involvement as they may have reported on involvement at different periods of time. There are also issues about the validity of the FIAS. The questionnaire is intended as a staff-observed measure of family motivation, but it is possible that staff perceptions of involvement and engagement may have been influenced by their relationship with the carer, their ideas about what constitutes family involvement and opportunities for this to take place.

Future Research

The present study led to the development of two questionnaires to measure carers' expectations and their engagement in the rehabilitation process. These measures had reasonable internal consistency, however there is a need for further research to evaluate the

psychometric properties of these questionnaires, particularly in relation to test-retest reliability and validity. There is also a need for further studies to look more closely at the subscales of the CEQ and their relationship with the self-regulation model of illness perceptions. It would also be useful to try to improve measures of family engagement by taking account of whether the carer had the opportunity to be involved in the rehabilitation process. There is also a need for further research to carry out a more rigorous investigation of carers' expectations, using samples that are more homogenous with respect to factors such as the type of relationship between the carer and the person with ABI, and the type of brain injury. This would provide a larger, more representative sample.

The study also found results to suggest that carers' pessimistic expectations were associated with lower levels of wellbeing and engagement. It would be interesting to investigate the fluctuation of these expectations over time during different phases of the rehabilitation process as found by Ruston (2007) and whether expectations and their engagement are correlated with their relatives' recovery. It would also be interesting to investigate what happens over time to optimistic expectations that are not realised; and what impact that has on the carer's well-being and commitment and relationship between the carer and the person they are looking after. Future research could also look more closely at the factors that influence the development of pessimistic or optimistic expectations, for example by addressing the carer's coping strategies, self efficacy, resilience, and the carer's perceptions about the pre-morbid character of the person with the ABI (Bellamy, 2008). Finally future research could also examine the factors that mediate the relationship between expectations and engagement/involvement in rehabilitation in order to develop a model to explain this.

Clinical implications

The findings of this study found an association between carers' expectations and engagement in the rehabilitation process and well-being. Although the causal nature of these relationships is unclear, the study suggests the importance of considering carer expectations in rehabilitation settings. Recent policy documents have emphasised the importance of the early detection of carers' needs and involvement in the rehabilitation process. The findings from this study support this view as it could be highly beneficial to the carer to assess their expectations at an early stage of rehabilitation. This could identify carers with unrealistically pessimistic expectations or optimistic expectations that influence their engagement and wellbeing. Unrealistic optimistic expectations may be beneficial in the short term in relation to engagement and well-being as they may motivate the person to get involved, however it may be that they lead to a lowering of wellbeing at a later stage when such expectations are not realised.

There is a need therefore for rehabilitation services to take more active steps to manage carer expectations to avoid the extremes of optimism and pessimism (Bellamy, 2008). This could be achieved through the provision of family interventions to address and modify maladaptive beliefs and expectations, which could facilitate carers' engagement and involvement in rehabilitation and potentially lead to better outcomes for both the carer and their relative.

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PUBLIC DOMAIN BRIEFING PAPER

AN INVESTIGATION OF CARERS' EXPECTATIONS OF RECOVERY AND THEIR ENGAGEMENT IN THE REHABILITATION PROCESS IN RELATIVES WITH ACQUIRED BRAIN INJURY

ANDREA HOUGH

Background and Aims

The role of the family carer in supporting individuals with acquired brain injury is gaining increasing recognition within health and social care policies in the United Kingdom. These policies acknowledge the impact that acquired brain injury can have upon the carer in terms of emotional distress and recommend the early detection of carers' needs and involvement in the rehabilitation process.

Literature Review

Anecdotal reports have suggested that family involvement can contribute to the recovery of individuals with Acquired Brain Injury. A literature review was carried out to examine the evidence for involving families in acquired brain injury rehabilitation and whether this can contribute to improvements in the outcomes of their relatives. The results of this review revealed that there is limited evidence to support this claim and there is a lack of research been carried out into routine aspects of rehabilitation including family involvement in goal setting and discharge planning. There is a need for more high quality studies to identify the factors that may support or impact on the involvement of families in rehabilitation.

