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The course and impact of family optimism in the post-acute period after acquired brain injury

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Short title: Family optimism

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**Abstract**

Objective:

To investigate the course and impact of family optimism in the post-acute stage of acquired brain injury.

Method:

At Time 1, 30 family relatives of in-patients in rehabilitation units, and 30 relatives of patients recently discharged from such units, completed questionnaires relating to their emotional health, engagement in the rehabilitation process, and expectations about the future consequences and controllability of the injury. At Time 2 (12-18 months later), 23 of the original sample completed questionnaires about their emotional health, and actual consequences and controllability of the injury.

Results:

At Time 1, optimism about future consequences and controllability was associated with greater engagement in the rehabilitation process and better emotional health. The two groups did not differ on any of the measures, which did not support the expectation that the patient’s discharge home would trigger a rapid loss of optimism and emotional upset for the family. At Time 2, the actual consequences were worse than had been expected at Time 1, and greater disappointment was associated with a greater decline in emotional wellbeing.

Conclusion:

Family expectations about recovery are linked with important variables such as emotional wellbeing and engagement in the rehabilitation process, and need careful management by clinicians.

Key words: psychological adaptation, rehabilitation, illness perceptions

**Introduction**

It has been suggested that, in the post-acute period after acquired brain injury (ABI) once the risk to life is past and the recovery process has begun, many families become unrealistically optimistic about the future (i.e. they develop expectations about recovery that eventually turn out to be false). This suggestion featured in the stage models of family adaptation to traumatic brain injury (TBI) that were developed in the 1980s [1, 2, 3, 4], and has also appeared in more recent versions of these models for TBI [5] and stroke [6]. Qualitative research has provided some support for the claim. Family optimism in the post-acute period has been highlighted in interviews with both family members themselves [5,6,7,8,9] and clinical staff [10,11]. Participants in some of these studies have also suggested that the optimism is unrealistic [5,6,10,11].

 A further suggestion is that, when families do eventually realise that their optimism is unfounded, this has a negative impact on their emotional state. In the stage models of family adaptation [1,2,3,4,5,6], when the reality of the situation becomes apparent, the family enters a stage of emotional turmoil, characterised by anger, resentment and depression. Again, more recent qualitative studies have provided some support to the notion that the disappointment of earlier expectations can lead to feelings of being overwhelmed and unable to cope [5,6,9]. Within some of the stage models [5,6], it has also been suggested that the family’s realisation that the optimism is unfounded and the consequent emotional crisis are triggered by the patient’s discharge home from post-acute rehabilitation services: Seeing the person with the ABI struggle in the home environment forces the family to realise the extent of the difficulties.

 The idea that the disappointment of earlier expectations triggers an emotional crisis has led some to suggest that optimism should be tackled at the post-acute inpatient stage, and that staff should work towards fostering more realistic expectations [12,13]. Others have challenged this viewpoint and argued that optimism may be beneficial during the post-acute phase [14]. Indeed, some qualitative studies have suggested that optimism is viewed positively by family members as a way of helping them cope with the situation, providing hope in the face of uncertainty [7] and helping the family to feel empowered [8].

Research in other areas of psychology also suggests that optimism can have positive benefits, some of which are particularly relevant to family members in the post-acute phase of ABI. According to the theory of Scheier and Carver [15,16], dispositional optimism (i.e. the general trait of expecting good outcomes) leads to active attempts to deal with obstacles to the successful pursuit of goals (problem-focused coping), whereas pessimism results in avoidance of the obstacles and withdrawal from pursuit of the relevant goals (avoidant coping). Optimism leads to more active attempts to deal with the obstacles because the person believes that the outcome of their efforts is likely to be positive, whereas pessimism implies a belief that these efforts will be fruitless. Evidence is generally supportive of this suggested link between optimism and coping response [16,17]. Application of the theory in the context of rehabilitation suggests that optimism may lead family members to be more proactive and engaged in the rehabilitation process because of their belief in the effectiveness of their contribution, whereas pessimism might lead to a more passive and avoidant approach. Scheier and Carver [15] also argued that, because optimism is associated with more effective coping responses to obstacles, optimists should be less distressed by those obstacles: Distress and a negative emotional response to stressful events and circumstances is more likely when the person perceives that they cannot cope with the situation [18]. In support of this, an association between optimism and better emotional wellbeing has often been reported [19,20,21]. Applying this to the context of rehabilitation, optimism may act as a buffer against the stresses and challenges the family face, and optimistic family members may enjoy better emotional wellbeing.