Empirical Study

The aim of this study was to gain a greater understanding of carers' expectations regarding the recovery process in relatives with Acquired Brain Injury and how these expectations may be related to their psychological wellbeing and involvement/engagement in the rehabilitation process with their relatives. In order to measure carers' expectations and perceptions of involvement in rehabilitation, two questionnaires were developed in a pilot study with sixty-two family members who completed an Internet survey. The questionnaires were then evaluated and used in the second phase of the study alongside questionnaires related to mood and well-being and a measure of staff perceptions of the involvement of the family member. The aim of the second phase of the study was to investigate whether the carer's expectations about their relative's condition are associated with the carer's emotional wellbeing and engagement in the rehabilitation process.

Participants

Participants for the initial phase of the study were recruited from an internet based website and sixty-two family carers completed this on-line questionnaire. In the second phase of the study, forty-two family carers were recruited from three Neurorehabilitation units in the UK. All the participants were relatives of individuals with an Acquired Brain Injury who were receiving in-patient rehabilitation.

Methodology

During the second phase of the study, questionnaires were completed by carers on NHS premises or in their own homes. Carers were asked to complete a set of five questionnaires relating to demographic information, expectation of recovery, perceptions of their

involvement and engagement in rehabilitation and two questionnaires related to emotional wellbeing.

Results and Conclusion

This research found support for a relationship between carers' expectations and positive emotional wellbeing. Although the causal nature of these relationships is unclear, the study suggests the importance of considering carer expectations in rehabilitation settings. Recent policy documents have emphasised the importance of the early detection of carers' needs and involvement in the rehabilitation process. The findings from this study therefore suggest that it may be beneficial to the carer to assess their expectations at an early stage of rehabilitation. This could identify carers with unrealistically pessimistic expectations, which may influence their level of emotional wellbeing and engagement.

APPENDIX 1

Author guidelines for submission to Disability and Rehabilitation and Neuropsychological Rehabilitation

APPENDIX 2

Ethical Approval

APPENDIX 3

Participant Information Sheet (Carer Version)

Study Title

An Investigation of Carers' Expectations of Recovery in Acquired Brain Injury

I am a Trainee Clinical Psychologist at the University of Birmingham and am conducting this study as part of my training. Before you decide whether to take part, 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 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?

The study is an investigation of what influences the emotional adjustment of carers and their involvement in the rehabilitation process. We hope that a better understanding of these issues will eventually help us promote better adjustment and coping in carers.

Why have I been chosen?

You have been chosen to take part in this research because you have a relative who has an acquired brain injury (e.g. a stroke or head injury) and is currently an in-patient on the rehabilitation unit.

What will happen to me if I take part?

Participation in the study is entirely voluntary. If you decide not to take part, this will not affect the service you or your relative receives in any way. 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 happen to me if I take part?

If you would like to take part, please either contact one of the researchers (contact details below) or ask the person who gave you this leaflet to contact us. Once I know that you are interested, I will contact you to arrange a meeting on the rehabilitation unit. If you cannot meet on the rehabilitation unit, please let me know so that an alternative can be arranged.

If you decide to take part, you will be asked to complete four questionnaires – two about your emotional well-being; one about your involvement in your relative's rehabilitation; and one about your expectations for your relative's recovery. You will also be asked for some background details, such as your age. The questionnaires should take about 30 minutes in total to complete.

We would also like a member of staff to complete a questionnaire about your involvement in your relative's rehabilitation. We will only do this if you give your permission. To help you decide whether to agree to this, you may see a blank copy of this questionnaire. However, once you agree, you will not be told which member of staff has completed the questionnaire; and you will not be shown or told their answers. This is to protect the confidentiality of the staff. If you do not want a member of staff to complete a questionnaire about you, you can still take part in the study.

What do I have to do?

If you agree to participate, I will ask you to complete four questionnaires which will take approximately 30 minutes to complete. I will also ask you for some background details, such as your age. I will be present to answer any questions or concerns you may have. You may choose to read through the questionnaire and record the answers yourself. If you prefer it, I will read out the questions to you and record your answers

What are the possible disadvantages and risks of taking part?