The ideas of Scheier and Carver relate to the general personality trait of optimism, and the evidence supporting the links between this and coping style and emotional wellbeing has used a generic measure of optimism. Stronger associations between optimism and family responses to ABI might be expected if the measure of optimism addressed specific beliefs about the ABI. A framework for assessing such beliefs is provided by the illness representations approach [22,23]. Developed within physical health, this approach suggests that people try to make sense of, and deal with, health conditions using representations that have both a cognitive and an associated emotional dimension. Six general categories of cognitive representation have been proposed, involving beliefs about the causes of the condition; its consequences (e.g. its impact on quality of life); its temporal course (e.g. whether it will resolve quickly or persist); its identity (beliefs about the diagnosis and associated symptoms); its coherence (whether the condition is understandable or puzzling); and its controllability (whether something can be done to treat or ameliorate the condition and its impact). In the present context, beliefs about the consequences and controllability of the condition are of particular interest because of evidence linking them to emotional wellbeing and engagement in treatment, the two effects of dispositional optimism of relevance proposed to be of relevance to family carers. Beliefs that the condition is controllable, and that the consequences are less severe, have been reported to be associated with better mood and mental wellbeing [20,24,25]. This has been found to be the case specifically for family carers, in conditions such as psychosis [26] and cancer [27]. Perceptions of controllability have also been found to be correlated with engagement in treatment [28,29]. These studies do not provide direct evidence of the benefits of optimistic expectations because the studies assess beliefs about the current situation, not about the future. Nevertheless, they do provide a rationale for using the illness perceptions framework as the basis for a more direct test of the claim that family optimism about the future may lead to more engagement in the rehabilitation process and better emotional wellbeing.

In summary, several suggestions have been made about family optimism in the post-acute stage of ABI. It has been claimed that many families are unrealistically optimistic at this stage; that the subsequent realization that the optimism is unfounded leads to emotional distress; and that discharge home is the trigger for this realization and consequent distress. A contrasting suggestion is that optimism may have benefits in terms of increased engagement in the rehabilitation process and better emotional wellbeing. The aim of the present study was to provide a quantitative test of these ideas. Convincing evidence to support them is currently lacking. The first set of claims is based on the stage models of family adaptation developed in the 1980s and more recent qualitative research. The empirical basis of the earlier stage models has been questioned [14,30]. For the most part, they were based on clinical experience and anecdotal evidence rather than systematic research. Because of the nature of qualitative research, the generalizability of the findings from the more recent qualitative research is unclear. The second set of claims is based on an extension of the general theory of Scheier and Carver, and there is currently no direct evidence to support them.

The present study used a longitudinal design. At Time 1, 60 family members completed a number of questionnaires, while their relative with an ABI was either still an in-patient on a rehabilitation unit (n=30) or had recently been discharged from such a unit (n=30). These questionnaires assessed controllability and consequence beliefs about future recovery; emotional wellbeing, anxiety and depression; and engagement in the rehabilitation process (which was also measured using a staff questionnaire). At Time 2, after an interval of 12-18 months, 23 of the original sample completed the same wellbeing questionnaire and a questionnaire that assessed controllability and consequence beliefs about their current situation.

Five hypotheses were tested:

* *Family members are unrealistically optimistic in the post-acute phase.* This was tested by comparing the controllability and consequence beliefs of the sample at Times 1 and 2. The hypothesis was that these would show a decline, indicating that the reality at 12-18 months was generally worse than had been anticipated during the post-acute phase.
* *There is a negative emotional impact when optimistic expectations are not fulfilled.* This claim was tested by correlating the decline in mental wellbeing between the two time points with the extent to which the optimism at Time 1 was not borne out by the reality at Time 2. If the disappointment of expectations does have a negative impact, those who experienced greater disappointment in their expectations would be expected to show a greater decline in emotional wellbeing between Times 1 and 2.
* *Discharge triggers a downward adjustment of expectations and a consequent emotional crisis.* This was tested by comparing the emotional health, controllability expectations and consequence expectations of the in-patient and recently-discharged groups. It was hypothesized that the recently-discharged group would show less optimism, reduced wellbeing, and more anxiety and depression.
* *Optimism about consequences and controllability will lead to better emotional wellbeing and less anxiety and depression.* It was hypothesized that, at Time 1, optimism about the controllability and impact of the ABI would correlate with better emotional wellbeing and less anxiety and depression.
* *Optimism about controllability will result in greater engagement in the rehabilitation process.* It was hypothesized that, at Time 1, optimism about the controllability of the condition would be correlated with higher levels of engagement in the rehabilitation process.

**Method**

Ethical approval for the research was provided through the UK’s National Research Ethics Service.

*Participants*

 A power calculation using G\*Power3 [31] indicated that to detect a large correlation (r=.5), with alpha set at 0.05 (two-tailed) and power at .80, a sample of 29 would be required. So at least this number was required at Time 2 to ensure adequate power. Assuming that around 50% would be lost to follow-up [32], a target of at least 58 participants was set for Time 1.

In the event, 60 participants were recruited from three rehabilitation units in the UK for Time 1. Information about their demographic composition is contained in table 1. Participants were required to be the main family caregiver of the person with ABI upon hospital discharge. All carers were approached within 14 months of their relative’s ABI (80% were within 7 months) and at least 6 weeks post-ABI. All patients had recovered sufficiently to be receiving a full programme of physical rehabilitation, and so there was ample opportunity for the family to be actively involved in their rehabilitation. In 30 cases, the relative was still an in-patient when the questionnaires were completed, and, in the remaining 30, the individual had recently been discharged (no more than 6 weeks). The two groups were compared on the demographic variables listed in table 1. Statistical analysis (t-test for continuous variables and chi-square for categorical variables) indicated no significant differences between the two groups on any of the variables with two exceptions. First, significantly more participants in the in-patient group reported that they were employed. This may reflect a tendency for family carers to give up work when the patient is discharged so that they can provide better care. Second, there was a significant association between cause of injury and patient status (i.e. in-patient or recently discharged), with more stroke cases in the recently-discharged group and more TBI cases in the in-patient group (chi-square=5.84; df=1; p=0.016).

At Time 2, the participants were followed up 12-18 months after their participation at Time 1. Fifty-one of the 60 had originally agreed to take part in the follow-up. For various reasons, 28 of these were not available or appropriate for the follow-up (e.g. death, address unknown, no longer living with the person with the ABI, not willing to participate), and so only 23 took part in the follow-up. The 23 who took part in both phases were compared with the 37 who took part only in the first phase. There were no statistically significant differences between the two groups in terms of the demographic variables (table 1) or in terms of the totals obtained on the questionnaires at Time 1.

**[Insert table 1 about here]**

*Measures*

At Time 1, participants completed the *Illness Perceptions Questionnaire – Carers in ABI* (IPQ-CABI), the *Involvement in Rehabilitation Questionnaire* (IRQ)*, the Warwick Edinburgh Mental Wellbeing Scale* (WEMWBS) [33] and the *Hospital Anxiety and Depression Scale* (HADS) [34]*.*  The IPQ-CABI is composed of six subscales, three measuring beliefs about consequences (for the patient, for the carer and for the family) and three measuring beliefs about controllability (treatability, patient control and carer control). Consequences for the family included consequences for the relationship between the participant and the person with the brain injury (e.g. ‘Our relationship will be put under stress by what has happened.’) and for the family as a whole (e.g. ‘Life for us as a family is never going to be the same again.’). For each item, the participant was asked to consider what they expected to be the case over the following 12 months. Items were in the form of statements to which the participant indicated the extent of their agreement using a five-point scale (strongly agree, agree, don’t know, disagree, and strongly disagree). The questionnaire was developed and evaluated in a previous study [35]. It was modelled on a version of the Illness Perceptions Questionnaire developed for use with family carers of people with schizophrenia [36] and adapted following the suggestions of French and Weinman [37]. Internal reliabilities (Cronbach’s alpha) in the previous study for the six subscales were good, ranging from 0.72 to 0.88. Hough [35] also developed and evaluated theIRQ (alpha = 0.85)*.* This questionnaire assesses how active the family member is various aspects of the rehabilitation programme. Participants indicated the extent of their agreement with 10 statements using the same response options as those used in the IPQ-CABI. Those whose relative had been recently discharged (n=30) were asked to complete the IRQ with reference to the in-patient stay. To provide a more objective assessment of the carer’s involvement in in-patient rehabilitation, a member of staff involved in the patient’s care completed the *Family Involvement Assessment Scale* [38]. Only the *Involved-Staff* (FIAS-IS) subscale was used in the analysis because this provides a measure of the family’s involvement in specific rehabilitation activities, which was the outcome of interest in the present study. The WEMWBS is a measure of emotional wellbeing that focuses entirely on positive indicators of emotional health, such as feeling confident and feeling relaxed. Using a five-point response scale, participants indicate the extent of their agreement with 14 statements. The measure has been reported to have good reliability and validity [33]. Further details of the measures are provided in table 2.

At Time 2, participants completed the WEMWBS and an adaptation of the IPQ-CABI that asked about the current situation rather than the future. The two versions of the IPQ-CABI were strictly matched so that they could be compared. Wording was identical with the exception that the first version assessed beliefs about what would happen over the following 12 months, whereas the second version assessed beliefs about the situation as it was at the time of the assessment. For example, on the Time 1 IPQ-CABI, one question on the consequences-carer subscale asked the person to rate the statement “My quality of life will not be the same” in respect of the following 12 months. On the Time 2 version, the corresponding statement was “My quality of life is not the same” and the participant rated this in terms of how their relative’s condition affected their life at the time of the assessment.

High scores on the IPQ-CABI indicate belief in less serious consequences and more control (i.e. greater optimism (Time 1 version) or a more positive assessment of the current situation (Time 2 version)); high scores on the IRQ indicate that the family carer reported more involvement in in-patient rehabilitation; high scores on the FIAS-IS indicate that staff perceived greater involvement of the family carer in rehabilitation; higher scores on the HADS indicate more anxiety and more depression; and higher scores on the WEMWBS indicate better emotional wellbeing.