It is possible that you may find some of the questions distressing. 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 assistance if this is required.

What are the possible benefits of taking part?

We hope that the findings from the study will help us to understand more fully the needs of families and carers. However, we do not expect that there will be any direct benefit to you personally.

What happens when the research study stops?

The results of this study will be written up and submitted as part of an educational qualification. A report will also be submitted to an academic journal. A summary of the findings will be made available to family members on the rehabilitation unit upon completion of the study.

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 have any concerns about the way in which the research is conducted, please contact the academic supervisor (contact details below).

Will my taking part in the study be kept confidential?

Yes, all information that is collected will be kept confidential. Your name will be recorded only on the consent form that I will ask you to sign. This form will be kept in a locked filing cabinet at the University for 12 months and then be destroyed. A code number will be written on the questionnaire you complete. This will tell us the identity of the carer you have completed the questionnaire about. The list that matches codes to names will be kept separately from all other data in a locked filing cabinet; and only Andrea Hough will have access to this list.

Contact Details:

If you would like any further information about the study or are interested in taking part, please do not hesitate to contact:

Andrea Hough, Trainee Clinical Psychologist, School of Psychology, The University of Birmingham, Edgbaston, Birmingham, B15 2TT. Email: [REDACTED]
Or

Dr Andrew Brennan, Clinical Psychologist, on [REDACTED]
Moor Green Inpatients Neurological Rehabilitation Unit
Moseley Hall Hospital
Alcester Road
Birmingham
B13 8JL

If you wish to raise any concerns about this project, please contact the academic researcher (Dr Gerry Riley) on 0121 414 4923 or G.A.Riley@bham.ac.uk or by writing to Dr G. Riley, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT

Thank you for your time,

Andrea Hough (Trainee Clinical Psychologist)

Dr Andrew Brennan (Clinical Psychologist)

APPENDIX 4

Participant Information sheet (Staff Version)

Study Title: An Investigation of Carers' Expectations of Recovery in Acquired Brain Injury.

I am a Trainee Clinical Psychologist at The University of Birmingham and am conducting this study as part of a Doctoral Programme in Clinical Psychology. Before you decide whether to take part, 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 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?

The purpose of the study is to investigate whether carer expectations about recovery from acquired brain injury (stroke, traumatic brain injury etc.) are associated with their emotional well-being and their engagement in the rehabilitation process. It is important to understand what factors influence their emotional well-being and engagement because rehabilitation is less likely to be effective if the carer is distressed and not participating in the rehabilitation process, and because the emotional well-being of carers is of importance in its own right.

Why have I been chosen?

You have been chosen to take part in this research because you are a member of staff and work with a carer who has agreed to take part in this study.

Do I have to take part?

Participation in the study is entirely voluntary and you can have the opportunity to think about it before you decide whether to take part. If you would like to take part, I will ask you to sign a consent form to say that you have agreed. 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 happen to me if I take part?

Carers who have agreed to take part will complete a set of questionnaires about their expectations, their emotional well-being and their engagement in rehabilitation. If you decide to take part, you will be asked to complete one questionnaire about the carer's engagement in rehabilitation activities on the Unit. The questionnaire will take approximately 5 minutes to complete.

What do I have to do?

If you agree to participate, I will ask you to complete one questionnaire which takes approximately 5 minutes to complete. I will be present to answer any questions or concerns you may have. You may choose to read through the questionnaire and record the answers yourself. If you prefer it, I will read out the questions to you and record your answers.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks.

What are the possible benefits of taking part?

We hope that the findings from the study will help us to understand more fully the needs of families and carers. However, we do not expect that there will be any direct benefit to you personally.

What happens when the research study stops?

The information from the questionnaires will be analysed to identify factors that may be associated with carers' well-being and engagement in rehabilitation. The results of this study will then be submitted to an academic journal. A presentation of the findings will be given to staff at the unit, and a written summary made available for staff, patients and families on the unit.

What if there is a problem?

You should contact the academic researcher (details below) if you are concerned about any aspect of this research.

Will my taking part in the study be kept confidential?