**[Insert table 2 about here]**

**Results**

The descriptive statistics for the questionnaires are given in table 2. Internal reliabilities for all scales were good, with the exception of the consequences-family subscale at Time 2 which fell just short of the 0.7 benchmark for good internal reliability. The means of the participants’ WEMWBS scores were significantly lower than the mean of 51 reported for a UK normative sample [39] (43 vs. 51: t=6.59, p<0.001; 45 vs. 51: t=3.09, p=0.002). The means of the participants’ HADS scores were also significantly higher than those of a UK normative sample [40] (anxiety 10.9 vs. 6.1: t=9.63, p<0.001; depression 7.4 vs. 3.7: t=9.08, p<0.001).

Data were inspected for missing values, outliers and suitability for parametric analysis. In the case that the participant had completed at least 80% of the items on a scale, missing values were substituted with the individual’s mean score for the completed items. If less than 80% had been completed, the score was entered into the analyses as missing. Two outlying scores on the IPQ-CABI subscales that were more than three standard deviations from the mean were adjusted to the next highest (or lowest) score. Distributions of the scores on the questionnaires did not show any excessive skew or kurtosis, and parametric statistics were therefore considered suitable.

*Hypothesis 1: Family members are unrealistically optimistic in the post-acute phase.*

This was tested by comparing the IPQ-CABI controllability and consequence beliefs at Time 1 with Time 2. The results are shown in table 3. The claim was supported for the consequence beliefs. Participants at Time 1 underestimated the impact that the ABI would have on the patient, their own lives and family life. The claim was also supported for treatability beliefs – participants had generally overestimated the likely effectiveness of treatment and rehabilitation. However, their beliefs about the ability of themselves and the patient to influence outcome remained steady throughout. It is worth noting that, although there was a mean decline on some of the subscales, not everyone reported a decline. For some, the reality at Time 2 was the same as, or better than, what they had been expecting at Time 1 (see table 3). For consequences-patient, only 61% of the sample showed a decrease, and the corresponding figures for consequences-carer and consequences-family were 70% and 87% . The figure for consequences-family indicated that only three participants did not show a decline. One obtained the same score, and two showed slight increases (of half a standard deviation). This raised the question of whether participants were significantly more likely to underestimate the impact on the family compared to the impact on themselves or the patient. However, a chi-square test indicated that the difference was not significant (chi-square=4.08; df=2; p=0.131).

**[Insert table 3 about here]**

*Hypothesis 2: There is a negative emotional impact when optimistic expectations are not fulfilled.*

To test this claim, the decline in emotional wellbeing between Times 1 and 2 was correlated with the extent to which the optimism at Time 1 was not borne out by the reality at Time 2. If there was a negative impact of unrealistic optimism, those who made more of a downward adjustment between Times 1 and 2 would be expected to show a greater decline in emotional wellbeing between Times 1 and 2. A wellbeing decline score was obtained by subtracting the WEMWBS score at Time 2 from the score at Time 1 (so positive values mean a decline in wellbeing over time) (Mean = -3.68). Difference scores (Time 1 minus Time 2) were also obtained for each of the four IPQ-CABI scales that showed a significant decline over time (the three consequences scales, plus treatability) (so positive values indicate events turned out worse at Time 2 than had been originally expected at Time 1) (difference scores: consequences-carer M=2.52; consequences-patient M=2.61; consequences-family M=3.65; control-treatability M=1.61). Consistent with the hypothesis, significant correlations were obtained between the WEMWBS difference score and the consequences-patient difference score (r = .448, p=0.025) and the consequences-family difference score (r=.480, p=0.019): Participants who reported that the reality at Time 2 (in terms of the consequences for the family and patient) was worse than their expectations at Time 1 were more likely to report a decline in wellbeing. However, there were no significant correlations with the consequences-carer difference score (r=.290, p=0.190) or the control-treatability difference score (r=.050, p=0.947). It is worth noting that the mean WEMWBS score was significantly higher at Time 2 compared to Time 1 (i.e. an overall mean improvement in wellbeing) (Time 1 mean = 40.8; Time 2 = 45.0; t=2.50, p=0.021).

*Hypothesis 3: Discharge triggers a downward adjustment of expectations and a consequent emotional crisis.*

This was tested by comparing the controllability and consequence beliefs, and the wellbeing, anxiety and depression scores of the in-patient and recently-discharged groups. The results are shown in table 4. Considering the sample as a whole, there were no significant differences on the emotional measures or on the IPQ-CABI and the hypothesis was not supported. As noted earlier, although the recently-discharged and in-patient groups were not significantly different on most of the demographic variables, they did differ in terms of employment status and the ratio of traumatic brain injury to stroke. To address the possibility that these demographic differences may have blurred differences between the groups in terms of emotional wellbeing and expectations, four additional analyses were run that involved only those who were employed, only those who were not employed, only those whose relative had a TBI and only those whose relative had a stroke. The analyses for those who were employed and those who were not employed showed the same results as the main analysis. In the case of the TBI-only analysis, the recently-discharged group reported significantly less anxiety than the in-patient group (contrary to the expected pattern of results). By contrast, in the case of stroke-only analysis, the recently-discharged group reported significantly more anxiety (the expected pattern of results). However, in the stroke-only analysis, the two groups did not differ on the IPQ-CABI (table 4) and so there is no evidence that lowered expectations triggered this anxiety, and therefore no evidence to support the hypothesis.

 **[Insert table 4 about here]**

*Hypothesis 4: Optimism about consequences and controllability will lead to better emotional wellbeing and less anxiety and depression.*

The results are shown in table 5. The hypothesis was partly supported. At Time 1, expectations about consequences were significantly correlated with wellbeing and anxiety, but not with depression. Expectations about control showed a weaker relationship with emotional outcome. The only significant correlation was that between expectations about control-patient and wellbeing.

*Hypothesis 5: Optimism about controllability will result in greater engagement in the rehabilitation process.*

This hypothesis was largely supported by both the self-report IRQ data and the staff-completed FIAS-IS data, with only the correlation between the FIAS-IS and control-patient beliefs being non-significant (table 5). There was a reasonably large correlation between the IRQ and the FIAS-IS (r=.574, p<.001), which provides some evidence for the validity of the two measures.

**[Insert table 5 about here]**

*Other analyses*

The relationships between the demographic variables (table 1) and the outcome variables at Time 1 were analysed (though not ethnicity, relationships other than parent, spouse or offspring, or type of brain injury other than stroke or TBI – because of insufficient numbers in the relevant categories). Only statistically significant results are reported here. Stroke was associated with significantly more optimistic expectations about consequences-patient than TBI. Female participants were significantly more anxious than males. Older age in the patient was associated with less optimism in respect of control- treatability and control-patient. Parents were more optimistic than spouses in respect of control-treatability and consequences-family; and more optimistic than offspring in respect of control-treatability, control-patient and control-carer. A longer time since the brain injury was significantly correlated with less optimism in respect of control-patient, consequences-patient consequences and consequences-carer. These relationships between optimism and time since injury held for both the in-patient and the recently-discharged groups.

Because stroke and TBI were associated with a different pattern of results in relation to the third claim, separate analyses for stroke and TBI were also run for the other four claims. The pattern of results in relation to these other claims was very similar for both types of injury.

**Discussion**

One aim of the present study was to provide a quantitative test of claims about family optimism in the post-acute phase arising from stage models of family adaptation [1,2,3,4,5,6]. The results provided a degree of support for some of the claims. There was evidence that the majority of participants were unrealistically optimistic at the post-acute phase, in that expectations about treatability and the consequences of the ABI at Time 1 were generally not borne out by the reality at Time 2 (Hypothesis 1). Furthermore, in the longer term, the extent to which the initial expectations were unrealistic (i.e. the difference between IPQ-CABI consequence scores between Time 1 and Time 2) was associated with more decline in wellbeing between Times 1 and 2, which is consistent with the idea that the disappointment of expectations may have a negative impact on wellbeing (Hypothesis 2).

On the other hand, the results suggest that other aspects of the stage models should be treated with caution. Contrary to some of these models [5,6], there was no evidence from this study that discharge served to trigger a disappointment of expectations and a consequent decline in emotional health (Hypothesis 3). Considering the sample as a whole, there were no differences on the IPQ-CABI or the emotional outcome measures at Time 1 between the in-patient and the recently-discharged group. Although those whose relative had a stroke were significantly more anxious in the post-discharge compared to the pre-discharge period, there was no evidence that this was due to a disappointment of expectations because there was no difference in terms of the IPQ-CABI between the in-patient and recently-discharged stroke groups. Moreover, there was a significant negative correlation between time since injury and optimism about consequences that was evident even amongst those whose relative was still an in-patient. This suggests that time since injury, rather than discharge, may play a more important role in the realization of how serious the consequences of the injury are, and that the process of realization may begin for many families while their relative is still an in-patient.

Another aspect of the stage models that the present study casts doubt on is the idea that all families follow a similar path in terms of an increasing realization of the seriousness of the injury and a consequent long-term deterioration in emotional health. Although there was a mean decline in IPQ-CABI consequence scores between Times 1 and 2, not everyone in the sample showed a decline (e.g. for the consequences-patient score, 39% of the sample showed no change or an increase IPQ-CABI - see table 3). In other words, for some participants the reality at Time 2 was what they had been expecting or better than what they had been expecting. Inconsistent with the idea that all families show a long-term deterioration in emotional health is the fact that the mean WEMWBS score was significantly higher at Time 2 than it had been at Time 1. These results highlight the dangers of trying to homogenise family experiences in the way that the stage models and some of the qualitative research have done. Families clearly differ in how they react to ABI, and attempts to support families that are based on oversimplified ideas about how every family copes may be misguided [4,14]. The fact that there was a mean increase in wellbeing scores over time, despite the mean decrease in positive consequence beliefs between Times 1 and 2, also suggests that long-term emotional health is dependent on many factors other than a failure of reality to live up to initial expectations.