Yes, all information that is collected will be kept confidential. Your name will be recorded only on the consent form that I will ask you to sign. This form will be kept in a locked filing cabinet at the University for 12 months and then be destroyed. A code number will be written on the questionnaire you complete. This will tell us the identity of the carer you have completed the questionnaire about. The list that matches codes to names will be kept separately from all other data in a locked filing cabinet; and only Andrea Hough will have access to this list.

The carer has signed a form agreeing that s/he will not be told the identity of the staff member who completes the questionnaire; and will not at any point be shown the completed questionnaire or told about its contents.

Contact Details:

If you would like any further information about the study or are interested in taking part, please do not hesitate to contact:

Andrea Hough, Trainee Clinical Psychologist, School of Psychology, The University of Birmingham, Edgbaston, Birmingham, B15 2TT. Email: [REDACTED]

Or

Dr Andrew Brennan, Clinical Psychologist, on [REDACTED]
Moor Green Inpatients Neurological Rehabilitation Unit, Moseley Hall Hospital, Alcester Road, Birmingham, B13 8JL

If you wish to raise any concerns about this project, please contact the academic researcher (Dr Gerry Riley) on 0121 414 4923 or G.A.Riley@bham.ac.uk or by writing to Dr G. Riley, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT

Thank you for your time,

Andrea Hough (Trainee Clinical Psychologist)
Dr Andrew Brennan (Clinical Psychologist)

APPENDIX 5
CONSENT FORM (Carer Version)
Carers' Expectations of Recovery in Acquired Brain Injury

(Form to be on headed paper)

Name and Affiliation of Researcher: Andrea Hough, University of Birmingham

Please initial box

1. I confirm that I have read and understand the information sheet dated..... ☐
version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. 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.
3. I understand that relevant sections of my medical notes and data collected during the study, ☐
may be looked at by individuals from the University of Birmingham, from regulatory
authorities or from the NHS Trust, where it is relevant to my taking part in this research. I
give permission for these individuals to have access to my records.
- 4.. I agree to take part in the above study. ☐

Name _____ Signature _____ Date _____

Researcher _____ Signature _____ Date _____

Please initial box as appropriate:

I hereby give permission for a member of staff from the rehabilitation unit to complete a ☐
questionnaire about my involvement in my relative's rehabilitation. I consent to the fact that I
will not be told the identity of this member of staff and will not be shown the questionnaire
that they complete about me.

I do not give permission for a member of staff to complete a questionnaire about me. ☐

Name _____ Signature _____ Date _____

Researcher _____ Signature _____ Date _____

Should you wish to discuss your involvement in the research or any concerns you may have,
the PALS (Patient Advice and Liaison Service support line can be contacted on 0800 389
8391 or 0121 627 8839.

APPENDIX 6

CONSENT FORM (Staff Version)

Title of Project: Carers' Expectations of Recovery in Acquired Brain Injury

(Form to be on headed paper)

Name and Affiliation of Researcher: Andrea Hough, University of Birmingham

Please initial box

1. I confirm that I have read and understand the information sheet dated.....☐
version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason.
3. I understand that the data collected during the study, may be looked at by individuals from ☐
the University of Birmingham, from regulatory authorities or from the NHS Trust, where it is
relevant to my taking part in this research. I give permission for these individuals to look at
this data.
4. I understand that my completed questionnaire will not be shown or discussed with the ☐
carer; and that the carer will not be told who has completed the questionnaire about them.
- 4.. I agree to take part in the above study. ☐

Name _____ Signature _____ Date _____

Researcher _____ Signature _____ Date _____

APPENDIX 7

Illness perceptions Questionnaire for Carers of relatives with schizophrenia (IPQ-SCV- Barrowclough et al 2001)

Consequences–patient

1. Their illness is a serious condition
2. Their illness has had major consequences on their life
3. Their illness has become easier for them to live with
4. Their illness has not had much effect on their life
5. Their illness has strongly affected the way others see them
6. Their illness has had strong economic and financial consequences for them
7. Their illness is disabling
8. (Their illness has strongly affected the way they see themselves as a person*)