Considering those whose relative had a stroke, the recently-discharged group did show an increase in anxiety compared to the in-patient group. This is consistent with another study that also reported increase in psychological distress amongst family carers of people with a stroke at six weeks compared to pre-discharge [41]. By contrast, those whose relative had a TBI showed a significant decrease in anxiety post-discharge. The explanation of this difference is unclear. As discussed in the previous paragraph, there was no evidence that the increase in anxiety for those whose relative had a stroke was triggered by a realization of the consequences of the stroke. One possibility is that stroke tends to make more immediate and obvious caring demands upon discharge because of the higher levels of physical disability, and it is the burden imposed by these demands that increases the anxiety. By contrast, the caring demands of TBI may be more likely to arise from emotional, cognitive, social and behavioural difficulties, and these may not be so immediately apparent. There is evidence that it may take families some time to recognise the presence of some of these difficulties [2]. The post-discharge decrease in anxiety may relate to the burden of hospital visits being removed and a sense of achievement and relief that an important milestone on the road to recovery has been achieved [2,9].

Consistent with general research on the benefits of optimism [15,16,19,20,21] and illness perceptions [26,27,28,29], optimism about controllability was associated with greater engagement in the rehabilitation process, and optimism about consequences was associated with higher wellbeing and less anxiety (Hypotheses 4 and 5). The prediction that optimism about controllability would also be associated with emotional health was less well supported, with only the correlation between WEMWBS and control-patient scores being significant. The association between optimistic beliefs and emotional health is also consistent with findings from qualitative studies that some family members view optimism in the post-acute phase as a useful coping strategy [7,8].

*Limitations of the study*

Some limitations to the study should be noted. The sample was self-selected and not representative of the wider population served by the three rehabilitation units involved in the study (e.g. ethnic minorities were underrepresented). The number of participants who took part in the follow-up was smaller than anticipated and consequently the associated statistical tests were under-powered. The restricted sample size also meant that the separate analyses of the stroke and TBI cases were under-powered. Other studies have similarly reported high attrition rates in longitudinal studies in ABI [32,41]. Because of the failure to meet the requirements of the power analysis, caution is needed in respect of interpreting non-significant findings and using sample statistics to estimate population parameters (e.g. the frequencies in table 3 may be inaccurate estimates of the population frequencies). For the third hypothesis (discharge triggers a downward adjustment of expectations and a consequent emotional crisis), a within-groups longitudinal design that assessed the same group of people, before and after discharge, would have provided a more convincing test than the between-groups design that was used, because it would have provided better control over other variables that may have affected expectations and emotional status. Although those who eventually took part in the follow-up did not differ from the others at Time 1 in terms of the demographic and questionnaire variables, it may nevertheless be the case that the follow-up group was not representative of the larger sample (e.g. those with higher wellbeing at Time 2 may have been more likely to agree to take part). No information was gathered about the nature or severity of the impairments resulting from the ABI, which may have been a relevant factor to consider. However, the fact that recruitment took place at post-acute rehabilitation units does indicate that all patients had a substantial degree of impairment. Although they generally performed well in this study, evidence about the psychometric properties of some of the questionnaires (specifically, the IRQ and IPQ-CABI) is limited. The validity of the IRQ in particular might be questioned because it relied on self-report and, in the case of the post-discharge group, on retrospective recall. However, it correlated reasonably well with the staff measure of participation, and results relating to the IRQ were largely consistent with those obtained using the staff measure (table 5). Finally, due to the nature of the study’s design, definitive causal interpretations of the correlations are not possible. For example, optimism may be the result, rather than the cause, of better wellbeing.

*Implications of present study*

Despite these limitations, the present study suggests that family expectations about recovery after ABI merit further investigation. The results suggest that optimism may contribute to the emotional health of family carers (both positively and negatively) and their involvement in the rehabilitation process. These are two outcomes that have been highlighted as an important focus for rehabilitation services. The impact of ABI on the emotional health of family carers has been well documented. Increased rates of stress and depression, and reduced quality of life and wellbeing, have often been reported [30,41,42,43]. This was also evident in the present study. Because of this emotional impact, care standards prioritize carer mental health as a target for services to address [44]. Likewise, involving family carers in rehabilitation is also highlighted as an important goal for services [45,46,47].

One particular issue that merits further investigation is how best to promote the potential advantages of optimism (better emotional health and more engagement in rehabilitation) whilst avoiding the potential disadvantages (disappointment of expectations may have a negative impact on emotional health in the longer term). The key to this may lie in the possibility that the potential disadvantages arise not from optimism per se, but *unrealistic* optimism about the *consequences* of the brain injury. The correlation between optimism and a long-term decline in emotional wellbeing applied only to optimism that turned out to be unrealistic, and only to expectations about the consequences of the ABI, not expectations about controllability. This implies that it may be useful to encourage optimism about the consequences of the ABI but to keep this optimism within the boundaries of what the clinician might reasonably expect to be the likely outcome; and that it may be useful to encourage optimism about the controllability of the condition. In the present study, initial optimism about the contribution of the patient and the family to the patient’s recovery was generally not disappointed in the longer term. Optimism about the treatability of the condition was disappointed, but was not associated with a decline in wellbeing.