Consequences–relative

1. Their illness has had major consequences on my life
2. (Their illness has become easier for me to live with*)
3. Their illness has not had much effect on my life
4. Their illness has strongly affected the way others see me
5. Their illness has had strong economic and financial consequences for me
6. Their illness has strongly affected the way I see myself as a person

Control–cure of illness

1. Their illness will improve in time
2. There is a lot they can do to control their symptoms
3. There is very little that can be done to improve their illness
4. Their treatment will be effective in curing their illness
5. (Recovery from their illness is largely dependent on chance or fate*)
6. What they do determines whether their illness gets better or worse

Control–cure by relative

1. There is a lot I can do to control their symptoms
2. What I do determines whether their illness gets better or worse

Timeline–chronic

1. (Their illness will last a short time*)
2. Their illness is likely to be permanent rather than temporary
3. Their illness will last for a long time

Timeline–episodic

1. Their illness may change from time to time
2. There will be periods of illness and periods of improvement

* Item removed to increase internal consistency of scale

APPENDIX 8

Version 1 of the Carer Expectations Questionnaire (CEQ)

(* refers to the items deleted to increase the internal consistency of the scale).

Section 1: Consequences for your family member (Consequences- patient)

1. Their condition will be serious
2. *Their condition will have serious consequences on their life**
3. *Their condition will become easier for them to live with **
4. *Their condition will not have much effect on their life **
5. Their condition will strongly affect the ways others see them
6. *Their condition will have strong economic and financial consequences for them)*
7. Their condition will be disabling
8. *There may be some significant changes in their personality **
9. My relative will feel frustrated and depressed at times *
10. *It will be hard for my relative to come to terms with what has happened**
11. My relative will get back to doing the things they enjoy in life
12. *My relative will have more difficulties doing the things they used to do**
13. My relative will be able to manage their responsibilities (e.g. financial and family responsibilities)

Section 2: Consequences for you (Consequences-Carer)

1. *Their condition will have major consequences on my life**
2. *Their condition will not have much effect on my life**
3. Their condition will strongly affect the ways others see me
4. *Their condition will have strong economic and financial consequences for me**
5. *Their condition will strongly affect the way I see myself as a person**
6. *It will be hard to cope at time**
7. *It will be stressful at times**
8. *It's going to be hard work**
9. My lifestyle will have to change
10. My quality of life won't be the same
11. I am worried that my relative will become completely dependent upon me
12. I won't be free to live my own life
13. *I will have to take on extra duties and responsibilities (e.g. in financial or family matters)*

Section 3: Consequences for the Family

1. *What's happened won't change the relationship we have with each other**
2. We won't be able to do a lot of things we used to enjoy
3. Our relationship will be put under stress by what has happened
4. *What's happened hasn't changed the how I feel about my relative**
5. *The way we interact with each other will change**

6. *Other people may find it difficult to adjust to the ways my relative has changed**
7. Given time, we will settle back into our old way of life
8. Life for us as a family is never going to be the same again
9. Our quality of life will be every bit as good as it was before

Section 4: Improvement of Condition (Control-treatment)

1.Their condition will improve in time*

2. There is very little that can be done to improve their condition
3. Their treatment will be effective in improving their condition

4. My relative will get back to normal in the next 12 months*

5. My relative will regain full independence
6. I'm confident that the therapy will help my relative improve

7. My relative won't ever fully recover*

8. Difficulties and obstacles can make me very downhearted about my relative's prospect for independence*

9. Looking back at how much my relative has improved gives me hope for future improvements

10. Seeing/reading about other cases gives me hope for my relative's recovery*

11. Because my relative pulled through the initial stages of treatment, I feel my relative can achieve a lot more*

Section 5: What influence your relative can have (Control- patient)

1. There is a lot they can do to improve their condition
2. What they do determines whether their illness gets better or worse
3. *If patients don't make the effort during rehabilitation, then they won't get better**
4. *Getting better is just a matter of time really- it doesn't matter how hard the person works at it**
5. *My relative is the kind of person who will stick at it for as long as it takes**
6. I doubt sometimes whether my relative puts 100% effort into getting better
7. My relative will recover well if they think positively
8. My relative has the strength of character to get back to independence
9. *My relative has always been successful and will, therefore recover well**