On the basis of earlier models of family adaptation to ABI, optimism has often been equated with denial and viewed as a pathological response that needed to be challenged by clinicians [1,4,12,13,14]. The present study suggests a more subtle approach is needed, and it may be that, with certain restrictions, clinicians should encourage optimism.

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**Declaration of interest**

The authors report no declarations of interest

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**Table captions**

Table 1: Demographic information

Table 2: Descriptive statistics for questionnaire scores

Table 3: Differences in IPQ-CABI Carers between Times 1 and 2 (n=23)

Table 4: Differences between inpatient and recently discharged groups on the IPQ-CABI and emotional health

Table 5: Correlations between IPQ-CABI and other questionnaires at Time 1

Table 1: Demographic information

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Time 1 In-patient group (n=30) | Time 1 Recently-discharged group (n=30) | Time 1 Full Sample n=60) | Sample participating only at Time 1(n=37)  | Sample participating at Times 1 and 2 (n=23) |
| **Participant** |  |  |  |  |  |
| Gender (% female) | 73% | 63% | 68% | 65% | 74% |
| AgeMean (range) | 48 (37-72) | 49 (17-79) | 49 (17-79) | 47 (17-72) | 51 (25-79) |
| Ethnicity (% white British) | 97% | 83% | 90% | 89% | 91% |
| Employment (% employed) | 87% | 40% | 63% | 62% | 65%\* |
| Relation to patient SP = spouse/ partner; P = parent; C = child; O = other | SP=50% P =23%C =10% O=17% | SP= 47% P=23%C=23% O=7% | SP=48%P= 23%C=17%O=10% | SP=43%P= 19%C=24%O=14% | SP=57% P=30%C=4% O=9% |
| **Person with ABI** |  |  |  |  |  |
| Gender (% female) | 20% | 23% | 22% | 35% | 13% |
| Age Mean (range) | 45 (16-80) | 51 (17-82) | 48 (16-82) | 50 (19-82) | 45 (16-82) |
| Type of brain injuryTBI=traumatic brain injuryS=StrokeO=Other | TBI=73%S=23%O=3% | TBI=43%S=53%O=3% | TBI=58%S=38%O=3% | TBI=59%S=41%O=0% | TBI=57%S=35%O=9% |
| Time since injury Mean (range) in months  | 5(2-9) | 5 (2-14) | 5 (2-14) | 5 (2-12) | 5 (2-14)\* |

\*For sample participating at follow-up, table shows percentage employed at Time 1, and time since injury at Time 1, to allow comparison with those not participating at follow-up. At Time 2, percentage employed was 64% and mean time since injury was 20 months (range 17-29).

|  |  |  |  |
| --- | --- | --- | --- |
| **Questionnaire** Subscale (number of items) - sample item | Mean (SD)Time 1 / Time 2 | Range of obtained scores Time 1 /Time 2 | Cronbach’s alpha Time 1 /Time 2 |
| **Illness Perceptions Questionnaire – ABI Carers** |  |  |  |
| Treatability (5)- I’m confident that the therapy will help my relative improve | 19 (3.6) /18 (3.2) | 5-25 / 11-24 | .88 / .71 |
| Patient control (5)- My relative will recover well if they think positively | 19 (3.6) / 19 (3.7) | 8-25 / 12-25 | .80 / .86 |
| Carer control (4)-I believe I have a really important role in helping my relative to make progress | 17 (2.8) / 17 (2.1) | 6-20 / 13-20  | .88 / .76 |
| Patient consequences (5)- My relative will get back to doing the things they enjoy in life | 14 (4.2) / 11 (4.3) | 5-25 / 5-21 | .82 / .77 |
| Carer consequences (5)- My quality of life won’t be the same | 15 (5.0) /12 (4.4) | 5-25 / 5-21 | .90 / .78 |
| Family consequences (5)- Life for us as a family will is never going to be the same again | 14 (4.1) /10 (3.9) | 5-25 / 5-18 | .82 / .69 |
|  |  |  |  |
| **Involvement in Rehabilitation Questionnaire** (10)- I carry out treatment recommendations made by the staff(Time 1 only) | 39 (5.8)  | 21-50  | .86  |
| **Family Involvement Assessment Scale –Involved-Staff** (22)- Actively engages in decision-making with staff(Time 1 only) | 63.7 (10.0)  | 44-85  | .89  |
| **Warwick Edinburgh Mental Well Being Scale** (14)- I’ve been feeling confident | 43.1 (8.7) / 45.0 (9.5) | 25-65 / 23-62 | .89 / .90 |
| **HADS Anxiety**(Time 1 only) | 10.9 (4.0)  | 3-20 | .74 |
| **HADS Depression**(Time 1 only) | 7.4 (4.4)  | 0-18 | .81 |