Section 6: What influence you can have (control-carer)

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 (Timeline)

1. Their condition is likely to be permanent rather than temporary
- 2. *Their condition will last for a long time****
3. Changes I've noticed in my relative's mood are only temporary
- 4. *Changes to my relative's personality will not be long-lasting****
5. Most of my relative's problems will sort themselves out with time
6. I am seeing aspects of my relative's personality returning as time goes on
7. I expect that being a carer will get easier as time goes by
- 8. *Their condition may change from time to time****
- 9. *There will be good and bad periods****

APPENDIX 9

CEQ- Carer Expectations Questionnaire

Item-total correlations on version 2 of the CEQ in Phase One and Phase Two

Section 1- Consequences for your family member

CEQ	V2 Phase 1	V2 Phase 2
1. Their condition will be serious	.65	.76
2. Their condition will strongly affect the way others see them	.64	.47
3. Their condition will be disabling	.78	.70
4. My relative will get back to doing the things they enjoy in life.	.62	.47
5. My relative will be able to manage their responsibilities (e.g. family and financial responsibilities)	.72	.59

Section 2- Consequences for you

CEQ	V2 Phase 1	V2 Phase 2
1. Their condition will strongly affect the way others see me	.60	.69
2. My lifestyle will have to change	.73	.76
3. My quality of life won't be the same	.73	.75
4. I am worried that my relative will become completely dependent on me	.71	.61
5. I won't be free to live my own life	.85	.81

Section 3- Consequences for the family

	V2 Phase 1	V2 Phase 2
1. We won't be able to do a lot of the things we used to enjoy together	.62	.46
2. Our relationship will be put under stress by what has happened	.51	.53
3. Given time, we will settle back into our old way of life	.72	.53
4. Life for us as a family is never going to be the same again	.79	.55
5. Our quality of life will be every bit as good as it was before	.55	.60

Section 4- Improvement of Condition

	V2 Phase 1	V2 Phase 2
1. There is very little that can be done to improve their condition	.70	.76
2. Their treatment will be effective in improving their condition	.67	.82
3. My relative will regain full independence	.52	.70
4. I'm confident that the therapy will help my relative improve	.68	.77
5. Looking back at how much my relative has improved gives me hope for future improvement	.5	.84

Section 5- What influence your relative can have

	V2 Phase 1	V2 Phase 2
1. There is a lot that my relative can do to improve their condition	.63	.64
2. What my relative does determines whether their condition gets better or worse	.52	.60
3. I doubt sometimes whether my relative puts 100% effort into getting better	.14	.38
4. My relative will recover well if they think positively	.62	.58
5. My relative has the strength of character to get back to being independent	.61	.65

Section 6- What influence you can have

	V2 Phase 1	V2 Phase 2
1. I believe I have a really important role in helping my relative to make progress	.69	.80
2 Family support is vital in overcoming many of the problems my relative has got	.52	.88
3. My relative's recovery will be better the more information I have about their disabilities	.58	.52
4. I need to have a high involvement with my relative for the good of their progress	.75	.74

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.

	V2 Phase 1	V2 Phase 2
1. Their condition is likely to be permanent rather than temporary	.62	.67
2. Changes I've noticed in my relative's mood are only temporary	.59	.53
3. Most of my relative's problems will sort themselves out in time	.74	.58
4. I am seeing aspects of my relative's personality returning as time goes by	.62	.41
5. I expect that being a carer will get easier as time goes by	.52	.51

APPENDIX 10

Carer Expectations Questionnaire (CEQ)

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					

Thank you for completing this questionnaire

APPENDIX 11

Item- Total correlations for the Involvement in Rehabilitation Questionnaire Version One

Item	Item-Total correlation
1. I take an active part in therapy sessions (with the occupational therapist, physiotherapist etc)	.59
2. Outside therapy sessions, I do activities with my relative that I think will help their recovery	.39
3. I carry out treatment recommendations made by staff	.80
4. <i>I read the information sheets that I have been given</i>	.24*
5. I regularly ask staff how I best can help my relative	.72
6. I tell staff my own ideas about what I think will help my relative's recovery	.65
7. I have regular discussions with the therapists and other staff about my relative's progress	.31
8. I am actively involved in decisions about the rehabilitation programme of my relative	.51
9. I ask staff if there are other ways I can help my relative's progress	.75
10. 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)	.28
11. 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	.46
12. <i>I find out from other carers what has helped their relative</i>	-.02*

* refers to items removed due to low or negative item total correlations

APPENDIX 12

Item- Total Correlations for Version Two of the Involvement in Rehabilitation Questionnaire

Item	Item-Total correlation
1. I take an active part in therapy sessions (with the occupational therapist, physiotherapist etc)	.60
2. Outside therapy sessions, I do activities with my relative that I think will help their recovery	.41
3. I carry out treatment recommendations made by staff	.56
5. I regularly ask staff how I best can help my relative	.70
6. I tell staff my own ideas about what I think will help my relative's recovery	.63
7. I have regular discussions with the therapists and other staff about my relative's progress	.58
8. I am actively involved in decisions about the rehabilitation programme of my relative	.66
9. I ask staff if there are other ways I can help my relative's progress	.65
10. 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	.45
11. 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	.57

APPENDIX 13
Involvement in Rehabilitation Questionnaires (IRQ)
Final Version (version 2)

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 14

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 15
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 Behavior 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 16

Family Involvement Scale (Involved- Staff Scale) (FIAS)

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 17

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)

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APPENDIX 18

Hospital and Anxiety Depression Scale

APPENDIX 19

A table to show the correlations for carers' perceptions of engagement/involvement and measures of wellbeing

Questionnaire	N	Wellbeing		HADS- Anxiety		HADS- Depression	
		Spearman's RHO Correlation	P value (2-tailed)	Spearman's RHO Correlation	P value (2-tailed)	Spearman's RHO	P value (2-tailed)
IRQ	41	.252	.112	-.163	.307	-.051	.753
FIAS	39	.163	.323	.108	.514	.102	.535

APPENDIX 20

A table to show the T-tests for the influence of Type of ABI on carers' score on all measures

	T	df	Sig (2-tailed)
CEQ	-2.36	19	.029
WEMWBS	.30	31	.766
HADS Anxiety	1.18	29.5	.248
HADS Depression	1.23	29	.227
IRQ	1.03	23	.314
FIAS	.85	15	.409

A table to show the T-tests for the influence of In-Patient versus Out- Patient Status on carers' scores on all measures

	T	df	Sig (2-tailed)
CEQ	-.764	19	.454
WEMWBS	-.990	28	.331
HADS Anxiety	.756	33	.455
HADS Depression	.409	28	.686
IRQ	.748	27	.461
FIAS	-.375	23	.711

APPENDIX 21

A table to show the correlations for the subscales of the CEQ.

Subscales of the CEQ	Questionnaires									
	WEMWBS		HADS Anxiety		HADS Depression		IRQ		FIAS	
	Spearman's Rho	<i>p</i>	Spearman's Rho		Spearman's Rho	<i>p</i>	Spearman's Rho	<i>p</i>	Spearman's Rho	<i>p</i>
Consequences										
Patient	-.284	.069	.110	.487	-.016	.920	-.141	.379	-.077	.642
Carer	-.300	.053	.051	.749	.092	.561	-.035	.830	-.223	.172
Family	-.324	.037	.107	.498	.003	.984	-.297	.060	-.324	.044
Total	-.349	.023	.123	.438	.035	.824	-.128	.424	-.212	.195
Consequences score										
Control										
Treatment	-.248	.113	.112	.480	-.046	.774	-.651	.000	-.425	.007
Patient	-.234	.136	.148	.350	-.056	.726	-.337	.031	-.078	.635
Carer	-.242	.123	.026	.870	.090	.571	-.641	.000	-.432	.006
Total control score	-.287	.066	.126	.425	-.034	.832	-.591	.000	-.341	.033
Timeline	-.185	.241	.198	.209	-.113	.478	-.305	.052	-.198	.228