Table 2: Descriptive statistics for questionnaire scores

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Mean (SD)Time 1 | Mean (SD)Time 2 | t-value (p-value) | Percentage of sample showing decrease in scores over time |
| **IPQ-CABI Consequences**  |  |  |  |  |
| * patient
 | 13.8 (4.06) | 11.2(4.31) | 3.43\*\* (.002) | 61% |
| * carer
 | 14.2(4.81) | 11.7(4.44) | 2.93\*\*(.008) | 70% |
| * family
 | 13.8(4.17) | 10.2(3.88) | 5.55\*\* (<.001) | 87% |
| **IPQ-CABI Control** |  |  |  |  |
| * treatability
 | 19.4(2.25) | 17.7 (3.19) | 2.72\* (.013) | 61% |
| * patient control
 | 18.9 (3.42) | 18.6(3.70) | 0.39(.701) | 39% |
| * carer control
 | 17.3(2.79) | 17.4(2.14) | -0.06 (.951) | 35% |

Table 3: Differences in IPQ-CABI Carers between Times 1 and 2 (n=23)

p-values in brackets: \*p<.05 \*\*p<.01

|  |  |  |  |
| --- | --- | --- | --- |
|  | Mean (SD) inpatient | Mean (SD) discharged | t-value (p-value) |
| **IPQ-CABI Consequences**  |  |  |  |
| Patient  whole sample TBI only stroke only | 14.37 (3.75)15.00 (4.07)12.87 (4.73) | 14.67 (4.60)16.62 (3.71)13.57 (2.23) | 0.28 (.783)1.20 (.240)0.21 (.833) |
| Carer  whole sample TBI only stroke only | 14.50 (4.42)14.73 (5.01)13.57 (2.23) | 14.90 (5.52)16.15 (4.81)14.00 (6.16) | 0.31 (.758)0.84 (.411)0.24 (.810) |
| Family  whole sample TBI only stroke only | 14.40 (3.66)14.50 (4.13)14.00 (2.24) | 14.40 (4.62)15.00 (4.36)13.81 (5.02) | 0.00 (1.00)0.33 (.741)0.12 (.903) |
| **IPQ-CABI Control** |  |  |  |
| Treatability  whole sample TBI only stroke only  | 18.80 (2.62)19.23 (1.88)17.43 (4.24) | 18.63 (3.89)19.69 (3.43)17.63 (4.18) | 0.20 (.846)0.45 (.658)0.10 (.920) |
| Patient control  whole sample TBI only stroke only | 18.43 (3.39)18.68 (2.51)16.86 (5.01) | 18.90 (3.57)19.54 (3.04)18.25 (4.01) | 0.52 (.605)0.86 (.401)0.65 (.530) |
| Carer control whole sampleTBI onlystroke only | 16.60 (2.39)16.86 (2.32)15.43 (2.44) | 17.03 (2.54)15.54 (2.15)17.25 (2.82) | 0.68 (.499)0.42 (.677)1.57 (.140) |
| **WEMWBS**  whole sample TBI only stroke only | 42.53 (8.38)41.91 (7.50)42.00 (9.49) | 43.72 (9.15)47.58 (9.94)41.19 (7.91) | 0.52 (.604)1.73 (.101)0.20 (.847) |
| **HADS anxiety**  whole sample TBI only stroke only | 11.20 (4.05)12.18 (3.86)8.14 (3.53) | 10.48 (4.03)8.83 (3.95)11.94 (3.70) | 0.68 (.498)2.38 (.026)\*2.34 (.038)\* |
| **HADS depression** whole sample TBI only stroke only | 7.50 (4.58)8.09 (4.66)5.43 (4.35) | 7.34 (4.34)6.83 (4.26)8.06 (4.37) | 0.13 (.894)0.78 (.434)1.33 (.205) |
| \*p<.05 \*\*p<.01 |  |  |  |

Table 4: Differences between inpatient and recently discharged groups on the IPQ-CABI and emotional health

Table 5: Correlations between IPQ-CABI and other questionnaires at Time 1

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | IRQ | FIAS-IS | WEMWBS | HADS anxiety | HADS depression |
| **Consequences** |  |  |  |  |  |
| * Patient
 |  |  | .289\* (.026) | .274\* (.036) | .126(.343) |
| * Carer
 |  |  | .374\*\* (.004) | .194 (.140) | .124(.348) |
| * Family
 |  |  | .382\*\* (.003) | .288\* (.027) | .127 (.338) |
| **Control** |  |  |  |  |  |
| * Treatability
 | .421\*\* (.001) | .311\* (.025) | .219 (.096)  | .163(.216) | -.011 (.932) |
| * Patient control
 | .333\* (.011) | .021 (.884) | .296\* (.023) | .211 (.108) | -.036 (.784) |
| * Carer control
 | .571\*\* (<.001) | .377 \*\*(.005) | .096 (.468) | -.039 (.770) | -.010 (.940) |
| p-values in brackets: \*p<.05 \*\*p<.01  |  |  |  |  |  |